# Providers' Perspectives on Identifying Ways to Mitigate Obstacles and Improve Opportunities for Assuring Patients' Care Preferences are Heard and Taken into Account

## FOCUS GROUP RESULTS

FEBRUARY 2025

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**ACKNOWLEDGMENTS**

Supported by a grant from The SCAN Foundation, based in Long Beach, California. The SCAN Foundation is an independent nonprofit but dedicated to advancing the development of a sustainable continuum of quality care for seniors that integrates medical treatment and human services in the settings most appropriate to their needs and with the greatest likelihood of a healthy, independent life. The SCAN Foundation supports programs that stimulate public engagement, develop realistic public policy and financing options, and disseminate promising care models and technologies.

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# Executive Summary

This report documents the attitudes and opinions of 28 healthcare professionals (physicians, nurse practitioners, and physician assistants) regarding whether and how they engage in shared decision-making, navigate barriers to honor patient preferences, and adapt strategies across diverse populations. The study aimed to understand obstacles affecting provider performance, reasons for patient distrust, and identify practical policy, administrative, and practice changes to improve patient care. These professionals were organized into four focus groups segmented by role: two groups of primary care physicians and two groups of physician assistants/nurse practitioners.

This report documents the attitudes and opinions of 28 healthcare professionals regarding whether and how they engage in shared decision-making, navigate barriers to honor patient preferences, and adapt strategies across diverse populations.

The challenges faced by this diverse group of professionals in their desire to honor patient preferences and assure that patients felt heard and listened too were varied, although certain themes dominated – most notably, time constraints and administrative burdens, communication and language barriers, and the fact that they could not address certain social determinants of health. Together these issues encumbered their ability to better able to meet patient preferences. Specific strategies were identified to facilitate successful patient engagement, including an emphasis on finding ways to balance clinical recommendations with patient preferences and in particular, engaging in shared decision-making, receiving additional policy and organizational support, as well as obtaining greater investments in training and education.

The findings suggest that while providers strongly support patient-centered care, systematic barriers often impede its implementation. Success requires a multi-faceted approach combining organizational support, provider training, and policy changes. The strong preference for shared decision-making indicates that future initiatives should prioritize this approach while addressing time constraints and administrative burdens that currently limit its effectiveness.

# Introduction

This report presents qualitative findings from a study that investigated how healthcare professionals engage in shared decision-making, navigate barriers to honor patient preferences, and adapt these strategies across socio-demographically diverse populations. The study engaged health care providers in focus group discussions to explore strategies to optimize health outcomes by ensuring that patients feel heard and that their care preferences and needs are taken into account, highlighting the emergent themes that reflected the dynamic interplay between patient care preferences, clinical decision-making, and systemic constraints within healthcare settings. Specifically, four focus groups were conducted with physicians and ancillary staff to examine what they view as key obstacles currently affecting their performance, the reasons they believe patients may have distrust or feel that they are not heard by providers, and what they identify as practical policy, administrative, and/or practice changes that should be made to address these issues. The purpose of this research was to gain a deeper understanding of the views of key stakeholders regarding the mechanisms that limit people's voices in the health care system, while also exploring their perspectives on potential improvements. This qualitative analysis complements and provides context to the quantitative data, offering a more comprehensive picture of stakeholder experiences and challenges.

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# Data and Methodology

This study utilized a qualitative research design with focus group discussions to gather in-depth insights from 28 healthcare professionals, including primary care physicians, nurse practitioners, and physician assistants. Sago, a specialized firm in participant engagement, facilitated recruitment, enabling a strategic selection of participants to reflect the diversity of the provider population. Participants were drawn from varied clinical settings—such as outpatient clinics, inpatient hospital environments, and home health services—to ensure a comprehensive perspective on taking patients' care preferences into account across different contexts. Each participant received a $300–$350 stipend for the 90-minute session to enhance participation and reduce barriers. Discussions were conducted virtually to improve accessibility.

A total of 28 healthcare professionals were divided into four focus groups, each comprising 6–8 participants. Groups were segmented by role, with two groups of primary care physicians and two groups of physician assistants and nurse practitioners. The focus groups were structured around a pre-defined discussion guide that encouraged participants to share their views on the challenges of engaging patients in their care, why patients may distrust or feel that they are not heard, and effective strategies to mitigate challenges and facilitate optimal health outcomes. All sessions were recorded and transcribed for accuracy. The data were then analyzed using the NVivo qualitative analysis software, with transcription, coding, and thematic analysis processes identifying recurring patterns and insights into the complexities of ensuring that patients feel listened to. The analysis followed an interpretive approach to deepen the understanding of healthcare professionals' experiences and perspectives within their clinical practices.

## Results

Table 1 presents the characteristics of the participants from all four focus groups. Respondents were, on average, 46.8 years old (SD = 12.3, range 29-72). Overall, the sample was 39% female and 61% male. The majority of the sample was white (47%) and half the sample was comprised of primary care doctors (14 individuals). Most participants worked in urban (29%) and suburban (39%) areas and 61% of the sample reported only speaking English. The number of patients that participants reported seeing daily ranged from 16 to 60 patients per day.

***Table 1. Sociodemographic Characteristics of the Study Sample (N=28)***

| **Measure** | ***n*** | ***M*** | ***SD*** |
|---|---|---|---|
| Age | | 46.8 | 12.3 |
| Gender | | | |
| Male | 17 | 61% | |
| Female | 11 | 39% | |
| Race/Ethnicity | | | |
| White | 13 | 47% | |
| African American | 4 | 14% | |
| Hispanic or Latinx | 2 | 7% | |
| Middle Eastern | 4 | 14% | |
| Asian | 5 | 18% | |
| Current Role | | | |
| Nurse Practitioner | 10 | 36% | |
| Physician Assistant | 4 | 14% | |
| Primary Care Doctor | 14 | 50% | |
| Practice Setting | | | |
| Inpatient/hospital-based clinic/office | 6 | 21% | |
| Home Health | 1 | 4% | |
| Outpatient clinic office | 21 | 75% | |

***Table 1. continued***

| Measure | *n* | *M* | *SD* |
|---|---|---|---|
| Geographic Area | | | |
| Urban | 8 | 29% | |
| Rural | 4 | 14% | |
| Suburban | 11 | 39% | |
| Mix | 5 | 18% | |
| Speak other language in addition to English | | | |
| Yes | 11 | 39% | |
| No | 17 | 61% | |

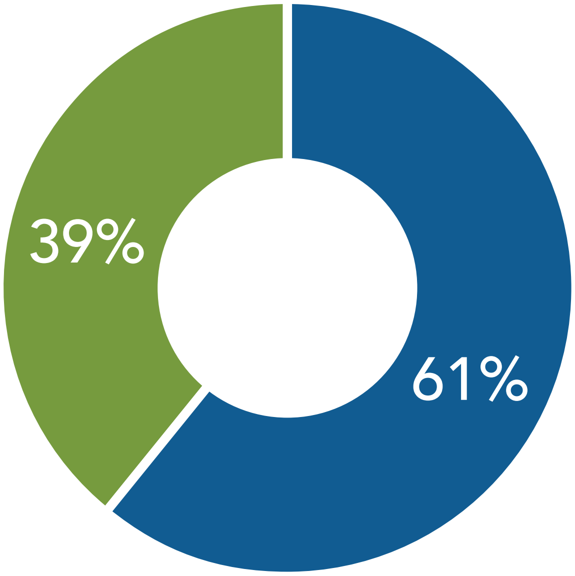
## Perspectives On the Co-production of Health Outcomes

To open the focus group discussion, participants were asked how much they agreed or disagreed with the following statement: "Health outcomes should be co-produced, involving both individuals and healthcare providers in shared decision-making and management of care." Response options for this question included "strongly agree," "agree," "disagree," and "strongly disagree." The question was asked in a poll format with anonymous voting so that responses would be confidential to each individual.

Figure 1 shows the distribution of responses to the poll across the four focus groups. Overall, the entire sample agreed that health outcomes should be co-produced, involving both individuals and healthcare providers in shared decision-making and management of care, with 61% of the sample (17 individuals) selecting "strongly agree" and 39% of the sample (11 individuals) selecting "agree." No participants selected "disagree" or "strongly disagree."

***Figure 1. How much do you agree or disagree with the following statement: "Health outcomes should be co-produced, involving both individuals and healthcare providers in shared decision-making and management of care"?***

● Strongly Agree
● Agree



*Source: Focus group responses. N=28.*

### *Balancing Treating a Person's Illness with Considering Their Care Preferences*

Participants were asked how they prioritize treating a person's illness/disease versus considering their care preferences. Overall, participants indicated that prioritizing treatment versus patient care preferences requires a delicate balance that emphasizes trust, individual preferences, the nature of the medical condition, and the provider's capacity to manage time effectively. The approach varied among healthcare providers based on their experiences and the specific context of each patient interaction.

A key strategy designed to successfully navigate the balance which was emphasized by multiple participants is the necessity of building trust and rapport with patients over time. Long-term relationships facilitate a deeper understanding of patients' values and preferences, leading to better patient engagement. As one provider noted, "…the duration of the relationship can lead to increased patient trust, making it easier to discuss and negotiate treatment plans." This trust allows providers to navigate conflicts between optimal care outcomes and patient preferences more effectively, as patients may be more willing to accept medical advice when they believe their provider has their best interests at heart.

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However, participants conveyed that it is essential to recognize that patient preferences can vary significantly based on their background, education, and prior experiences. Some patients, especially those younger or more tech-savvy, may arrive with pre-formed opinions and specific demands based on their own investigatory research, which can complicate the decision-making process. Providers emphasized the importance of having open conversations to understand these preferences fully and ensure that they are addressed in treatment plans.

Furthermore, the balance between treating diseases and acknowledging patients' preferences often hinges on the severity of the medical condition. Providers shared that they might prioritize evidence-based treatment recommendations more strongly for serious conditions, sometimes leading them to override patient preferences if they believe it is in the patient's best interest. Meanwhile, the emphasis shifts to shared decision-making for chronic conditions with multiple options, incorporating patients' desires into treatment discussions.

Time constraints present a significant challenge. Many providers highlighted the pressures they face to see multiple patients in a limited timeframe, which can impede their ability to engage meaningfully with each patient. As one provider stated, "…having more time would allow them to listen actively and ensure that patients feel their preferences have been respected and incorporated into their care plans."

### Trade-offs Between Respecting Patient Desires and Achieving Optimal Health Outcomes

Participants were also asked if there were trade-offs between having someone's desires respected and achieving optimal health outcomes over time. Providers often face challenges aligning patients' preferences with clinical recommendations, especially when the latter are based on clinical evidence and best practices. These conflicts can arise in various scenarios, such as when a patient insists on a particular treatment that may not be in their best interest or when they prioritize quick fixes that don't align with long-term health strategies.

For instance, one focus group participant mentioned that he often encounters patients with preconceived notions about their treatment in primary care. He noted that sometimes it might be necessary to emphasize the importance of certain therapies over the patient's immediate desires, particularly when it involves serious conditions. He suggested that while he tries to incorporate patients' input, he occasionally must prioritize what he believes is essential for their health, thereby creating a trade-off between compliance with patient preferences and optimal treatment choices. This highlights healthcare providers' struggle to preserve the shared decision-making process while ensuring patients' health isn't compromised by their preferences.

Additionally, focus group participants pointed out that younger patients often expect immediate solutions based on information from the internet. They may demand treatments that aren't necessarily appropriate for their conditions, creating a tension between their desires and medical appropriateness. He noted that establishing a trusting relationship can help bridge this gap but doesn't eliminate the trade-offs inherent in these complex interactions.

Moreover, another participant echoed concerns about how misconceptions surrounding conditions can complicate care and affect patients' receptiveness to recommendations. If the patient doesn't perceive the condition seriously due to misinformation, it can lead to a conflict between respecting their desires and achieving a favorable health outcome.

Time constraints also play a crucial role in this trade-off. One participant stated that limited time during appointments often makes it difficult to fully explore patients' preferences and ensure they feel heard. This fast-paced environment can inhibit meaningful dialogue and make it challenging to reconcile patient desires with the recommendations necessary for their health.

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In summary, while comprehensive care models advocate for respect and consideration of individual preferences, achieving optimal health outcomes often requires navigating complex trade-offs. Providers must balance the need for informed clinical decision-making while ensuring the patient feels valued and respected. This dynamic becomes increasingly difficult when external pressures, such as time constraints and misinformation, complicate the situation.

## ***Focus Group Discussion of Challenges to Ensuring that Patients Preferences are Taken into Account***

### *A. Time Constraints and Administrative Burdens*

One of the most pervasive barriers identified was the constraint of limited time during patient visits, which restricts the ability to engage in meaningful discussions about patient preferences. Administrative tasks, including paperwork and navigating insurance requirements, were cited as significant factors that detract from patient interaction. These challenges highlight the need for systemic adjustments to alleviate provider workload, allowing more dedicated patient care time. Participants suggested that reducing administrative burdens and streamlining documentation processes could enhance the quality of patient-provider interactions.

> *"One of the major things I deal with is patients getting their medications on time. There seems to always be lags between getting medications covered in the pharmacy and then, it could take weeks before they get the medication, and we don't even know about that. We assume that we prescribe it and everything's fine, only to find out that they haven't had the medication filled in time because of insurance rejections, the pharmacy trying to reach the office, and us not getting the messages to provide a substitute for the patient."*

The increasing bureaucracy and reliance on electronic medical records (EMRs) can impede effective communication between providers and patients. Many noted that the necessity of completing multiple quality measures and documentation often detracts from the time available for meaningful patient interaction. There was consensus that this shift toward a metric-driven approach leads to the commoditization of healthcare, transitioning the dynamic from a patient-provider relationship focused on collaborative and individualized care to a more transactional interaction. Providers felt that this results in patients feeling like they are just a number rather than individuals with specific needs.

> *"I think there's just too much of a focus on charting, charting, charting, charting. And it takes away the time you can spend face to face."*

> *"The biggest challenge for me and I hate to say this is the staffing. I can have a great rapport with my patients, have a great plan, educate them, and have great discussions and things like that. And then, a nurse doesn't want to help them to the bathroom or doesn't want to, you know, help them stay clean or doesn't uphold the same rapport and things like that as I have. So, honestly, in the inpatient world, I have the biggest challenge and setback: just having staff that doesn't carry through the same values and perspective that I do."*

### *B. Communication*

The proliferation of misinformation through the internet was cited as a major hurdle. Providers expressed frustration as patients often arrive with misconceptions based on online research, which complicates the provider's role in fostering understanding and trust. This scenario frequently requires dealing with a patient's preconceived notions before even addressing their immediate medical needs, consuming valuable time and reducing the chances of a productive, trust-building interaction.

> *"A lot of times it has to do with medical jargon in general just not understanding what's truly going on. So, trying our hardest to speak in layman's terms is important. Um, but that also goes back to staff sometimes I don't realize that. And we need to lay things out in a better manner. So, communication in general."*

> *"We have a lot of consulting services for these patients and a lot of times they're hearing multiple plans from different providers and then they're confused and why are we doing this? Why did this person say this? Even within our own group, our surgeons rotate every week and change plans and like to micromanage from afar. So, trying to make sure that everybody's on the same page and we're communicating the same message to the patient so they're not confused about plans, especially with complex patients and multiple consulting services, that can be very confusing to patients."*

### *C. Social Determinants of Health as Barriers to Care Engagement*

Social determinants, including transportation, financial constraints, and health literacy, were discussed as significant barriers to achieving optimal health outcomes. Providers emphasized the importance of understanding patients' social contexts to effectively tailor care plans. Participants shared that addressing social determinants of health requires a holistic approach, integrating services that support patients' broader needs, such as social work, community resources, and care coordination. Closely related, socioeconomic status was repeatedly mentioned as a significant barrier, where patients may struggle with compliance due to financial constraints affecting their ability to access care or medications. The lack of understanding surrounding insurance policies, prior authorization needs, and even transportation issues further complicate patient involvement in their care, often leaving them feeling unheard or neglected.

> *"The biggest hurdle for me in my field is insurance coverage. Most of the time that is dictating what I can do for my patient. So, I always start with what is covered because I hate for my patients to pay anything out of pocket if we can avoid it. The other thing I typically do is to triage their complaints. I get multiple complaints in one visit, and sometimes it's a matter of how much time I spend with my patient, and that's frustrating."*

> *"Staffing is one of those things that tends to be one of my primary challenges. I deal with, I'd say probably 70% geriatric and it's rural on top of that. A lot of times, people have trouble getting to appointments, they don't drive, they have trouble getting rides, they can only get assistance on certain days, certain times, and things like that. So, it's trying to accommodate those things as much as possible. Maybe going a bit longer and calling in prescriptions, using mail order pharmacies, to simplify things."*

## *D. The Interplay of Sociodemographic Characteristics and Care*

Participants were asked how challenges or successes differ across individuals from various demographic groups. Some participants felt older adults tend to be more likely to discuss their care preferences than younger patients and many noted that older patients are more appreciative of the established relationships they have built over time. Trust is a significant factor; with longer durations of care, patients often feel more comfortable discussing their preferences and concerns. They were viewed by providers as generally more respectful and loyal, which enhances the provider's ability to meet their needs. A notable point is that the longitudinal nature of these relationships provides more opportunities for understanding and collaboration, leading to better adherence to care plans and improved health outcomes.

In contrast, younger patients often come in with preconceived notions influenced by social media and personal research. They may demand specific treatments or medications based on limited knowledge or misinformation, making it harder for providers to align on care approaches. The need for immediate gratification also plays a role, as younger patients may express frustration if their expectations are not met quickly. Providers highlighted the importance of addressing this disconnect by educating younger patients about the complexities of their conditions and treatment options, promoting shared decision-making.

Education level also plays a crucial role in how challenges are navigated. Generally, patients with lower educational backgrounds trust their providers more readily and are less likely to challenge medical advice. Those with higher education may come in with a wealth of knowledge but may also have heightened expectations, leading to possible misunderstandings when recommendations differ from their independent research. Overall, while high education can empower patients to engage meaningfully in their care, it can also create friction if their understanding conflicts with clinical recommendations.

Race and ethnicity can further complicate interactions. Some providers expressed that patients from minority backgrounds may hold historical mistrust toward the medical community, impacting their willingness to accept care. This mistrust requires providers to be sensitive and flexible, fostering a safe environment where patients feel comfortable sharing their experiences and preferences. The need for cultural competence is evident; discussions that incorporate an understanding of a patient's background can improve rapport and willingness to engage in shared decision-making.

New patients often present more significant challenges than those with whom healthcare providers have established relationships. The lack of prior rapport means new patients may be less open about their concerns and preferences, often requiring more time to build trust. Engaging with a patient for the first time may necessitate a comprehensive understanding of their history and expectations, which can be daunting under time constraints of most primary care practices. In contrast, having built a foundation of trust, long-term patients may more readily express their concerns, leading to more fruitful discussions about their care needs.

Overall, age, education level, race and ethnicity, and the duration of the patient-provider relationship all influence the success of healthcare interactions. Acknowledging these demographic differences can help healthcare professionals develop strategies that improve communication and ensure patient preferences are considered in care decisions.

Healthcare providers frequently face difficulties addressing care preferences due to language barriers and cultural misunderstandings. Participants expressed that differences in language and cultural norms can complicate the establishment of trust and impede effective communication. This theme pointed to the necessity of interpreter services, cultural competency training, and strategies to ensure that care is sensitive to diverse cultural backgrounds. For example, providing education in multiple languages and visual aids was recommended as practical solutions.

## *E. Experiences Demonstrating Well-Considered Patient Preferences*

Respondents were asked to describe a recent experience where they felt an individual's preferences were heard and respected and how they knew their preferences were well-considered.

> *"I knew their preferences were well-considered when, at the end of our discussion, the patient thanked me and mentioned they felt more confident in understanding their treatment options. Their body language—relaxed and engaged—along with a follow-up appointment scheduled, indicated that they were satisfied with our conversation and the planned approach."*

> *"A recent experience where I felt that individuals' preferences were well-considered involved a patient with diabetes. During the visit, I took the time to ask open-ended questions about their understanding of their condition and the treatment options available. This approach allowed me to gauge their knowledge and preferences effectively. I explained the pros and cons of different medications, ensuring they knew that we could collaborate on the treatment plan based on what they were comfortable with. This not only involved discussing injectables but also assessing their willingness to incorporate lifestyle changes."*

### *F. The Importance of Having a Usual Source of Care*

Participants expressed that having a usual source of care is foundational to establishing trust and the continuity of the provider-patient relationship. When patients regularly see a healthcare provider, they develop a deeper rapport, which fosters trust. This trust allows for more open communication, enabling patients to share their concerns and preferences without fear of judgment. As one provider mentioned, "…patients often feel comfortable discussing issues because they have established a lasting relationship with their provider, enhancing the quality of care received."  A long-term relationship builds a sense of security and reassurance for patients, knowing they are heard and understood.

Additionally, familiarity with patients allows providers to better understand their medical histories and preferences, leading to more personalized care. This understanding contributes to more effective treatment plans, as healthcare providers can utilize insights gained from previous encounters to tailor their approach. One participant noted that "…long-time patients' experience and accumulated knowledge allow for a more seamless healthcare journey, as previous successes and failures inform current treatment strategies."

Furthermore, when healthcare providers know their patients well, they are better equipped to advocate for their needs and navigate the complexities of healthcare systems on their behalf. This is particularly true in settings where patients may lack comprehensive health literacy, enabling providers to effectively educate them on their health conditions and treatment options. It helps bridge the gap between medical jargon and patient understanding, reinforcing the importance of having a usual source of care for achieving optimal health outcomes.

Lastly, having a usual source of care means that providers can engage in shared decision-making processes more effectively. By actively involving patients in their care plans and considering their values and preferences, healthcare providers can empower patients and often see better compliance and satisfaction. This collaborative model reinforces that health outcomes should be co-produced, ultimately enhancing the overall healthcare experience for both parties involved.

> *"Yeah, I think this is a crucial issue and why it's better for people to have a regular physician. It all boils down to trust and confidence. When patients trust me and feel comfortable, they will tell me what's wrong. Even if they, you know, if they're not, they're not afraid of being judged or being embarrassed. I think a lot of patients are afraid to verbalize those things. I think that's why it's so important to build that; it makes my job easier, and I can do a much better job if we've had the chance to build that relationship."*

> *"When you have a usual source of care, it's not just providing a service. There's a relationship that builds there. All the things that you mentioned, the longevity, um, that you realize that the person, you know, has your best interest at heart and that they're honest and sincere, et cetera as opposed to if you don't have that usual source of care, it's like you're providing a service rather than a service plus a personal relationship with it."*

> *"Trust has already been mentioned, but I think patients also value if we know them as a person, who they are, their beliefs, and how those beliefs translate into medical care. And if we have those pieces, it makes our job a lot easier. I'm sure all of us who've taken care of patients for a long time, you know, it's not unusual that they may have some other life-threatening events, somebody may need a bypass surgery, or they may have some other neurosurgical procedure. Still, they want to talk to you, you know, and while there's somebody, an expert has already made, you know, a recommendation, it goes down to the trust and confidence, you know?"*

> *"I agree that along with trust you have to give that sense to the patient and their family members that at the end of the day, you are working for the healthcare system, but you're a patient advocate. Nowadays, the healthcare system is viewed as a business strategy in many ways. But as NPs, physicians, advanced practice providers, I feel we come off more as patient advocates. And I think that helps to take that encounter even further and more personal, that, I'm invested in your care as much as you are invested in yours."*

## *G. Focus Group Discussion of Strategies Contributing to Optimal Health Outcomes*

The following strategies were explored with focus group participants to assess their perceived effectiveness in meeting patients' preferences and optimal health outcomes; also discussed were provider views on each strategy. The strategies presented included: 1) shared decision-making; 2) training and education; 3) integration of patient reported outcomes; 4) reported experience measures; and 5) policy and organizational support. Table 2 provides a detailed description of the strategies presented and discussed.

***Table 2. Strategies Contributing to Optimal Health Outcomes***

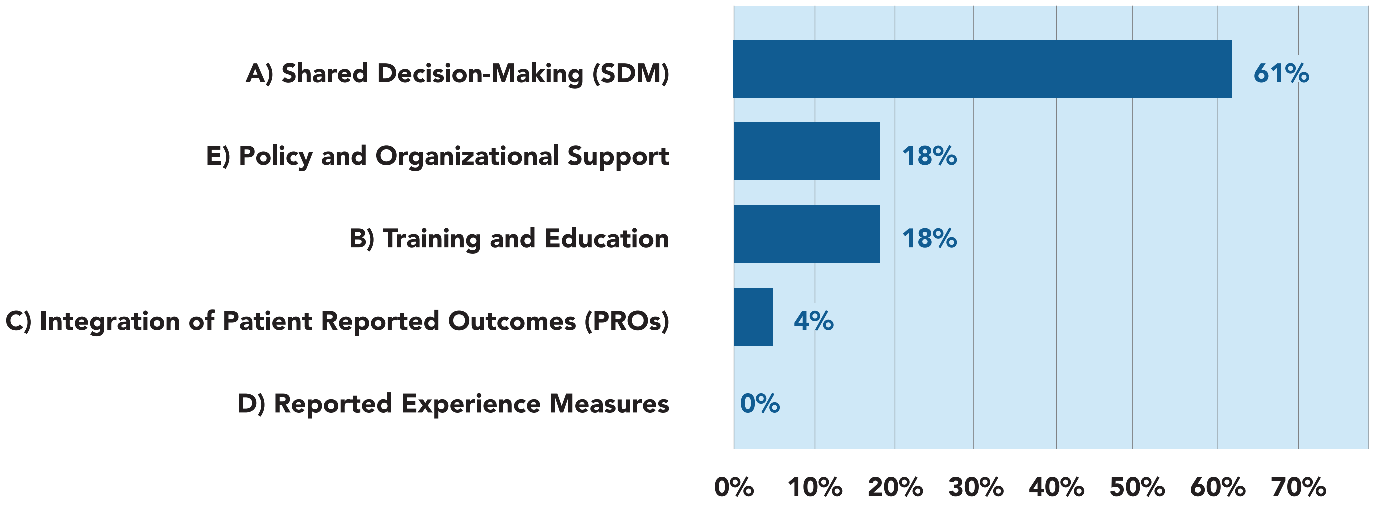
| Strategy | Strategy Description |
|---|---|
| A) Shared Decision-Making (SDM) | *Promoting collaborative decision-making processes where individuals and providers discuss treatment options, risks, benefits, and align care plans with individuals' values and preferences.* |
| B) Training and Education | *Providing healthcare providers with training in effective communication skills, cultural competence, and ethical principles that can enhance their ability to navigate sensitive discussions and respect diverse individual preferences.* |

*Table 2. continued*

| Strategy | Strategy Description |
|---|---|
| C) Integration of Patient Reported Outcomes (PROs) | *Incorporating PROs into routine clinical practice allows individuals to express their preferences, symptoms, and treatment goals directly, providing valuable insights for personalized care planning.* |
| D) Reported Experience Measures | *Standardized tools that allow patients to provide feedback on their experience of the healthcare services they receive. These measures serve as an indicator of the quality of care provided.* |
| E) Policy and Organizational Support | *Establish health policies to prioritize enhanced consideration of patients' wishes regarding care and implement organizational practices that support continuity of care, interdisciplinary teamwork, and advocacy can facilitate the integration of individuals' care preferences into clinical practice.* |

Focus group respondents were asked to rank the strategy options from most effective to least effective in contributing to patient preferences being met and optimal health outcomes, and all votes were recorded. Shared decision-making (SDM) was the most popular of the five strategies presented. Specifically, 61% of focus group participants (17 individuals) selected SDM as the most effective. This strategy was followed by policy and organizational support and training and education, each ranked as most effective by 18% of participants (5 individuals each). While 4% (1 individual) identified integration of patient reported outcomes (PROs) as the most effective, reported experience measures were not identified by any focus group participants as the most effective by number one ranking. Figure 2 displays the strategies presented by ranking the most effective.

*Figure 2. Distribution of Top Ranked Strategy by Perceived Effectiveness*



## *H. Focus Group Discussion of Facilitators of Successful Patient Engagement*

To mitigate challenges associated with patient care and ensure that individuals feel heard, several strategies were identified by focus group participants as successful across different healthcare settings.

One effective approach cited by many participants involves “active listening”. Practitioners can better understand the patient’s needs by allowing patients to express their concerns before the provider jumps into a diagnosis or treatment plan. This might include asking open-ended questions and ensuring that the conversation starts with the patient discussing what’s important to them, rather than the provider dictating the agenda. Asking “What other questions do you have?” at the end of visits reinforces this approach and signals the patient that their concerns are valued. Moreover, maintaining eye contact and personal connection helps build rapport, allowing patients to feel more comfortable sharing their issues.

Another promising strategy cited was the importance of the involvement of interdisciplinary teams. Access to social workers, pharmacists, and care managers can streamline communication about patient care. For example, utilizing a care management team to facilitate discussions about transportation issues or medication assistance can positively impact the patient’s experience and improve adherence to treatment plans. Implementing team-based care allows for sharing the workload which can aid in reducing time pressure on individual providers and encouraging patient engagement.

Cultural competence and understanding the unique backgrounds of patients are also seen as crucial when addressing their care preferences. Engaging with patients on their level of understanding, and providing tailored communication based on their cultural and educational backgrounds was seen by participants as enhancing the effectiveness of care provided. Some participants felt that engaging in shared decision-making was easier when patients felt their background was acknowledged and understood.

Utilizing technology effectively is also a strategy many practitioners are exploring. Some have mentioned using electronic health records to minimize time spent on documentation during patient visits. For instance, leveraging tools that transcribe visit details can allow healthcare providers to focus more on the patient during consultations, potentially fostering a better environment for discussing care preferences.

Educating patients about their conditions and options is fundamental. Empowering patients with knowledge aids their understanding and can open the door for collaborative discussions regarding their treatment. When patients come to the table informed, they may feel more confident in the decision-making process and the recommendations made by their healthcare providers.

These strategies collectively can help create a healthcare environment where individual preferences are heard, recognized, and respected, enhancing overall patient satisfaction and healthcare outcomes.

# Conclusion

This study highlights the critical importance of being conscious and intentional about ways to ensure that patients feel listened to regarding their care preferences and achieve optimal health outcomes, even when there are challenges to doing so. The need for strategies that prioritize patient engagement, communication, and cultural competence present opportunities for achieving both of these objectives or at the very least, finding a proper balance when need be. While challenges persist, particularly those related to systemic and social barriers, developing supportive policies, training, and interdisciplinary collaboration can enhance healthcare systems' capacity to respect and incorporate patient preferences into care planning to achieve optimal health outcomes. Future research should further investigate the application of these themes across different healthcare settings and populations to develop tailored strategies that ensure equity and effectiveness in patient care. Additionally, future studies should prioritize the development of patient-guided initiatives and explore how these can be effectively applied alongside provider-developed strategies. This combined approach can help ensure that interventions are both inclusive and aligned with the diverse needs and preferences of individuals.

This study highlights the critical importance of being conscious and intentional about ways to ensure that patients feel listened to regarding their care preferences and achieve optimal health outcomes, even when there are challenges to doing so.

# Appendix A

## Focus group Discussion Guide: Identifying Ways to Mitigate Obstacles and Improve Opportunities for Assuring Individuals' Care Preferences are Heard and Taken into Account

Discussion Guide:

Good [MORNING/AFTERNOON/EVENING]. My name is [NAME] and I work at UMass Boston and will be moderating today's focus group. We appreciate your willingness to participate in today's discussion.

I want to disclose a few things before we get started. As you know, we will be recording today's session. That's really so that I may focus on what we're talking about without needing to capture detailed notes during today's discussion. I can then go back and review the recordings to make sure that I have interpreted your feedback correctly and in context. Other than that, the recording will remain confidential and private and nothing that anyone says will be attributed back to them.

I want to start by thanking you for participating. Your honest feedback will help us better understand how to ensure that individuals' care preferences are heard and taken into account by healthcare providers and learn about what sometimes makes it hard to do this. We will discuss your personal experiences, the barriers you face, and potential solutions. I am looking for you to share insights from your personal experience with persons you provide care to as medical professionals.

At the same time, I also want to hear your opinions about what might be done to help you deal with these challenges. There are no right or wrong answers to any of the questions we'll discuss. I also don't expect people to always agree. I know that everyone we talk with is going to have different perceptions and views that are important to them.

Sometimes, I may ask you to elaborate further. I want to clearly capture your thinking. If I notice that some voices are not being heard, I may intentionally call on individuals to get their perspectives. On the other hand, you may have longer stories to share and I may need to stop you before you are finished. This doesn't mean that I don't want to hear your thoughts, just that we have limited time in today's session. In that case, I may follow up with you outside of this meeting.

To make this the most productive and safe space I'm going to offer the following guiding principles.

1) Active listening and respectful dialogue
2) Avoid interrupting others
3) Commit to open-mindedness
4) There are no right or wrong answers

So, let's get started by learning a little bit about one another.
*Introduction*

- Let's go around the room and share your first name, your current role, and tell us very briefly how you enjoy spending your free time. I'll get us started. [Name, specialty, years of practice, hobbies.]

- We're going to be talking about your experience as a medical professional. Let's begin by telling us about the nature of the care that you provide. What healthcare setting do you work in? What population do you work with? How many people do you see daily?

- **Poll Question:**

  How much do you agree or disagree with the following statement: "Health outcomes should be co-produced, involving both individuals and healthcare providers in shared decision-making and management of care"?
    - Strongly agree
    - Agree
    - Disagree
    - Strongly disagree

- How do you prioritize treating a person's illness/disease versus considering their care preferences? Are there trade-off between having someone's desires respected and achieving optimal health outcomes over time? How does your organization guide this balance, and how does it match your personal care style?
    - Given any trade-offs mentioned is there still a value in considering care preferences? How would they articulate that value proposition or return on investment?

- What are the main challenges you experience in ensuring that individual preferences are heard and respected?

    - *[Probe for: Are there external/environmental factors that directly influence or impact the healthcare setting? Are there systemic barriers within your healthcare setting? How does time pressure influence these challenges?]*

- Can you describe any recent experiences where you felt that individuals' preferences were well-considered? In other words what factors contributed to successfully ensuring that individual care preferences were heard and respected?
    - How did you know they were well-considered? How was this validated?

- How do these challenges or successes for that matter differ across various demographics? That is, is it more or less difficult when you are dealing with older or younger people, people with more or less formal education, or people from a different racial or ethnic background than your own? Is this more or less difficult with new people versus people with whom you have had a longer-term relationship?
    - If it is more difficult, what do you do to mitigate those challenges? What strategies have proven to be more successful?

- What is it about having a usual source of care that is so important to the relationship between individuals and providers?

    - *[Probe for: does the length of time and/or quality of relationship help the providers understand and meet an individual's preferences? Building trust?]*

- Given the lessons learned as a medical professional, what do you think would be the best ways to better address individual care preferences?

    - *[Probe for: What support or resources would help you overcome these obstacles? What training or resources would support you in this effort? Training or resources, translation, more time with person, etc.]*

- **Poll Question:**

  Can you rank the following strategies in terms of what you believe would be the most effective to least effective in contributing to more optimal health outcomes for individuals?

A. **Shared Decision-Making (SDM):** Promoting collaborative decision-making processes where individuals and providers discuss treatment options, risks, benefits, and align care plans with individuals' values and preferences.

B. **Training and Education:** Providing healthcare providers with training in effective communication skills, cultural competence, and ethical principles that can enhance their ability to navigate sensitive discussions and respect diverse individual preferences.

C. **Integration of Patient Reported Outcomes (PROs):** Incorporating PROs into routine clinical practice allows individuals to directly express their preferences, symptoms, and treatment goals, providing valuable insights for personalized care planning.

D. **Reported Experience Measures:** standardized tools that allow patients to provide feedback on their experience of the healthcare services they receive. These measures serve as an indicator of the quality of care provided.

E. **Policy and Organizational Support:** Establish health policies to prioritize patient-centered care and implement organizational practices that support continuity of care, interdisciplinary teamwork, and advocacy can facilitate the integration of individuals' care preferences into clinical practice.

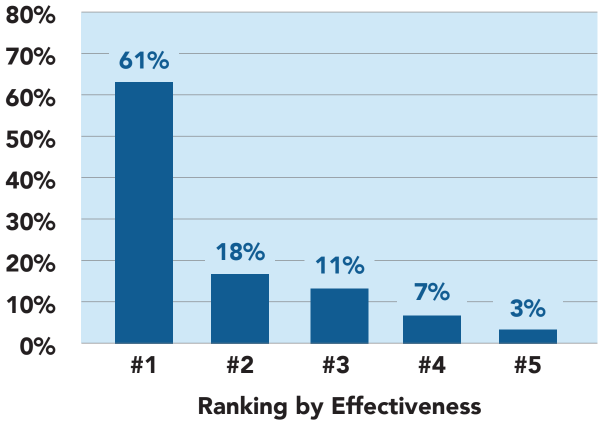
We're almost done and you have been really terrific! I appreciate how open and honest you have been in sharing your thoughts and experiences with me. Just one more thing.

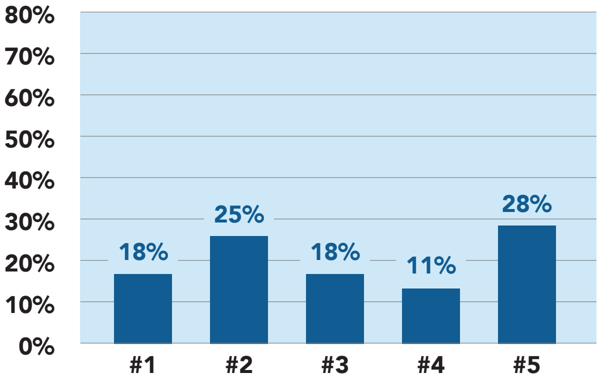
- Is there anything else that you believe is important for us to know about ways to help improve the consideration of individual' care preferences that I may have missed?

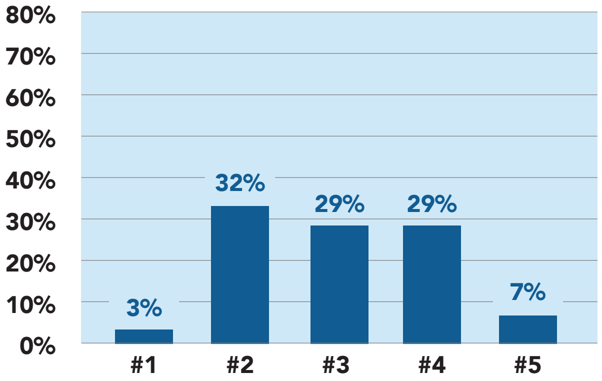
Thank you all so much for your participation.

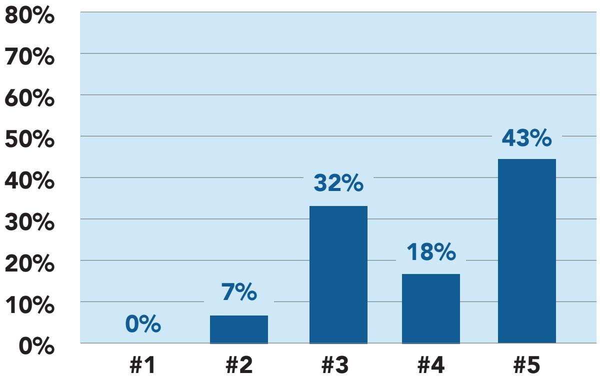
# Appendix B

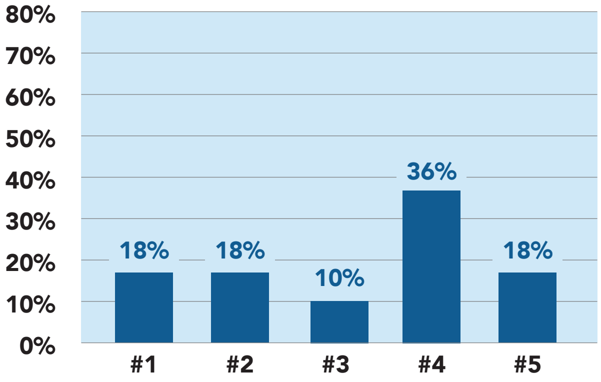
The following section highlights how focus group respondents ranked each presented strategy contributing to optimal health outcomes in order of effectiveness.


Strategy A: Shared Decision-Making


Strategy B: Ranking by Effectiveness


Strategy C: Integration of Patient Reported Outcomes (PROs), Ranking by Effectiveness


Strategy D: Reported Experience Measures, Ranking by Effectiveness


Strategy E: Policy and Organizational Support, Strategy Ranking by Effectiveness

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