NEJM Catalyst

Measuring What Matters and Capturing the Patient Voice

ROUNDTABLE REPORT

NEJM GROUP

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Incorporating the patient voice into health care delivery has proved challenging—particularly when there is little agreement about how to define and discuss the concept nor about how to measure its impact. NEJM Catalyst convened an in-person roundtable to address these issues in depth. The roundtable and an accompanying survey of our Insights Council point the way toward a framework for defining the patient voice and integrating it into care delivery.

Roundtable Participants

Michele Heisler, MD, MPA
Professor of Internal Medicine, Health Behavior, and Health Education, University of Michigan

Kate Niehaus, MBA
Chair, Patient and Family Advisory Council for Quality, Memorial Sloan Kettering Cancer Center, New York

Carol J. Peden, MD, MPH
Professor of Anesthesiology and Executive Director, USC Center for Health System Innovation, Keck School of Medicine, University of Southern California

Neil W. Wagle, MD, MBA
Associate Chief Quality Officer, Partners HealthCare; Primary Care Physician, Brigham and Women's Hospital, Boston

Namita Seth Mohta, MD
Clinical Editor, NEJM Catalyst (moderator)

Edward Prewitt, MPP
Editorial Director, NEJM Catalyst (moderator)

Namita Seth Mohta
Clinical Editor,
NEJM Catalyst

Edward Prewitt
Editorial Director,
NEJM Catalyst

Roundtable Discussion

Understanding the patient voice is an important but elusive goal. Health care providers seek to listen to the patient voice and integrate it with care delivery to improve health outcomes. Patients increasingly demand to be heard. But encompassing the patient voice in care has proved challenging—particularly when there is little agreement about how to define and discuss the concept nor about how to measure its impact.

NEJM Catalyst convened an in-person roundtable, "Measuring What Matters and Capturing the Patient Voice," to address these issues in depth. The roundtable—among clinicians, researchers, and a patient advocate, moderated by NEJM Catalyst editors—and an accompanying survey of our Insights Council point the way toward a framework for defining the patient voice and incorporating it into care delivery.

To begin with, what exactly is the patient voice and why is it important? Neil W. Wagle, MD, MBA, Associate Chief Quality Officer at Partners HealthCare and a primary care physician at Brigham and Women's Hospital in Boston, says, "Capturing the patient voice is a proxy for putting the patient at the center of our care—so it [means] capturing their goals and preferences. It's also capturing their data and orienting our care around outcomes that reflect a patient's well-being." Listening to the patient voice thus requires "shifting the whole system from what providers can ascertain about the patient using skills and equipment, to high-fidelity capture of what the patient is telling us directly," he says.

Clinical visits and patient sensors generate "mountains of data at every moment," Wagle notes. But the patient voice is more than data, says Kate Niehaus, MBA, Chair of the Patient and Family Advisory Council (PFAC) for Quality at Memorial Sloan Kettering Cancer Center in New York City. "The patient voice is in part a collection of stories. Looking at the commonalities among the stories that the patients tell you, and also looking at the differences, [clinicians should determine] how you can improve your care delivery based on those commonalities, and how you adjust the care to take care of the individual needs."

In drawing on data and stories, "how do you elicit what's most important?" asks Michele Heisler, MD, MPA, Professor of Internal Medicine, Health Behavior, and Health Education at the University of Michigan in Ann Arbor. "It's critically important that we're asking the right questions [of patients], we're asking

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them in the right way, in a non-burdensome way, and we're feeding that back immediately to the point of care and engaging clinicians so that they see a reason to respond." Thus capturing the patient voice "is much more complex than just asking, 'Are you satisfied?," says Heisler.

For example, it is more useful to ask patients if they received specific components of patient-centered care, such as whether their providers

asked them about their own goals in caring for their health and were helped to set specific goals, rather than vague, poorly defined questions such as "Do you feel your care is patient-centered?," which can be interpreted in multiple, unclear ways, she says.

Indeed, the terminology commonly used for the patient voice is imprecise. "What's the dividing

line between experience versus engagement?," asks Carol J. Peden, MD, MPH, Professor of Anesthesiology and Executive Director, USC Center for Health System Innovation at the Keck School of Medicine of the University of Southern California in Los Angeles. "We want to improve outcomes, and we can define that broadly, whether it's better experience, reduced complications, or improved quality of life, as we think about that patient voice."

To resolve the lexicological confusion, the roundtable panelists tackled how terms such as patient experience, engagement, and satisfaction relate to one another, along with approaches including patient-centered design and patient-reported outcomes measures (PROMs). Patient engagement is an input that improves care, whereas patient experience and satisfaction are ideal outcomes of care. See "Taxonomy of the Patient Voice" for a framework emanating from the roundtable.

The NEJM Catalyst Insights Council survey, which went to clinical leaders, clinicians, and health care executives at organizations directly involved in health care delivery, reveals a considerable gap between perception and action around the patient perspective. Although two-thirds of Insights Council members consider measuring and improving the patient experience a significant priority and strategic goal for their organizations, 42% say their attempts to incorporate patient feedback for systemic improvements are not very effective or not at all effective.

This discrepancy did not surprise our roundtable panelists—after all, they witness the challenge to properly hear patient voices every day in their own organizations.

Heisler, who as an internist sees mainly middle-aged and older veterans with multiple morbidities, says quality measures ironically can make it difficult to incorporate the patient voice in care. "We can't really introduce the individual patient voice and goals when we're also dealing with one-size-fits-all quality measures," she says. If she takes patient preferences into account, then her performance measures could suffer. She argues for change in the design of measures.

For instance, guidelines suggest that adults with diabetes should have an HbA1c level of

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less than 7%. But Heisler says that could fail to meet the preferences of a patient with multiple morbidities and a limited life expectancy who chooses to focus on quality of life rather than taking insulin and multiple medications to meet that quality metric.

Wagle, who splits his time between being an internist and a quality chief, echoes the complaint about poorly focused measures. "Once you're measuring [providers] on cost and asking them to lower their costs, you need a counterbalance, and that counterbalance has been quality measures," he says. "And then you realize, wait a minute, the quality measures we're using are a terrible counterbalance for what we're trying to do in terms of cost reduction, because they capture only a narrow slice of the care we deliver and they don't capture it particularly well."

A good first step in overhauling today's metrics would be for health care providers to move beyond the concept of patient satisfaction,

which is too simplistic, Heisler says. A patient can be satisfied that the doctor gave him antibiotics for the sniffles but that doesn't mean the doctor or the organization understands how confident the patient is in their ability to deliver quality care. Therefore, making system-wide changes based on poorly conceived satisfaction scores alone is often misguided, she says.

It is imperative that clinicians work to understand each patient's values, culture, and belief system as well as the health-related social needs, including economic status and education background, she says. In addition, clinicians should take the time to find out whether patients' preferences and goals are at odds with standard treatment and be sure patients are fully informed when they participate in treatment decisions.

Mohta asks, "How many patient preferences are universal truths?" Some patients care deeply about bedside manner, others put much more value on health outcomes.

Whatever care plan is needed, two-way communication creates confidence, says Peden. From the patient point of view, "if you understand the process of what's going to happen to you, you can work with it as an engaged patient. With acute illness and acute episodes of care, if you keep the patient informed, say, immediately after surgery that you are going to have pain but it will get better, then patients will do better than if nobody's told them about the pain. Whereas that's different

with a chronic illness—you need to be informed and perhaps given coping mechanisms, because it may not get better. So information back and forth is very important."

At Memorial Sloan Kettering Cancer Center, Niehaus and the PFAC she founded and now leads works to keep patients and families in close collaboration with clinicians and administrators on many system improvements. For instance, the PFAC is helping clinicians understand patient crisis points, such as when cancer patients transition from months of active treatment and monitoring and are sent home. "One would think that would be a happy moment, but it's a terrifying moment for some people because they feel lost and set adrift," Niehaus says.

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Patients say to themselves, 'I'm used to coming here every three weeks. Now you're telling me come back in six months? Who's watching me? How do I work with a primary care physician? Do I call you if I have a cold? What's the science behind scans every six months?'"

Another crisis point surfaced by the Memorial Sloan Kettering PFAC is discussions about the end of life. Clinicians tend to shy away from this topic, Niehaus says, but she believes that how well a patient and family is kept informed in the months and weeks leading up to death should be assimilated into quality measurements. The family caregivers in the PFAC have suggested three buckets for end-of-life metrics: discussions on values and goals of care frequently throughout cancer treatment; access to services such as social work, chaplaincy, and counseling; and the transition to hospice, complete with continued communication from the primary oncology team.

The process of mapping the cancer journey based on the patient voice helps patients access the resources and information they need and helps clinicians learn how to address patient fears and allay them, Niehaus says. In the Insights Council survey, the creation of patient representatives and patient councils was rated the most promising trend for capturing the patient voice.

One of the biggest barriers today is being able to adequately capture the patient voice at all steps along their journey. Peden expects consumer technology such as apps to help and enable more patient-generated inputs to be automatically factored into care delivery. How to handle the volume of data that might be generated will have to be considered carefully, she says.

Patient data from sensors might overwhelm clinicians today, but Peden anticipates that in five to 10 years, artificial intelligence, machine learning, and analytics will be used to seamlessly blend the petabytes of data into electronic health records so physicians can easily digest it and discuss the highlights in a meaningful way with patients at the point of care.

Heisler is eager for that advance to arrive. She says technology also could help mitigate the burden that many patients and clinicians feel today when filling out feedback forms such as HCAHPS and patient-reported outcomes. Ideally, an intelligent system would record critical information such as patient preferences and goals as well as their social and behavioral determinants of health, and prompt clinicians via an automated dashboard to ask just one or two targeted questions in person rather than sending the patient off to answer 50 standard questions.

A key potential for patient engagement technology, in Peden's opinion, is the ability to automate the mapping of the patient journey. Instead of limiting their patient connection to episodes of care, providers will be able to visualize overall patient health and how the patient interacts with the entire health system. Gaps in care will be easier to spot and address. And clinicians will be able to use the data to better set patient expectations and work with them. For instance, heart failure management programs in many practices already employ smart scales that communicate the patient's daily weight directly to their management team. The patient and team can learn at a much faster rate about what individual factors influence fluid retention and how to avoid them.

The roundtable panelists agree that integrating the patient voice into care delivery is a necessity today, not a nicety. Clinicians are more willing

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than ever to take patient preference into account. Wagle points to a recent spine surgeon summit among Partners' five major hospitals. The surgeons were shown unblinded data variations in their care, including PROMs. "There was significant variation, as you might expect," he says. "But I was impressed with how people received the information." The neurosurgeons and orthopedic surgeons were rated in terms of function, pain, quality of life after surgery, their cost versus average cost, length of stay, and use of opioids. Wagle says they approached the exercise with great humility, eager to explain what they do and why they do it but willing to accept that there might be a better way.

Peden says that capturing the patient voice has helped give provider organizations a different perspective on the need for certain procedures and practices. In the case of prolonged epidural infusions for joint replacements, for example, clinicians' priority was to reduce patients' pain, but patients reported they wanted the tradeoff of faster mobility, she says.

Transparency in health care should be embraced rather than feared, Peden says. Wagle adds, "You hear all the time this theory that clinicians are afraid that if you add patients to this conversation, it changes the nature of the conversation in negative ways, and then every time people do it, they say the patient completely transformed the conversation in totally positive ways."

"From a patient standpoint," Niehaus says, "there is incredible power in transparency. They feel [from clinicians], 'You trust me. And I can see how hard you are working to make this better.' … It's a wonderful thing [for patients] to be included in care processes."

Ultimately, say our roundtable panelists, the patient voice reflects patient and provider wishes alike. "The patient voice is about capturing what really happens to patients. So for providers, living that journey with them, understanding their personal experience," Peden says. "It really is getting to the heart of what makes good care."

Taxonomy of the Patient Voice

By Neil W. Wagle, MD, MBA

While health care pursues the important trend of putting patients at the center of care, the terms used to describe this goal are proliferating. From patient experience to patient satisfaction, patient engagement to patient activation, patient-reported outcome measures to patient-generated health data, these terms muddy the discourse instead of crystallizing it. The following taxonomy is an attempt to classify some of these terms and make some distinctions. It is by no means the final word, but may serve to push forward a dialogue on what we mean when we talk about the patient voice.

In the Design of Care

Too often, the health care system has designed patient care around the needs of providers and around infrastructure—particularly high-cost fixed infrastructure. This is common in industries where resources are centralized, specialized, and over-capacity, but it is unsustainable in health care. The design of care must ultimately be centered on patients.

Patient-centered design (system design)

Patients should play a leading role in designing all aspects of health care—from physical spaces, to workflows, to communication templates. Provider systems and payers have an important perspective but often assume knowledge of the patient's perspective, sometimes incorrectly. Incorporating the patient's voice in the design of systems of care can improve the quality of care delivered. Patient-Family Advisory Committees (PFACs) are a great place to gather this input.

Co-production of care (individual design)

As important as the patient voice is in system design, it is equally important in the care of each individual. Treating patients as the object or even the subject of care is a misconception in today's world. Instead, patients should be considered co-producers of care, because every health outcome is the product of provider activity and patient activity. Patients should have a say in the strategies to pursue certain outcomes and how the logistics of how those strategies are carried out.

As an Input to Care

Thankfully, health care has moved away from the notion that "objective" data is all that is needed. There are numerous ways in which providers should consider an individual patient's voice as an input variable in deciding what care to deliver and how to deliver that care. All of these inputs can be considered patient-generated health data.

Goals, values, and preferences

All patients are not the same. Even in the case of the same diagnosis, there are differences in what individual patients want out of their care (outcomes) and what is important to them along the way (processes). Trying to achieve a good result without understanding how a patient defines "good" requires assumptions that often lead providers astray.

Patient engagement

Patient engagement—how much a patient is willing and able to take in new information and grapple with the realities of care—is an important input. Treatment tactics used for a highly engaged patient may fail on a less engaged patient. Conversely, a lowest common denominator approach may squander opportunities for exceptional results in more engaged patients. Patient engagement is an important pre-condition for patient activation, which is using one's own health care knowledge, skills, and confidence to take independent action related to one's health.

Biometric data / sensors

Our bodies and activities speak volumes—often generating much more relevant information than labs or radiographs. Biometric data, such as

Taxonomy of the Patient Voice

The patient's voice is critical to health care. Here are the ways it can be included.

In the *Design* of care	As an *Input* to care	As the *Outcome* of care
Patient-centered design (system design) • Patient and Family Advocacy Council (PFAC) Co-production of care (individualized design)	Patient goals, values, and preferences Patient engagement → activation Biometric data / sensors Patient Reported Outcome Measures (PROMs) Patient needs • Health-related social needs • Informational needs (language, preferred communication, health literacy, knowledge) • Social isolation	PROMs • Symptoms • Physical function • Mental / social health • Quality of life Patient experience • Confidence/trust • Peace of mind Patient satisfaction • How did the process of care compare to my expectations?

steps or sleep, will increasingly be a critical input to patients' risks for particular outcomes as well as rich targets for intervention.

Patient-Reported Outcome Measures (PROMs)
PROMs validly quantify symptoms, physical function, mental health, and quality of life. Quantifying symptoms and function allows providers to augment history-taking with reliable numerical measurement to determine the most appropriate intervention.

Patient needs

• *Health-related social needs*
Social determinants of health (SDH) are known to contribute more to the health outcomes of a population than to care delivery. Health-related social needs indicate patient needs related to housing, food, the ability to afford medications, community safety, etc. Trying to treat medical conditions without considering the context of these needs will often be less effective.

• *Informational needs (language, preferred communication, health literacy, knowledge)*
People consume information differently, and have different preferences for formats and channels such as a text message, phone call, or written letter. Understanding the health literacy of a patient is also crucial for accomplishing one of the most important levers in health care: communication.

• *Social isolation*
Loneliness can be deadly; the social context of a patient is an important input to care. It's important for providers to know whether a patient lives alone or has a supportive spouse or children, whether there is a friend or a community to provide support, and who a patient can go home to after an episode of care.

As the Outcome of Care
Health care commonly measures hard outcomes like mortality, but some of the outcomes that matter most to patients are only measurable by quantifying the voice of the patient.

PROMs
Patients usually seek care to ameliorate a symptom, improve physical function, or protect mental health. PROMs measure these outcomes.

Patient experience
In addition to the length and quality of life, one important outcome of care is peace of mind. When a care episode is over, it matters to patients whether they feel confidence that all that should have been done was done, independent of other outcomes. Confidence is built through good communication, a sense of teamwork among providers, and the belief that the provider cares about the patient.

Patient satisfaction
This measure of how well health care meets the patient's expectations is distinct from having confidence in care. Aspects of satisfaction include wait times, amenities, the processes of receiving care, and how the patient felt along the care journey.

Data Analysis

Kevin G. Volpp, MD, PhD
Janet and John Haas President's Distinguished Professor and Director, LDI Center for Health Incentives and Behavioral Economics, Perelman School of Medicine and the Wharton School, University of Pennsylvania; NEJM Catalyst Patient Engagement Theme Leader

Health care providers invest enormous time and money trying to capture the patient voice through standardized measurement tools such as HCAHPS and patient-reported outcome measures (PROMs). Nonetheless, our latest NEJM Catalyst Insights Council survey, "Measuring What Matters and Capturing the Patient Voice," reveals that many providers haven't figured out how to incorporate patient feedback in a way that systematically improves the care they provide. Nearly three-fourths (73%) of survey respondents consider this a major barrier to truly capturing the patient voice.

Insights Council members include clinical leaders, clinicians, and health care executives. Two-thirds of these respondents consider measuring and improving the patient experience to be a significant priority and a strategic goal for their organizations. Despite this, only 18% think their organizations' efforts have been very effective or extremely effective in leveraging patient feedback for systemic improvements. This gap between the desired and current state suggests that health care providers should

make a concerted effort to design the health delivery system of the future in a way that better incorporates the patient voice.

As an industry, we need to find ways of eliciting feedback that provides a truer and more real-time view of the patient experience. Consumerism, which ranks second among the most promising trends for capturing the patient voice in our survey (chosen by 48% of respondents), could prove an excellent opportunity to amplify the patient voice.

In a recent article, "Learning by Listening – Improving Health Care in the Era of Yelp," my co-authors Raina Merchant, MD, David Asch, MD, and I argue that "a record like Yelp provides insight into the patient experience" that is not restricted by any biases that may be embedded within questionnaires and surveys. Online review platforms like Yelp can be an interesting complement to institutional feedback mechanisms such as HCAHPS surveys, which, as we write, can be expensive to deliver and have low response rates that threaten their validity.

Many health care providers worry that complaints on Yelp and other unstructured forums about such things as crowded parking lots and waiting room times will drown out comments about the technical quality of care. However, a large percentage of our respondents indicate that gathering patient input (45%) and feedback (30%) to improve the delivery of health care and to improve quality outcomes are important, highlighting that we should be open to input from a variety of channels.
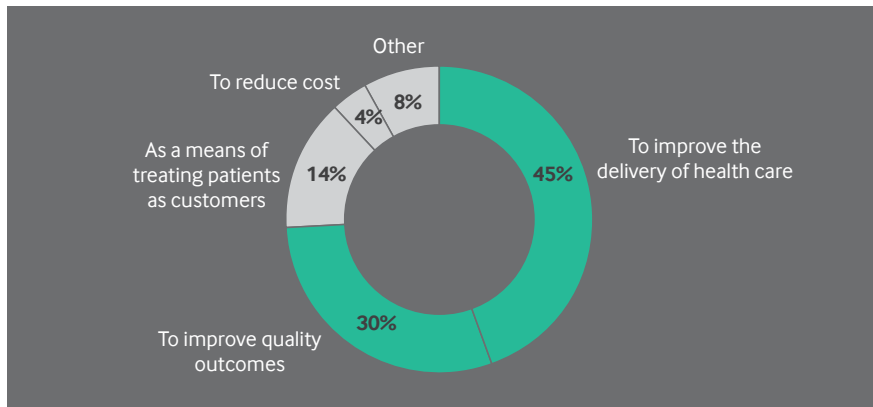
Moreover, many provider organizations have in place ways to quickly fix issues such as parking (which does materially affect the experience of patients), but not their systems of care. If health systems expeditiously resolve such complaints, then the free online review platforms will capture a better sense of patient sentiment about the quality of care delivered to them.

Free online reviews also provide a forum for families and caregivers to express their opinions about the patient experience – a viewpoint that is highly informative but often overlooked.

For providers worried about the chaos that could come with this democratization of the patient voice, consider the travel industry and the remarkable transformation brought about by online review platforms. Where travelers once relied on travel agents or a review from a single expert in a travel guide, they now have the reviews of many other customers to inform their decisions. Doctors have to trust that when the same platforms focus on the experience of patients with health care, then patients who choose to use these services, like travelers, will find tremendous value.

Data Discussion

What is the most important reason health care organizations gather patient input and feedback?

Other 8%
To reduce cost 4%
As a means of treating patients as customers 14%
To improve the delivery of health care 45%
To improve quality outcomes 30%

Is measuring and improving patient experience a meaningful priority at your organization?

No 2%
Stated as a priority but not in actuality 18%
Yes, but a minor priority 14%
Yes, a signifcant priority and strategic goal 66%

Michele Heisler, MD, MPA

"It's a sign of respect to recognize that patients are informed consumers of health care and you need to meet their needs."
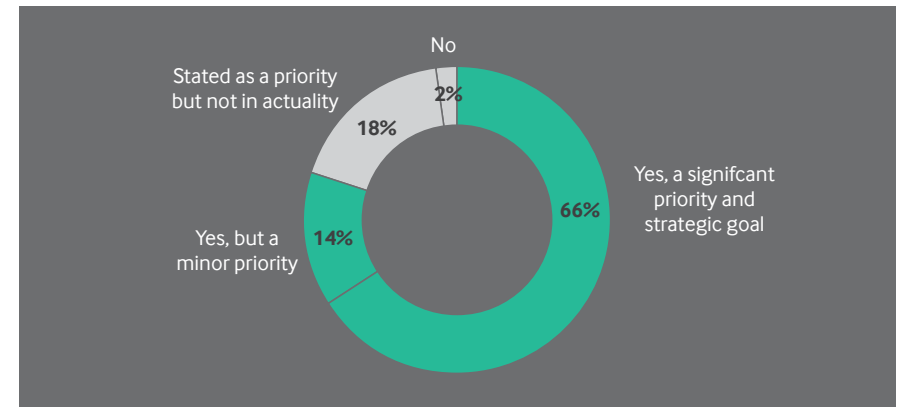
Namita Seth Mohta, MD

"This is where the value of apps and sensors is realized. Subjective and objective data provide regular and timely feedback about what a patient is experiencing. We can better appreciate what an individual patient is going through, as well as identify overall themes within populations of patients."

Neil W. Wagle, MD, MBA

"Capturing the patient voice is a proxy for putting the patient at the center of our care."

Kate Niehaus, MBA

"This should be a priority and strategic goal for everyone. Health care institutions are supposed to be caring about patients."

Neil W. Wagle, MD, MBA

"People say that [patient experience] is significant, and yet [they're] not really effective at doing anything about it, and often when [they] do something about it, it doesn't make a difference or there's no return on investment. That's an interesting dichotomy."
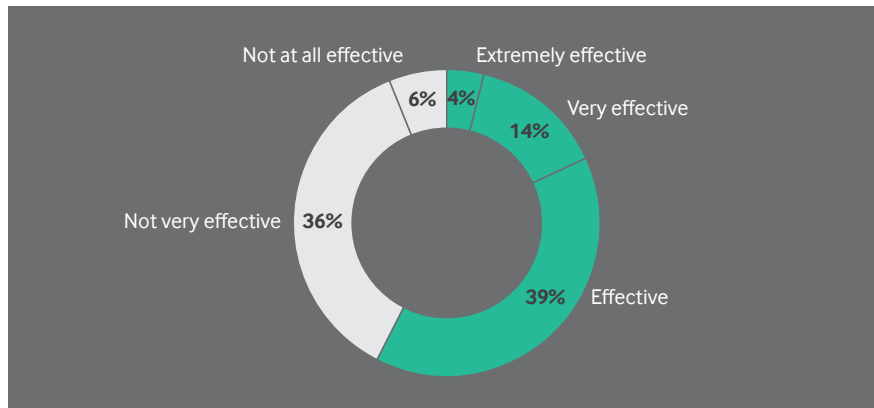
Carol J. Peden, MD, MPH

"It's more about the will than the actions at present. We all think [measuring and improving patient experience is] a good idea."
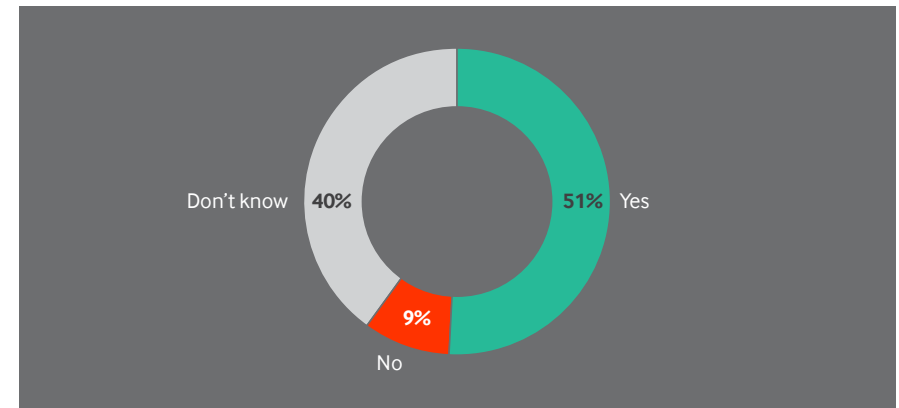
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Data Discussion

How effective is your organization in leveraging patient feedback or data to make systemic improvements to care delivery?

Does measuring and improving patient experience have a tangible return on investment?

Michele Heisler, MD, MPA

"At the Veterans Administration, [capturing the patient voice] will be greatly facilitated when it's automated and … when it's seamlessly integrated, so it's right there [on my screen] and I can be primed to focus right in on the patient's identified key concern: 'I'm sorry you're depressed today. Tell me more.'"

Namita Seth Mohta, MD

"What gets put on that [hospital] dashboard conveys a strong message about what leadership thinks is important. If you spend more time evaluating whether the patients liked the décor of a hospital room than evaluating how effectively a discharge coordinator came in and talked to a patient about their discharge options … you're sending a certain message."

Edward Prewitt, MPP

"There is a will to make patient experience a priority, but it's often not matched with action."

Neil W. Wagle, MD, MBA

"Redesigning the process [of care] has a tremendous ROI."

Edward Prewitt, MPP

"Many, many hospitals and health systems market how they score on various aspects of patient experience."
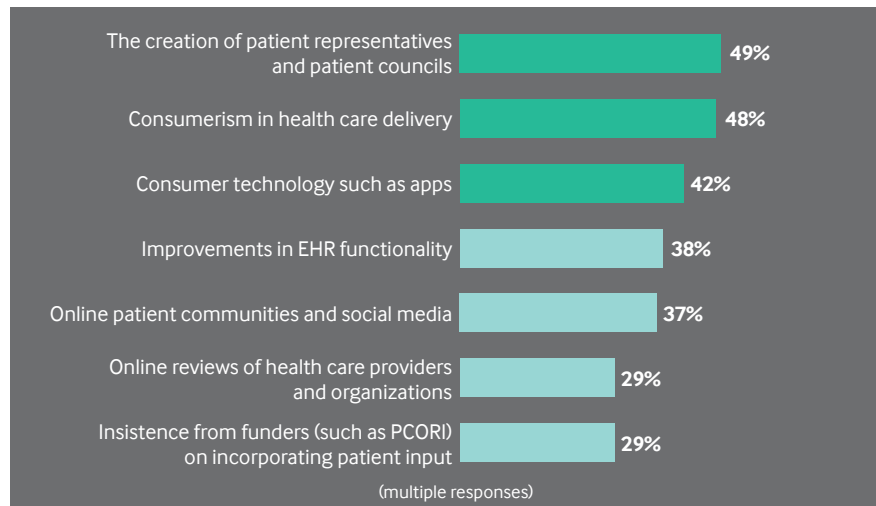
Namita Seth Mohta, MD

"People might answer this differently if they're thinking about patient experience versus patient satisfaction."
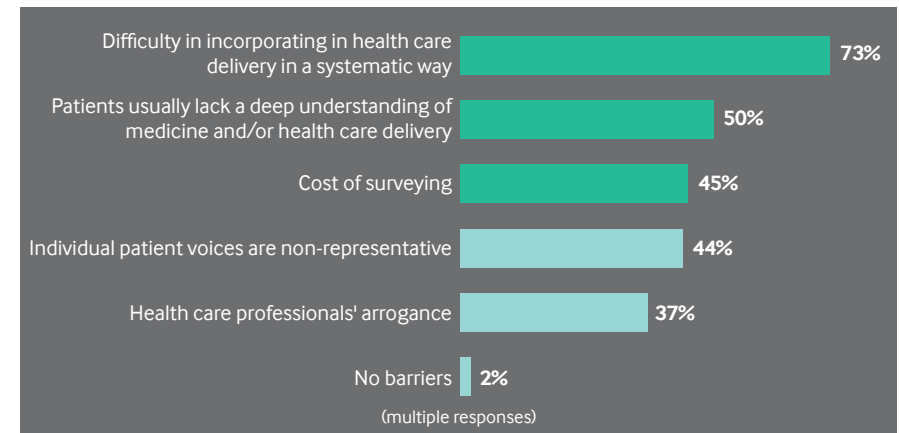
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Data Discussion

What are the top three most promising trends for capturing the patient voice?

The creation of patient representatives and patient councils	49%
Consumerism in health care delivery	48%
Consumer technology such as apps	42%
Improvements in EHR functionality	38%
Online patient communities and social media	37%
Online reviews of health care providers and organizations	29%
Insistence from funders (such as PCORI) on incorporating patient input	29%

(multiple responses)

What are the top three major barriers to capturing the patient voice?

Difficulty in incorporating in health care delivery in a systematic way	73%
Patients usually lack a deep understanding of medicine and/or health care delivery	50%
Cost of surveying	45%
Individual patient voices are non-representative	44%
Health care professionals' arrogance	37%
No barriers	2%

(multiple responses)

Kate Niehaus, MBA

"There's a whole shift to consumerism in general, and health care is certainly not immune to that. It's a whole generation that's used to questioning everything they are purchasing and consuming, and wanting to understand what the value is and how high the quality is."

Neil W. Wagle, MD, MBA

"Consumerism would be great if the variables that people were using were appropriate, but they're using bad variables because those are the only variables out there."

Carol J. Peden, MD, MPH

"Physicians and administrators worry about getting extreme views [of individual patient voices], but from every opinion there are things you need to think about and look at."

Kate Niehaus, MBA

"You're not going to capture the patient voice if you're talking all the time."
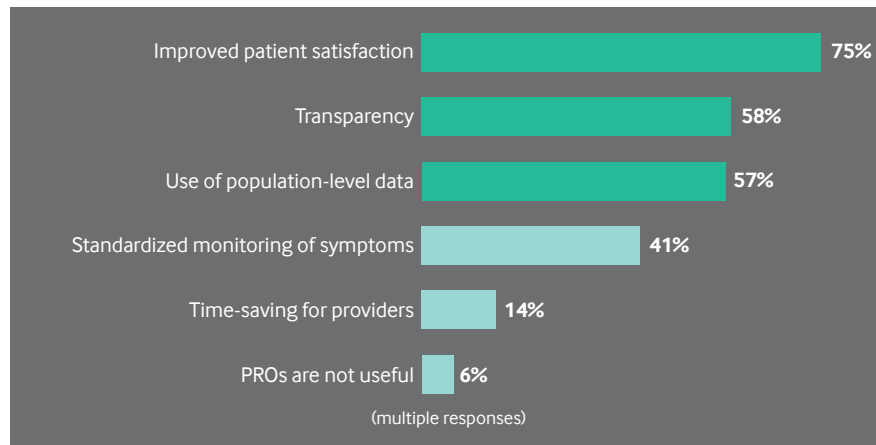
Michele Heisler, MD, MPA

"I was a little concerned that 44% of people said individual patient voices are non-representative. I think what they are saying is that you need to [capture patient voices], just not randomly."
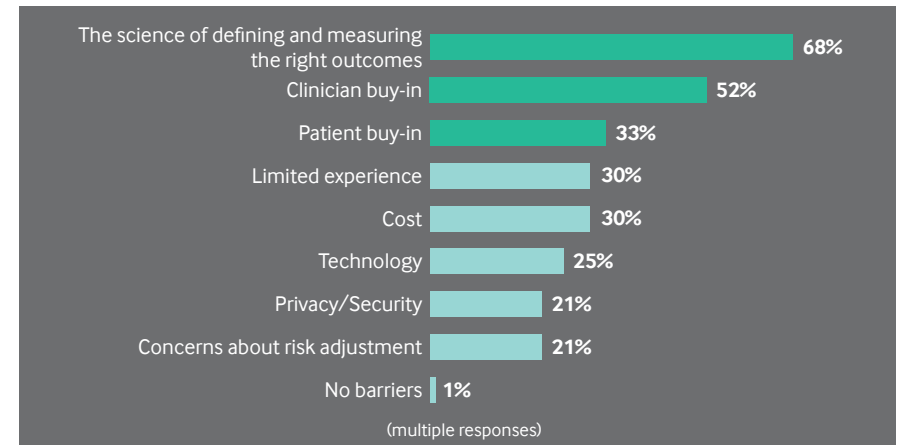
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Data Discussion

What are the top three most important uses of patient-reported outcomes (PROs)?

Improved patient satisfaction	75%
Transparency	58%
Use of population-level data	57%
Standardized monitoring of symptoms	41%
Time-saving for providers	14%
PROs are not useful	6%

(multiple responses)

What are the top three major barriers to collecting patient-reported outcomes (PROs)?

The science of defining and measuring the right outcomes	68%
Clinician buy-in	52%
Patient buy-in	33%
Limited experience	30%
Cost	30%
Technology	25%
Privacy/Security	21%
Concerns about risk adjustment	21%
No barriers	1%

(multiple responses)

Carol J. Peden, MD, MPH

"There's some good examples now of how [patient-reported outcomes] are being used to redesign care or simplify options offered."

Kate Niehaus, MBA

"It may be that if I get to fill out a form where I get to answer questions about quality of life, mental health symptoms, and functionality, then I will be more satisfied with my care."

Neil W. Wagle, MD, MBA

"Probably the biggest determinant of whether a patient fills out their PROM is the providers' engagement in the data."

Kate Niehaus, MBA

"What would happen if you stopped measuring things like food and parking and appearance of the room? Would performance fall off in those areas, or would it create just a shift in emphasis to the things that we really care about? I'm not implying that you wouldn't pay attention when people complain. But it's the formal reporting of that score that I think drives behavior that way."

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Survey Methodology

- The Patient Engagement Survey: Measuring What Matters and Capturing the Patient Voice was conducted by NEJM Catalyst, powered by the NEJM Catalyst Insights Council.

- The NEJM Catalyst Insights Council is a qualified group of U.S. executives, clinical leaders, and clinicians at organizations directly involved in health care delivery, who bring an expert perspective and set of experiences to the conversation about health care transformation. They are change agents who are both influential and knowledgeable.

- In May 2017, an online survey was sent to the NEJM Catalyst Insights Council.

- A total of 774 completed surveys are included in the analysis. The margin of error for a base of 774 is +/-3.5% at the 95% confidence interval.