The Power of the Patient Voice

How Health Care Organizations Empower
Patients and Improve Care Delivery

NEJM Catalyst

For the past few years, patient-centered care has been an intense focus of health care leaders as well as a byword for excellence in care delivery. Yet patients still have little influence in matters that impact them the most. The jury is still out on how to rethink care in a way that amplifies the voice of the patient.

In this eBook, *The Power of the Patient Voice,* we examine how leading health care organizations have given patients a more prominent voice, so they can take greater responsibility and be more accountable for their own care. We use data gathered throughout the past year from NEJM Catalyst Insights Council surveys and one-on-one interviews with Insights Council members to illustrate the need for health care professionals and health systems overall to listen more intently to patients in order to strengthen engagement and adherence to care plans.

Insights Council members – a qualified group of executives, clinical leaders, and clinicians directly involved in health care delivery – share firsthand their challenges and experiences in evolving care delivery to empower patients. They discuss how their organizations are:

• *moving away from fee-for-service models to empower the patient voice;*

• *integrating social determinants of health and patient values into care plans;*

• *improving collaboration, including care team documentation, to carry the patient voice through the continuum of care;*

• *adapting health care access to align with patient needs; and*

• *updating medical training to include the importance of patient empowerment.*

Throughout this eBook, Insights Council members share their experiences, ideas, and best practices to help you improve care delivery in your own organization by hearing the patient voice more clearly.
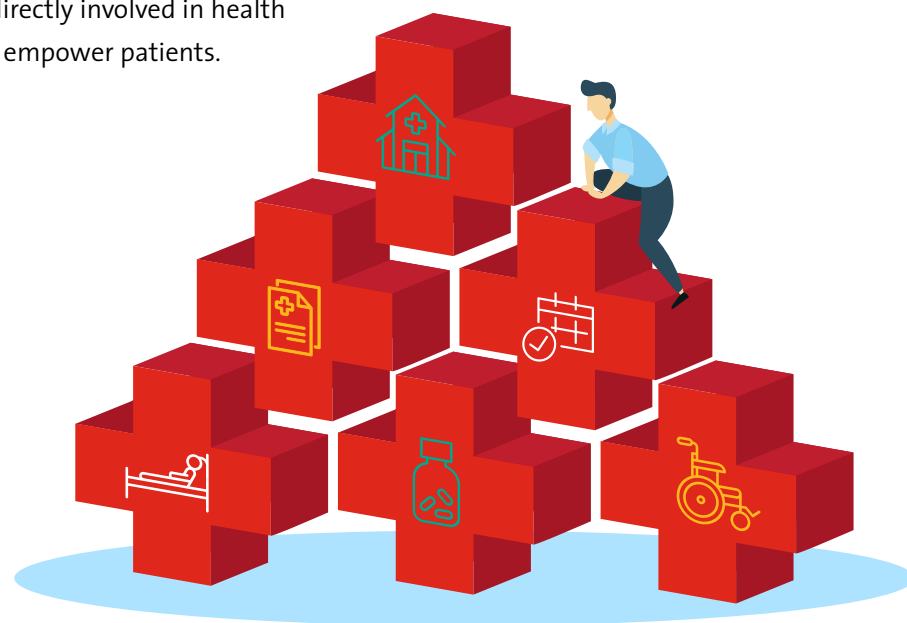
KATE NIEHAUS, MBA

Patient Advocate for the Patient Family Advisory Council for Quality at Memorial Sloan Kettering Cancer Center

"The patient voice adds a different perspective to everything that goes on in health care and can point out real gaps in the system."

Defining the patient voice

Patients are said to be the center of health care but too often their voices are ignored or put to the side when decisions are being made – decisions about their health, their treatment plans, the cost of their care, and more. Care that is patient-centric can still be lacking if gaining input from patients themselves is not an integral part of the process.

"The patient voice adds a different perspective to everything that goes on in health care and can point out real gaps in the system," especially systems that are physician-focused, says Kate Niehaus, MBA, patient advocate for the Patient Family Advisory Council for Quality at Memorial Sloan Kettering Cancer Center in New York.

Amplifying the patient voice requires buy-in from the entire organization. "This can't just be a one-off effort. If the patient voice is not embedded in your organization's processes and systems, then real change won't happen," says Mary O'Connor, MD, Professor of Orthopedics and Rehabilitation at Yale School of Medicine in New Haven, Connecticut.

Patient-reported outcome measures, or PROMs, are an example of how to institutionalize the concept of patient voice as the validated questionnaires enable patients to report back about their own symptoms and functions.

In a survey on the topic, 60% of NEJM Catalyst Insights Council members say the top reason to collect and use PROMs is to improve the patient experience. Yet, only 38% of respondents say their organization currently uses a PROMs system.

60% 38%
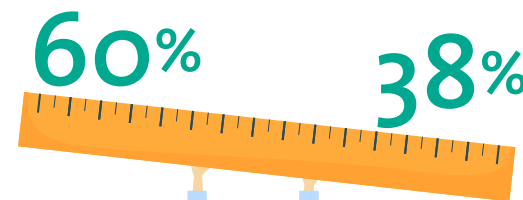
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CALUM A. MACRAE, MD, PHD

Vice Chair of Scientific Innovation for the Department of Medicine at Brigham and Women's Hospital and Associate Professor at Harvard Medical School

"Medicine is designed to hold onto patients and we have often inadvertently trained them to be dependent on us."

Making the patient voice a centerpiece of the organization's business model can sometimes result in a power shift. "Medicine is designed to hold onto patients and we have often inadvertently trained them to be dependent on us," says Calum A. MacRae, MD, PhD, Vice Chair for Scientific Innovation in the Department of Medicine at Brigham and Women's Hospital and Professor at Harvard Medical School. "Part of the reason the patient doesn't have a voice is because we tend to medicalize and consequently take over everything around certain activities while blaming patients for poor outcomes."

MacRae attributes this dysfunctional dynamic to liability. "Liability has driven the situation where all of the activities which are not fully described in protocols become the clinician's responsibility," he says. Everything from calling a patient to convey a test result to offering referrals for other health care services such as a physical therapy or nutrition have to go through a physician because of medicolegal and billing constraints, he points out. The solution, in his opinion, lies "in systematically transferring more power and responsibility to patients, thereby providing them with a louder voice."

How payment models can mute the patient voice
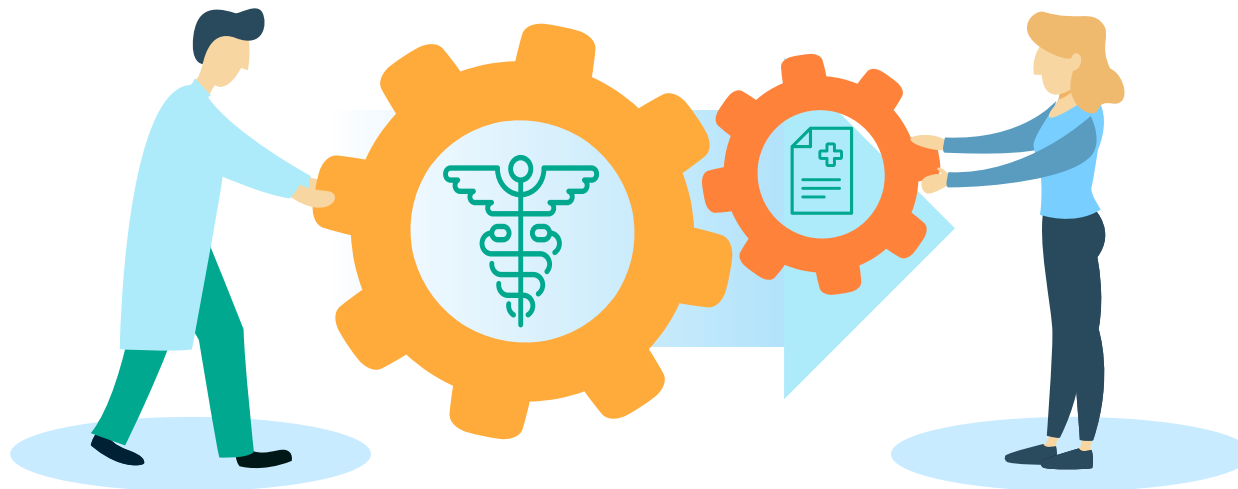
JEFFREY LOWENKRON, MD, MPP

CMO at The Villages Health

"We had to figure out how to stay viable and generate enough revenue to keep the lights on and staff paid while still spending enough time to really get to know our patients."

When The Villages Health was launched in Florida nine years ago, the health system's leaders wanted to overcome a common obstacle to hearing the patient voice: the financial reward for keeping visits short.

"We had to figure out how to stay viable and generate enough revenue to keep the lights on and staff paid while still spending enough time to really get to know our patients," says Chief Medical Officer Jeffrey Lowenkron, MD, MPP. Leadership wanted to avoid the trap of the dreaded 15-minute visit, "which just does not align well with the patient voice concept."

Managing a largely elderly population that often has multiple chronic conditions is made more difficult by the traditional reimbursement model, "which drives fragmented care and loses the patient voice," Lowenkron says. For example, under fee-for-service, while a primary care physician wouldn't get paid to treat multiple problems during a visit, the multiple specialists he might refer the patient to would get paid.

The Villages Health settled on a primary-care-driven, patient-centered, community-based care model that allows time to be spent with patients and aligns with improved care outcomes of the population as a whole. With this model, "patients we don't know get an hour with a PCP and patients we do know get a half hour," which Lowenkron says gives patients ample opportunity to share their stories and health concerns and physicians better ability to connect with them.

While a volume-based model suggests that if patients do poorly, health systems may do better because they run more tests, a full-risk model aligns outcomes with compensation so if patients do poorly, the health system also does poorly. This moves care delivery from "no money, no mission" to "no outcome, no income," Lowenkron says.

RENÉE CRICHLOW, MD, FAAFP

Director of Advocacy and Policy and Assistant Professor at University of Minnesota School of Medicine and Community Health

"When it's just the physician and patient – when the patient is the center of the discussion, not RVUs – we can work together to figure out what's effective, efficient, and appropriate."

Renée Crichlow, MD, FAAFP, Director of Advocacy and Policy and Assistant Professor at University of Minnesota School of Medicine and Community Health in Minneapolis, believes "there is a deep desire in health care right now to have the patient's voice, if possible, be central to care conversations." However, she also has found the patient voice "drowned out" by money interests.

"At some organizations, patients are treated like customers in that there is profit to be made," she says. "When it's just the physician and patient – when the patient is the center of the discussion, not RVUs – we can work together to figure out what's effective, efficient, and appropriate."

Crichlow believes universal access could be a cost-effective and clinically effective way to alleviate some of the industry's financial pressures. Insights Council members surveyed on the topic of Medicare for All, a form of universal coverage, say cost, quality, equity, and access to care would improve with Medicare for All, but 44% say the patient experience would worsen.

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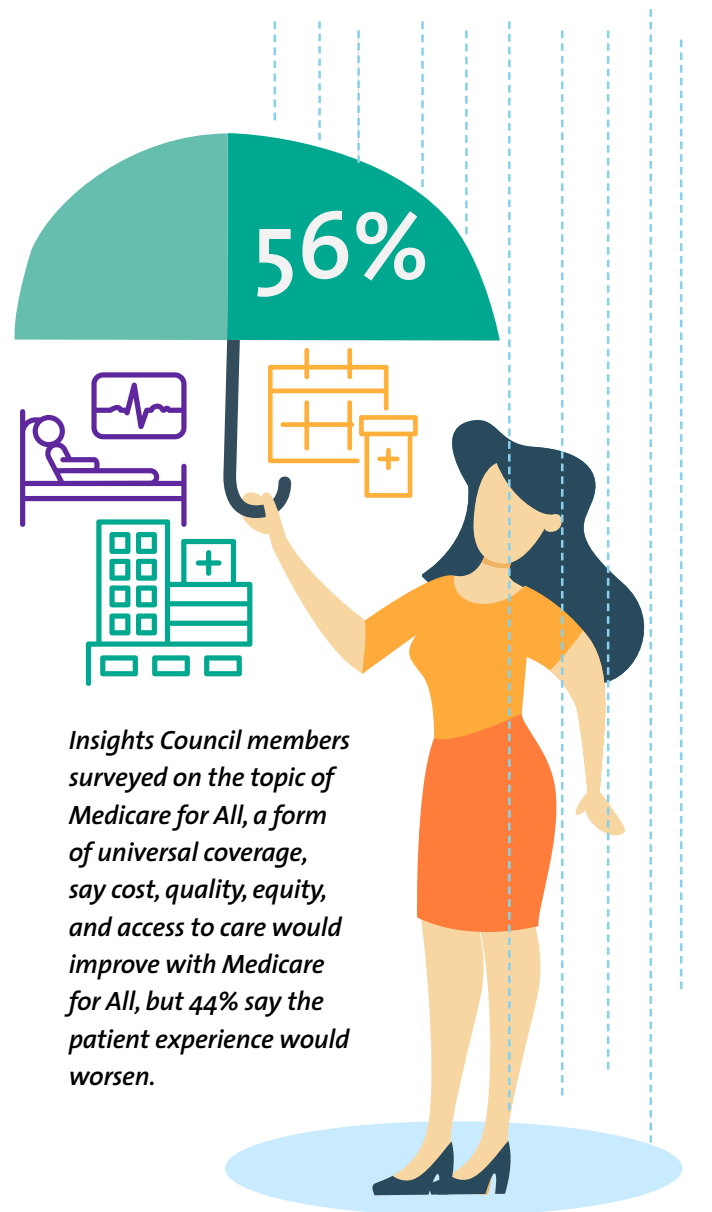
The power of integrating social determinants of health and patient values into patient care

JONATHAN DAVID, MSN, RN, CCRP, NE-BC

Cardiac Rehab Nurse Coordinator for Inpatient Cardiac Rehab at Stanford Health Care

"Sometimes our systems can be so complex and fast-paced that we don't take the time to pause and understand our patient enough. [Yet] there lies the opportunity to learn barriers to following provider recommendations and reduce readmissions."

When Crichlow practiced medicine in a rural Montana town, one of her patients, a farmer, required hospitalization for a critical condition. She arranged for him to be admitted but he refused, telling her, 'If I go to the hospital, we will lose our farm.' Crichlow told him that she didn't know how to care for him outside of the hospital, but the farmer proposed that he would come to the outpatient clinic every day and he kept his word.

"For me, that was a real eye opener to understanding a patient's needs and values, and being prepared to alter care plans accordingly," says Crichlow, who today cares for low-income populations. "You can't make assumptions about what a patient's resources are or the care they are capable of adhering to – you have to listen and meet them where they are."

Many organizations have started to dig into patients' social determinants of health such as health literacy and socioeconomic status to understand what might prevent them from showing up for follow-up visits, understanding how to manage their disease, or adhering to care plans. Nearly 100% of Insights Council members believe in the importance of using social determinants of health in patient care and they consider the top two benefits to be improving patient experience or satisfaction.

Understanding a patient's social determinants of health also can be instrumental in avoiding unnecessary readmissions, according to Jonathan David, MSN, RN, CCRP, NE-BC, Cardiac Rehab Nurse Coordinator for Inpatient Cardiac Rehab at Stanford Health Care. "Sometimes our systems can be so complex and fast-paced that we don't take the time to pause and understand our patient enough. [Yet] there lies the opportunity to learn barriers to following provider recommendations and reduce readmissions," he says.

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MARY O'CONNOR, MD

Professor of Orthopedics and Rehabilitation at Yale School of Medicine

"If I hadn't put the clinical decision-making within the context of her psychosocial environment, I would have come up with a different recommendation. Instead I amplified her voice above all others."

While 86% of Insights Council members say the patient has some degree of responsibility for avoiding unnecessary readmissions, trying to predict who might be at high risk for being readmitted based on their social determinants of health is the care team's responsibility, according to David.

For example, if an inpatient with a sternal incision has poor mobility and lives on the second floor of a motel with no elevators, the care team, as part of the discharge process, would advocate to seek living arrangements in a single-story shelter. That way, the patient wouldn't have to walk upstairs and risk the integrity of surgical incision. "Patients aren't always going to offer that information up, so you have to ask the right questions," David says.

O'Connor agrees, but sometimes that means overruling other caregivers such as family members. An elderly patient and her children recently came to O'Connor's office for a consultation about a knee replacement to resolve her arthritis. Her children thought the operation might help their wheelchair-bound mother walk again. In talking to the patient, O'Connor learned her values – and that she didn't want to go through rehab and was happy having people in her retirement community push her around in her wheelchair – she only agreed to the consultation to appease her children. O'Connor did not recommend the operation, instead explaining to the patient's children their

mother's point of view and that she would not be a good candidate for rehab. "If I hadn't put the clinical decision-making within the context of her psychosocial environment, I would have come up with a different recommendation. Instead I amplified her voice above all others," she says.

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JONATHON FIRNHABER, MD, MAED, MBA

Residency Program Director, Vice Chair of Academic Affairs, and Associate Professor for the Department of Family Medicine at the Brody School of Medicine at East Carolina University

"If a health care professional is going to ask about social determinants of health, they have to be able to back it up with resources."

If a health care professional is going to ask about social determinants of health, they have to be able to back it up with resources, according Jonathon Firnhaber, MD, MAEd, MBA, Residency Program Director, Vice Chair of Academic Affairs, and Associate Professor for the Department of Family Medicine at the Brody School of Medicine at East Carolina University. For instance, if a physician asks a patient about food insecurity and they admit to it, the physician should have information about a food pantry or grocery cards ready as a next step. "You might want to ask the question and be comfortable asking the question, but if you don't have the resources, you can't. That's where the difficulty often lies," he says.

Austin T. Welsh, MD, Geriatrician at Partners in Primary Care in Raytown, Missouri, says he dives into patients' social needs intentionally now, after doing so haphazardly for years. "I used to step into issues accidentally and it would be like stepping on a land mine. Now I go looking for the land mines," he says. The difference is he now devotes more time to each visit and has a comprehensive care team, including a social worker, at the ready to deal with whatever comes to light. For instance, an elderly patient recently came to see him complaining of repeated falls. After seeing her walk during the exam, he asked if she consumed alcohol and found out she drank often to cope with being raped at age 12. "I didn't find that out until an hour in. If I didn't have the practice I do, I would have never gotten to that – to her voice – or have been able to help her with trauma therapy," he says.

How pain can impact the patient voice

> "Pain is a great example of how we have overmedicalized and also not listened to the patient voice."
>
> CALUM A. MACRAE, MD, PHD

Pain is a multifactorial issue for patients and providers alike. Treatment begins with listening to the patient.

"Pain is a great example of how we have overmedicalized and also not listened to the patient voice," MacRae says. "Simple things like using a scale to describe pain are miscued and don't represent the overall impact of pain on their life. This is a more complex problem that demands a more inclusive approach to understand what pain means in each patient's life."

NEJM Catalyst Insights Council members seem to agree, with only 58% of survey respondents saying their organization's management of patients' pain is sufficient.

Firnhaber says the medical profession has allowed patients to assume that they should be able to live completely pain free. "Once you've squirted that toothpaste out, how do you put it back in the tube? You can't," he says, adding it is difficult to convince patients that they might have to live with some discomfort to avoid addiction. "And we can't just say we no longer value your opinion about your own pain."

Council members are split (36% say yes and 36% say no) on whether opioid reduction efforts led to

adverse consequences for patients with pain but a majority, 59%, agree that the benefits of limiting opioids in care delivery outweigh adverse consequences for patients with pain.

"People just want to feel like they can function and it is so important to critically listen to them in that moment," Crichlow says, adding that her practice uses a multifactorial approach to chronic pain, calling on an in-house behavioral health expert as needed.

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of Council members agree that the benefits of limiting opioids in care delivery outweigh adverse consequences for patients with pain.

Documenting the patient voice
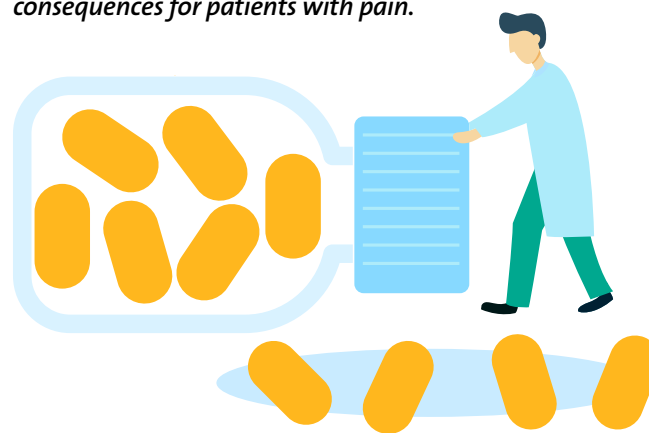
AUSTIN T. WELSH, MD

Geriatrician at Partners in Primary Care

"How can I make a note [that everyone down the line can access] when there are 10 different EHRs in one town?" he says. "The American health system gets an F for that. Electronic records are making doctor's lives difficult and hurting patient care."

It's one thing to get a patient to open up about their social determinants of health, their health goals, and their values; it's another to document that information so that the patient doesn't have to repeat it all along the care continuum.

"Those discussions about social determinants of health have an incredible amount of gravity," Firnhaber says. If they aren't documented properly and patients have to keep relaying their story, "the message back to the patient is 'you bared your soul, and no one cares.'"

But Welsh says the reality is more difficult. "How can I make a note [that everyone down the line can access] when there are 10 different EHRs in one town?" he says. "The American health system gets an F for that. Electronic records are making doctor's lives difficult and hurting patient care."

Niehaus says Memorial Sloan Kettering has a "patient values" tab in the EMR that acts as a repository for all the things that are important to a patient, including how they want to be cared for at end of life. "It's hard to get busy doctors to look at that tab, especially since it doesn't have clinical information about the patient," she says.
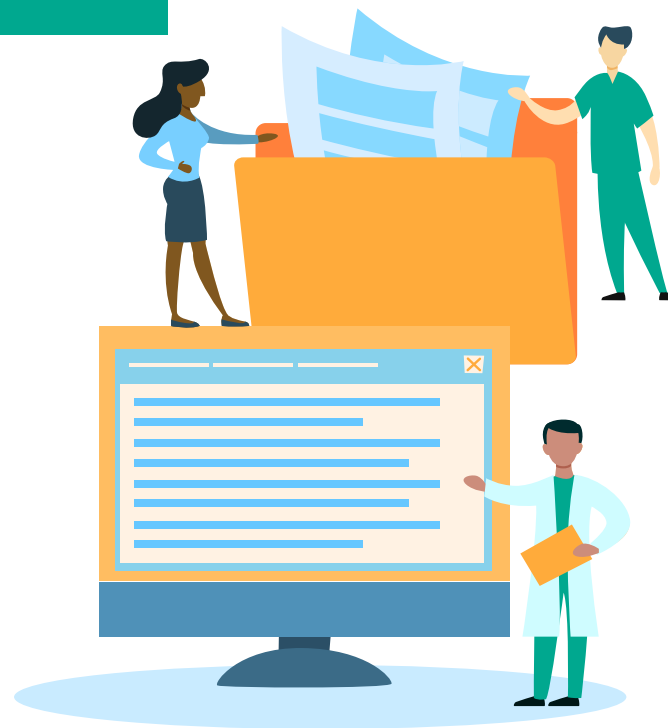
Although Yale University has a program called "PatientWisdom," which integrates with the Epic EMR and tracks patient goals, priorities, and barriers to staying healthy, O'Connor says it is not universally available for all the settings in which she practices. Standardizing the application would save time because everyone wouldn't have to ask patients the same questions.

"We are on the verge of being able to use our cell phone apps [with AI] to augment patient exams."

AUSTIN T. WELSH, MD

Information gathered from patients helps fuel applications driven by artificial intelligence and machine learning to spot trends and patterns. While only around a quarter of Insights Council members say their organizations make use of artificial intelligence/machine learning, nearly half have experienced a net improvement in patient health as a result.

In cardiology, AI, fueled by patient-reported outcomes and clinical data, is used to help patients understand the status and likely progression of their disease. "We can share proven predictive models that show the next three years of disease progression as well as how certain interventions and lifestyle changes will help them move up on their health curve," David says.

"We are on the verge of being able to use our cell phone apps [with AI] to augment patient exams," Welsh says, pointing to retina scans, hearing tests, and breathing checks for COPD or asthma as applications for AI. "A patient could read a standard passage and the app would pick up on irregularities in breathing." AI also will be able to detect patterns in labs, patient histories, and more to prompt physicians to ask questions or remember certain diagnostics.

MacRae says that patients should be empowered to provide their health data in meaningful ways outside of a clinic visit or transaction. "It is bizarre that we try to force so much of what we do into particular venues and particular models of care," he says. Health care, in his opinion, should be treated more like the rest of our lives and have patients join in the redesign of the system, including the tools they would be willing to use to share information, even when they are healthy. "Why do we wait until patients are sick to listen to them?" Boosting patients' voices means giving them ways to be heard outside of the four walls of the health system.

Educating next-generation medical professionals about the patient voice

"In terms of hierarchy, a medical student is not very likely to say to their attending physician, 'We should ask the patient what her preferences and values are.' That has to be a culture change from the top."

MARY O'CONNOR, MD

"Medical students should be trained in the importance of the patient voice," O'Connor says. Unfortunately, only 56% of Insights Council members believe that the education and training medical students receive in medical school is preparing them for the reality of health care.

Crichlow says students need to learn that patients can't heal unless their physicians know what healing means to them: "Patients need to know someone is listening to their story."

In David's opinion, medical and nursing school curricula need more emphasis on patient-centered care. For instance, an evidence-based treatment plan might seem appropriate but if the patient's values or socioeconomic situation don't support it, then it won't be adhered to, he says.

In the end, medical students are going to do what the faculty tells them to do, according to O'Connor. "In terms of hierarchy, a medical student is not very likely to say to their attending physician, 'We should ask the patient what her preferences and values are.' That has to be a culture change from the top," she says.

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How COVID-19 changed access and the patient voice

"We resisted the use of virtual care for the better part of a decade and yet we were able as an industry to pivot to deliver nearly 100% virtual care in only a few days when it suited us."

CALUM A. MACRAE, MD, PHD

COVID-19 has altered the trajectory of the patient voice in a positive way, according to Insights Council members.
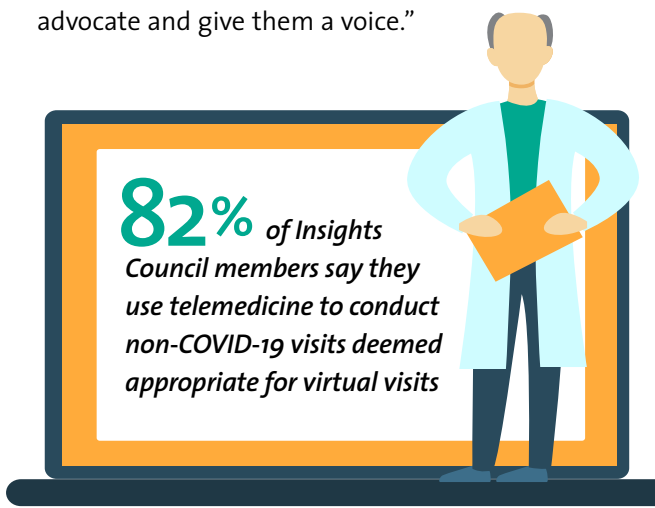
Patients decided early on in this pandemic that it was going to be too risky to come into health care settings for non-COVID care and "that decision was in conflict with fee-for-service care delivery systems, [which] needed patients to consume their services," Lowenkron says.

The result was the rapid adoption of telemedicine, which was approved for reimbursement by CMS. An overwhelming majority of Insights Council members, 82%, say they use telemedicine to conduct non-COVID-19 visits deemed appropriate for virtual visits.

"We resisted the use of virtual care for the better part of a decade and yet we were able as an industry to pivot to deliver nearly 100% virtual care in only a few days when it suited us," MacRae says.

Crichlow says the pandemic has been a learning experience, including that patients don't have to come to the office every time in order to stay healthy. That relationship can be sustained via telehealth. Another lesson: "In our society, we pay the least for the things that are most essential. In this case, primary care. We never stopped seeing patients and yet we can barely keep the lights on," she says.

Another way to help empower patients – outside of telemedicine – is to make their access to services a much smoother process. Before discharge, Cardiac Rehab inpatients are given the referrals they need and team members work to secure follow-up appointments for them, according to David. "We need to have a system that ensures patients get a follow-up appointment before discharge so they can quickly begin changing their lives in positive ways and not have to wait or come back due to a delay in care," he says. He pays particular attention to patients who don't have the health literacy to get proper follow-up care on their own. "They don't know the natural progression of the disease and I do, so I advocate and give them a voice."

82% *of Insights Council members say they use telemedicine to conduct non-COVID-19 visits deemed appropriate for virtual visits*

Empower your own patients today

"My institution is starting to recognize the real power in listening to the patient. The patient voice is getting louder all the time and being brought into more and more conversations."

KATE NIEHAUS, MBA

Change is happening already and organizations are making strides in amplifying the patient voice.

"My institution is starting to recognize the real power in listening to the patient. The patient voice is getting louder all the time and being brought into more and more conversations," Niehaus says.

MacRae believes all institutions can empower their patients by reimagining the allocation of responsibility from the ground up – rebalancing the partnership between physicians and patients.

"It won't be easy but it's something we really need to do," he says.

And O'Connor offers this advice to get started: "Measure patient-centered goals and patient-centered outcomes because whatever we measure, we work towards."

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We'd like to acknowledge the members of the NEJM Catalyst Insights Council. It is through their voice and commitment to the transformation of health care delivery that we are able to provide actionable data that convenes a collaborative dialogue about moving the industry forward in a positive direction. Insights Council members participate in monthly surveys and the results are published as NEJM Catalyst Insights Reports, including summary findings, expert analysis, and commentary from NEJM Catalyst leaders.

To join your peers in the conversation, **apply to the Council** today.

About NEJM Catalyst

NEJM Catalyst brings health care executives, clinical leaders, and clinicians together to share innovative ideas and practical applications for enhancing the value of health care delivery. From a network of top experts and advisors, our digital peer-reviewed journal, live-streamed events, and qualified Insights Council provide real-life examples and actionable solutions to help organizations address urgent challenges affecting health care.

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