

## COMMENTARY

# Getting to Patient-Centered Care in a Post-Covid-19 Digital World: A Proposal for Novel Surveys, Methodology, and Patient Experience Maturity Assessment

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July 14, 2020

DOI: 10.1056/CAT.19.1106

Covid-19 has challenged nearly everything about health care delivery, including the experiences of patients and families. Although the *how* of delivery has changed, the timeless and universal *commitment to patient-centered care* should not. We will keep patients safe, we will care for them as people, we will partner with them, and we will make it easier. The same is true of our own people, and their collective trust depends on our ability to keep these promises. We need to capture (or recapture) the humanity that is at the heart of health care. We need to design our operations to support true patient-centered care: *operationalized empathy*. Redesigning patient experience measurement and assessing our organizations' readiness to deliver on the promise of patient centeredness, will empower us to deliver not just *care*, but actual *caring*.

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*“One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.” — Francis W. Peabody, MD<sup>1</sup>*

If caring for the patient has been the goal in health care, we have not achieved it . . . yet. Don't get me wrong, we do kind things for patients on a daily basis. The *honor walks* that caregivers support when they line the hallway for organ donors. The *pause*, when clinicians take a moment to honor the end of a life and the efforts made to save the patient. Despite these and countless other quiet moments created when the clinician or employee takes a human interest in the patient, the vast majority of patients think health care is in a crisis and are dissatisfied with costs of care,<sup>2</sup> and for those who are having positive experiences, they rely on the individual heroes to deliver not just *care*, but actual *caring*.

The concept of *patient experience*, which clearly should be associated with patient-centered care, has become, over time, however, tied to HCAHPS scores, the mandated Centers for Medicare and Medicaid (CMS) inpatient satisfaction survey, and this is where patient centeredness has completely lost its way.

In this paper, we'll look at patient centeredness as it was originally intended, the practices that have emerged to operationalize these principles, how our organization is addressing the issue, and we'll share a vision of where the field still needs to go. Intentionally, these design principles and promises don't just apply to patients; they should be strategically expanded *to our employees and staff*.

In the midst of Covid-19, patient trust is on the line, virtual care has been embraced as never before, and the urgency to not slip back into complacency has implications for patient experience moving forward. Safety is paramount and demands inclusion into patient centeredness. Empathy is transcendent. Nearly everything has become virtual; families visit with each other over Skype given visitation restrictions, and barriers to virtual reimbursement and accessibility have come down, at least temporarily. We needed change before, and now it has arrived with a pandemic.

Amidst Covid-19, we must accelerate the maturity of the patient experience as a field by asking new questions and tracking new metrics with a focus on true patient centeredness. We need to embrace the interest in humanity and its expression through caring that Dr. Peabody described; and we do that by tapping our own empathy for the fragmented and complex system our patients attempt to navigate today: Imagining — and at times feeling — what another person feels, and then doing something about it. Imagine what empathy can do when fully operationalized.<sup>3</sup>

## The Evolution of Patient Centeredness

Almost 2 decades ago, the Institute of Medicine (IOM) published a report called “Crossing the Quality Chasm.”<sup>4</sup> The report highlighted that much progress had been made in health care at the time, but that improvements were still needed. Specifically, the report called out six improvement efforts essential to health care achieving its full potential; such a system would be safe, effective, patient-centered, timely, efficient, and equitable. *Patient centeredness* as a term was born with that paper and was defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” The definition remains the gold standard of patient centeredness, although multiple variations have been offered over the years.<sup>5,6</sup>

“*When was the last time you called your own practice? If you find yourself subject to multiple holds, prolonged messaging, and transfers that sometimes wind up as a dead end, you have some sense of what patients go through on a routine basis.*”

Less remembered, but equally important, are the design principles articulated for improvements in health care. One of these design principles recognizes the need for health care to center on

continuous healing relationships, which require a responsive system. Another principle calls out the need to customize care to preferences, and yet another emphasizes shared decision-making to the extent the patient wishes to be involved. Transparency and open access to information are also fundamental principles.

The IOM report was published in 2001. In 2006, the Picker Institute commissioned a report on patient-centered care to guide hospitals and organizations on how to actually achieve it. After a review of nine different patient-centered models, they identified several critical themes to all, which serve as the springboard for our maturity model:

- Education and shared knowledge
- Involvement of family and friends
- Collaboration and team management
- Sensitivity to nonmedical and spiritual dimensions
- Respect for patient needs and preferences
- Free flow and accessible information

Shortly after, Beach and Inui published on a new paradigm: relationship-centered care, an important evolution from patient-centered care.<sup>7</sup> Relationship-centered care is grounded in four principles, reciprocal influence, personhood, therapeutic potential of healing in relationships, and emotions as foundational. This addition was a pivotal expansion beyond just the patient — health care will never deliver the healing we want if patients are having great experiences and outcomes, but clinicians and employees are exhausted, disconnected, and burned out.

The past should inform us. And, accomplishments in the patient experience field — such as developments in bedside shift reports,<sup>8-10</sup> purposeful hourly rounding,<sup>11,12</sup> public transparency of patient satisfaction data, service excellence training,<sup>13,14</sup> clinician communication training,<sup>15</sup> and patient/family involvement in care<sup>16,17</sup> — must evolve even further if we are to truly deliver on the promise of putting patients at the center of all we do.

Two decades after the IOM report detailed the principles that should be respected for all patients, its concepts are even more relevant today. I've framed nearly all of them under the enduring umbrella of patient-centered care and associated promises we must keep if we are to earn trust and provide value in the wake of Covid-19: promises of safety, empathy, teamwork, and ease. They were essential before Covid-19, and I have no doubt they will outlive Covid-19 (and any other pandemics). We are thrust into a digital explosion that could serve to amplify these promises — if we design it to do so.

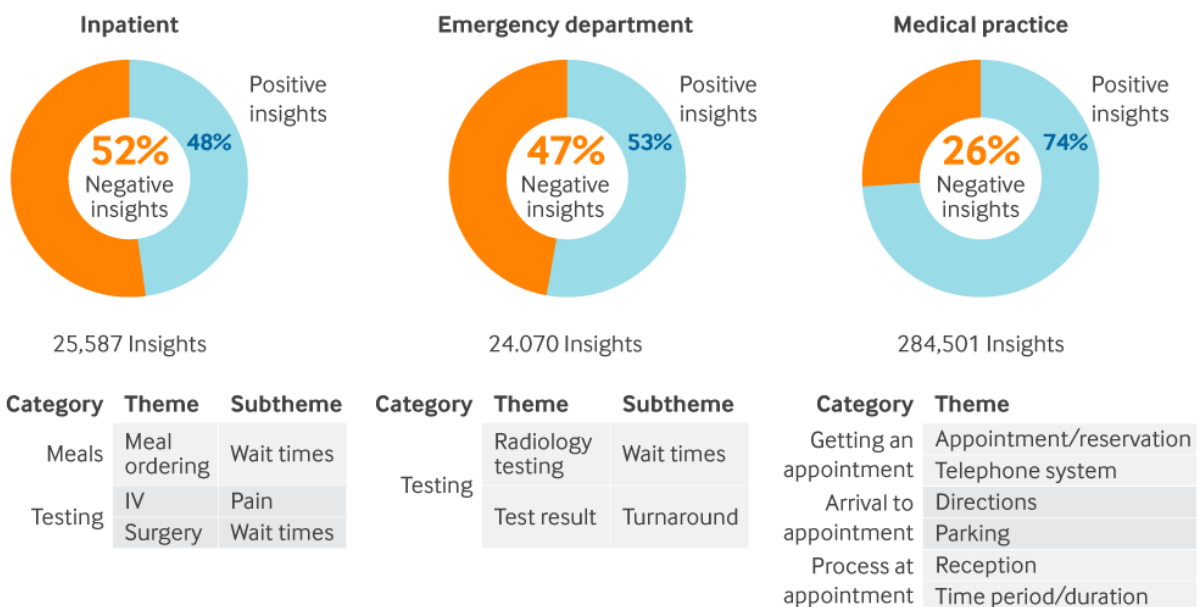
# Addressing Systemic Dissatisfaction

To get a better sense of what continues to drive systemic patient dissatisfaction in health care, at Cleveland Clinic, we categorized all patient comments from September 2019 to April 2020 patient satisfaction surveys (Figure 1).

FIGURE 1

## Negative Patient Comment Insights at Cleveland Clinic

Natural language processing was applied to all comments from September 2019 to April 2020. Categorized by three care settings — Medical Practice (Outpatient), the Emergency Department, and Inpatient — we further identified themes associated with negative comments from patient satisfaction surveys (boxes below). Lack of ease of access and timely responsiveness are drivers of negative comments, whereas positive insights (not detailed here) are driven by courtesy/respect, kindness, and empathy of doctors, staff, and especially nurses.



Source: Narrative Dx, a Press Ganey Solution.  
 NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

We find that positive experiences are significantly dependent upon communication with patients, their inclusion into care team, and their sense of being cared for by doctors, staff, and in particular, nurses. The pain points across all settings are a general lack of ease of use (waits for appointments, ineffective anticipatory guidance), a lack of timely responsiveness, and lack of communication and empathy around all of these issues. Importantly, the surveys do not ask about the billing experience, safety, nor empathy directly, which we continue to hear about from patients (and from caregivers as patients) through other data sources, and we hope to change.

Combining these real-world issues with the standards articulated by Picker and the IOM, the pain — and joys — become our patient-centered opportunities. Let's take a look at each one.

## Ease

### *Access to Data*

The use of patient portals has shifted both the work of the care team and the volume of messages for hospital systems and practices. The advantage of portals is that patients can do certain tasks when they want to: request refills or schedule an appointment without needing to go through a gnarled phone tree. Patient portals have led to new ways to communicate; however, pre-Covid-19 adoption rates by the health care industry and by patients were limited. In 2018, 51% of individuals were offered online access to their medical record by a health care provider or insurer, which is up from 42% in 2014. Among these individuals, in 2018, 58% viewed their online medical record at least once within the past year. Nationally, this represents about three in 10 individuals.<sup>18</sup> Building upon research in behavioral economics, when we offered opt-out access to the portal rather than opt-in, the numbers improved and Covid-19 has driven a rise in portal enrollment of about 30%.

An important feature of patient portals is the ability to access your own medical information, a core tenet of patient-centered care. Although hospitals are required to make medical records available upon request, gathering records often still involves significant fees, multiple phone calls, delays, and even fax machines. Recent regulatory proposals indicate that data availability is being increasingly advocated by the government, not just to drive interoperability of the electronic health record, but also to empower patients to make decisions regarding their own health.<sup>19</sup> How can you participate in shared decision-making if you don't have access to your own data when you want it? And it should be free.

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In 2014, CMS published **an amended final rule** that allowed patients to bypass their physician and get lab data directly from the lab where it was performed. Physician groups were (and remain) concerned that information without context and explanation might harm patients. Yet again, patient preference differs from clinicians'; the overwhelming majority of patients would prefer to access their own outpatient imaging results within 1 to 3 days, and would contact providers if they have not received the results within 1 to 5 days.<sup>20</sup> Responses varied within the time ranges based on underlying indication, which included tests for chest pain, back pain, pneumonia, brain tumor, and cancer treatment. Anxiety was common among patients who waited for results, also seen for Covid-19 testing results. The solution, though, is not just to enable patients to access the results sooner, but to pair the result with a phone call, a virtual visit, a bit of education so that we proactively address fears, and don't amplify them.

Beyond patient portal use and auto-release of laboratory data, organizations should also have public posting of their patient feedback from all sources to enable patients to select the best fit clinician for their care. To the patient, the experience of other patients is their surrogate for quality.

### *Access to Appointments*

A 2017 Merritt Hawkins survey found the average wait for an appointment for a new patient was 24 days in a large metro area. The survey involved researchers calling for an appointment for a routine, nonemergent matter among five specialties (cardiology, dermatology, obstetrics-gynecology, orthopedic surgery, and family medicine) in 15 large metro markets. They did the same for 15 mid-sized metro areas, where the average wait time was 32 days. Those waits had increased 30% and 32.8%, respectively, since the firm's 2014 survey.<sup>21</sup>

For large markets, the average wait time to see a family medicine physician is 29 days (up 50% from 2014); that ranges from a high of 109 days in Boston to a low of 8 days in Minneapolis. When a patient can walk into a retail care or urgent care center and be seen without an appointment, our cumbersome, friction-filled access fails to meet patient needs and expectations and is, simply, unacceptable. Contrast this reality with what patients want. An Advisory Board study of patient preferences for primary care shows that the Number 1 attribute, in both 2014 and 2019, is the ability to walk in without an appointment and be guaranteed to be seen within 30 minutes.<sup>22</sup>

Access, from an experience perspective, can be measured in a variety of ways. At Cleveland Clinic, we measure our performance on appointment access in an outpatient survey metric known as Appointment When Wanted (AWW). By making access an organizational priority, and opening administrative and block time on clinician schedules, we were able to move the AWW metric from the 21<sup>st</sup> percentile rank to 76<sup>th</sup> in just over a year.

It is worth noting that when Cleveland Clinic did a multiple regression analysis of AWW, the drivers of how patients answered the question actually have more to do with how calls are managed, rather than the actual time to appointment. In 2019, an average call center hold time for health care and pharmaceutical organizations was 9 seconds, with average abandonment rate of 7% after interactive voice response, which is the automated menu phase.<sup>23</sup> When was the last time you called your own practice? If you find yourself subject to multiple holds, prolonged messaging, and transfers that sometimes wind up as a dead end, you have some sense of what patients go through on a routine basis.

The Covid-19 crisis has certainly taught us about the power of virtual care. In total, the Cleveland Clinic went from 10% virtual visits to approximately 70% over the course of 2 months. Satisfaction, including likelihood to recommend the virtual visit and *ease* of the technology recently peaked with more than 80% of patients giving top ratings for both. Waiting for access should be a relic of the past.

As social distancing continues, making it *easier* for the patient to schedule an appointment online and see the doctor anytime anywhere — and on any device — are patient-centered imperatives.

## Access and Cost

Historically, cost was one of the most influential factors of patient choice and has been rising faster than the GDP for decades, although that disparity has slowed and narrowed in the current decade.<sup>24</sup> According to a 2017 Health Affairs study, 52% of patients were not aware of the price of the service before they received the care; just 13% searched for out-of-pocket spending; and only 3% compared costs across providers.<sup>25</sup> Consumers in virtually every other industry know in advance the cost of the service or goods they are purchasing. We will never exceed expectations of consumers in health care as long as the costs are hidden from patients.

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The escalating costs, and now Covid-19–related furloughs and closures, have far-reaching impacts — leading to bankruptcy of families, distress, and lack of trust in the physician and the system. Consider: 61% of patients are confused or very confused by their medical bills.<sup>26</sup> When Cleveland Clinic studied this internally, we found five reasons that the vast majority of patients who fail to pay their medical bill don’t pay: skepticism of accuracy, confusion, searching for answers about bill, struggling to pay, and prioritizing their spend. In addition, we know patients may receive multiple bills for a single experience of care if organizations have not created a centralized bill and patients are deep in the dark about what insurance covers.

As voices for cost transparency get louder, change will come; but even today change remains hindered by competitive concerns, comprehension, willingness to share pricing models, rising pharmaceutical costs, and stacked-on, opaque fees. Organizations can mobilize by implementing cost estimator tools, unifying the patient bill, mobile bill pay, home registration with electronic health record (EHR) tools, testing their bills for comprehension with patient groups or in design sessions, accelerate real-time insurance verification, and proactive financial counseling (virtual or in person) when predicted ability to pay is a concern. Because of visitor restrictions imposed by Covid-19, home registration, remote financial counseling, phone consents, and paperwork has been fast-tracked to digital enablement. Patients are making tough choices to afford care for themselves and their families, especially if they have lost their jobs in Covid-19, and we have an opportunity to be a resource if we grab it now.

## Timely Responsiveness

In health care, time is an especially precious commodity. People wait at nearly every turn in traditional in-person visits. At the doctor’s office, they wait in waiting rooms. Then they wait again in the exam room. And they wait again to schedule the next appointment. In the hospital, they wait mostly to go home after being told they will. When faced with a wait without an explanation, the brain will create a narrative. And for patients, it may be “they don’t care about me” or “they forgot I was even here” — not so helpful for your retention rate.

Likely due to concerns of becoming infected with Covid-19, patients are actively delaying visits and care, a concerning trend.<sup>27</sup> And, we literally make patients sicker by making them to wait. Communicating wait times, focusing on new metrics like *time-to-treat* rather than *time-to-appointment*, and capturing experience with texted pulse surveys represent some methods to enhance transparency and ease of access when it comes to respecting a patient's time.

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If a patient concern cannot be resolved at the point of service or comes as a written complaint, it becomes a grievance. Before it becomes too sterile, think about the emotions that must drive someone to sit down and write a letter or send an email or post a comment. The richness of the detail and depth is not classically included anywhere in an organization's evaluation of patient centeredness, but it is critical. According to CMS, grievances must be resolved within 7 days. Many health care organizations have patient advocates or ombudsman offices to manage this process. Notably, complaints about visitor restrictions have more than quadrupled since February 2020, and responsiveness is key to caring about what is important to families today. Grievances represent patient feedback from which organizations can learn, and this is a neglected mechanism to track performance.

Lastly, the immediate capture of experience will require automated first-touch resolution, as there will be an implicit expectation that if an issue is identified in real time, that we can solve it in real time.

## *Safety*

Although safety isn't typically associated with patient-centered care, there is little purpose to talk about experience efforts if our patients are harmed under our watch. They are inextricably connected.

In the past, patients trusted that when entering a reputable hospital that they would be safe. Covid-19 now has hospitals working to rebuild trust by messaging safety with videos, socially distant furniture arrangements, robust screening and masking, etc. Covid-19 aside, patients may yet lack awareness of safety risks and what they can do to help keep themselves safe. The Joint Commission has found repeatedly that sentinel events are usually related to human factors, and high on the *leading cause list* is communication failure. As a result, as we assess safety, we must also assess communication practices like doctor and nurse communication, as well as the implementation and sustainability of evidence-based communication practices like bedside shift report, hourly rounding, and plan of care visits.

In addition, OpenNotes, Patient Reported Outcome Measures, and Patient Reported Experience Measures all add value to your organization's efforts at inviting and understanding patient input and delivering patient-centered care.<sup>28-31</sup> But we should not overlook the basic real-time human interaction between clinician and patient (even if Covid-19 makes us ask over a computer screen) and the act of simply asking the patient: What is important to you? What are your goals for your treatment? For your life? Helping patients achieve *their* goals ushers in — finally — a new era of experience performance measurement.

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Shared decision-making has also made it into the health care nomenclature as a gold standard in communication with patients. SDM is associated with multiple benefits for patients, including improved safety, better outcomes, better experience, and more trust. From my vantage point, SDM is a core component of relationship-centered communication and informed consent, and should not become just some new metric that we add on the pile without meaningful commitment. Organizations committed to SDM must have internal communication training and formal policies that cover SDM, including the use of patient decision aids when appropriate.<sup>32</sup>

Most important to keeping patients safe is that patients have, and take advantage of, methods to speak up. Although law requires that patients receive a Bill of Rights that encourages mechanisms for speaking up, patients are reticent to criticize their care. And to be fair, we don't always listen. When mistakes happen in a hospital system, transparency is key. Disclosing the event to patients and families in a timely fashion is known to decrease lawsuits and build trust, not to mention it is just the right thing to do. A mature system would have mechanisms to support its patients and families before and after disclosure, and also to emotionally support the clinicians as they prepare and disclose.

## **Teamwork**

Because many patient-centered practices have already been implemented at the bedside and in clinics, further adoption of these practices is an important means of evaluating the maturity of patient centeredness. Including the patient in the bedside shift report and using your tiered huddles to discuss experience issues in your hospital represent ways we operationalize partnering with our patients. Covid-19 created Hero Huddles for us that would recognize individual and teams who then receive a personal phone call from an executive leader thanking them.

As the pandemic continues, relationships with patients are distributed onto teams to keep patients safe and deliver exceptional experiences consistently. At Cleveland Clinic, we noticed that when the care team (doctor, nurse, and patient) are all in the room discussing the daily plan of care, all domains of patient satisfaction surveys show dramatic and significant improvement. This isn't a new concept, but multidisciplinary rounding is a good example of something we say should happen and then just doesn't (instead, we card flip in a conference room without the patient).

For Covid-19 and non-Covid-19 patients, rounding now often occurs with a virtual interface and patients and families are at risk for not being included. Important to any *Plan of Care Visit* concept is making sure the patient stays a part of the team and that processes exist to ensure their involvement in care — to the extent they wish to be involved, so that it isn't an additional burden to the patient. Implementing standard process for bedside rounding as a team and documenting the frequency of occurrence in the EHR was a highly effective enterprise effort.

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A patient's engagement in their own health is demonstrated by behaviors that take maximal advantage of resources available to them. During its existence (1992–2014) the Center for Advancing Health (CFAH) listed numerous behaviors as part of its Patient Engagement Framework, including completing advance directives, knowing your medications, and showing up to appointments among others; but in the end, we want the engaged patient to have better health outcomes. Active research in this space suggests that more engaged patients have better health outcomes and lower annualized costs.<sup>33</sup> Judith Hibbard's [body of work](#) in this space is a resource for anyone committed to understanding what works.

There is a gold standard for measuring engagement, and it isn't patient satisfaction surveys. It is called the Patient Activation Measure, or PAM.

Covid-19 sparked digital engagement with patients out of necessity. Digital engagement platforms were leveraged to extend the clinical reach to patients who tested positive for Covid-19 and fell into either low- or high-risk categories.<sup>34</sup> Approximately 36% of our outpatient Covid-19 patients and employees are using these tools, and the rate is rising. Effective use requires strong connected clinical teams, content that is relevant and valuable to the patient at right time, and empathic language that humanizes the digital conversation. How we keep patients part of the team and feeling supported beyond our walls is ripe for development and expansion post Covid-19.

Patient centeredness is intended to mean that the patient is at the center of all we do; yet, in practice, the concept is sometimes relegated to a pretty graphic or wonderful patient stories. Hospitals and systems are increasingly being incentivized to partner with patients; the value and evidence for including patients in their own care is overwhelming. But confusion remains about how to define and distinguish patient *engagement* from patient *experience* (Table 1).<sup>35</sup>

Even for organizations that are committed to partnering with patients, figuring out whether they have moved the needle is difficult. In a survey of 110 New York state hospitals published in 2018, 59% had a patient and family advisory council, but only 29% were considered highly functioning.<sup>36</sup> CMS had attempted to drive patient and family engagement in part by providing additional financial savings to organizations that provide five primary care functions, including one around including patients in design of care, decisions, and system fixes. According to the CMS [website](#), in

Table 1. The Differences Between Patient Engagement and Patient Experience

	Patient Engagement	Patient Experience
Goals	1. Drive better health and outcomes 2. Empower patients and loved ones to be active in their own care 3. Reduce costs	1. Drive better health and outcomes 2. Exceed expectations 3. Reduce suffering 4. Brand differentiation
Stakeholders	Patient, likely others	Patient, likely others
Context	Patient's own health	All-encompassing (access, communication, food, etc.)
Patient involvement (behaviors and ownership)	Required	Not required (though in an ideal experience, patients are partners and codesigners)
Time	Transactional and longitudinal	Transactional and longitudinal
Use of health self-management tools/services	Yes	No
Validated measurement	Patient Activation Measure (PAM), Patient-Reported Outcomes Measurement Information System (PROMIS), Patient Health Engagement (PHE) Scale	HCAHPS, CGCAHPS, etc.

Health care teams need to recognize the difference between patient engagement and patient experience, which involve distinct sets of goals, stakeholders, and metrics, among other factors.

Source: The author. Originally published in Boissy, A. Patient Engagement versus Patient Experience, NEJM Catalyst: <https://catalyst.nejm>.

2016, at the end of the 4-year initiative, only 442 practices and an estimated 2,188 physicians had participated in the Comprehensive Primary Care (CPC) model (which is a fraction of the roughly 480,000 practicing primary care physicians in the United States).<sup>37</sup>

Thus, although evidence supports models of engagement in their care, actual implementation of engagement falls short. Rather than designating patients for focus groups, we have found success in onboarding patients to become health care partners who can then serve on our committees and more actively guide projects as part of the team. Our health care partners were involved in crafting messaging for visitation and resource allocation. We can also do even better by including patients and family members in codesign of our processes, our digital tools like engagement platforms, and our operations with design thinking (nearly universally adopted by customer-obsessed industries) and on continuous improvement project teams.

## Empathy

### *Enhance Service*

Consumers purchase and use products and services. In other venues, I have described how patients will never be fully engaged without the same *rights* and *capabilities* that consumers have in any other industry.<sup>38</sup>

In a NEJM Catalyst survey, 71% of 766 health care leaders and clinicians agreed or strongly agreed that patients should be treated as consumers.<sup>39</sup> They went on to indicate that top two areas in which health care providers can learn the most from other industries are improved customer service and customization to individual needs and preferences. As patient trust is tested, service represents an opportunity to differentiate in this new world. But I have yet to see most organizations make

substantial investments in service training, even though the cost of getting a new patient is multiple factors higher than keeping the one you have. We know effective service recovery can increase loyalty, so organizations serious about Net Promoter Scores need to make substantive investments in service excellence training for all employees. Geisinger attempted to address this issue by offering money-back guarantees. Patients could select how much money they thought they should be refunded pending the service failure.<sup>40-42</sup>

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Classic hospitality efforts like in-room ordering with fresh inspired meals, digital valet, human-centered environments, concierge coordination, and rewards programs are wonderful, but enhancing service should also mean addressing food insecurity, health literacy, and social determinants of health in our communities.

Because devastating things will happen to patients and families — before, during, and after Covid-19 — our systems should be prepared to care for the spirit and the soul of patients and caregivers alike 24-7 by phone or Skype or Duo or whatever. Grief and mental health issues have been exacerbated by Covid-19 for those who witness the trauma, death, and loss, for patients and caregivers alike. Simply stated, this means that services such as bioethics, volunteers, crisis support, moral distress teams, and especially spiritual care must be available anyhow, anytime, anywhere.

### *Expression of Caring*

As Dr. Peabody highlighted, a deep interest in connecting to a person’s emotional state, required for empathic connection, is fundamental to our patients feeling cared for. But empathy is neither measured, nor asked about, in traditional patient satisfaction surveys.

We know it is foundational to relationships — and it is associated with *trust*, another complex topic in health care and one notably at risk in the current environment.<sup>43</sup> The absence of empathy also impacts burnout, satisfaction, engagement, and malpractice risk. As a result, many communication models exist, and empathy training is a core component of onboarding and ongoing training at Cleveland Clinic, founded on the REDE model. (The model applies effective communication skills to optimize personal connections in three primary phases of Relationship: Establishment, Development, and Engagement). When staff physicians who completed our REDE to Communicate training were compared to those who had not, validated scales of empathy, patient satisfaction, and the emotional exhaustion of burnout showed significant improvement.<sup>44</sup> We have anchored all Covid-19 communication resources in this model as it encompasses breaking bad news, advance care planning, and how to build relationship and empathy in virtual platforms.<sup>45</sup> The call for all of us is to incorporate empathy into survey design *and* to give the time to employees and staff to attend training we say is so important.

## Customized Care

Respecting the needs, values, and preferences of patients may be the land of greatest opportunity. Today, if a patient only eats gluten-free foods or only speaks Italian, I have no way of easily knowing that as their clinician. Today, if the patient says, ‘Don’t ever call me,’ we can’t yet operationalize via the EHR never calling them. Today, we might have 46 different apps that all tell the patient to do something different every day, even when the patient has asked not to be contacted more than once a day. I cannot imagine a quicker demise of a health care experience than the organization *knowing* your preferences and completely *ignoring* them. Previously, customer relationship management (CRM) systems were on the rise in health care — including at Geisinger, Stanford, and the VA — as a means of knowing and respecting these preferences. In addition, the health care disparities exacerbated by Covid-19 can be more balanced by addressing social determinants of health (SDOH) and creating customized journeys for all the populations we serve. As health care systems reactivate, CRMs offer critical capability to enable proactive, informed, personalized outreach for all.

## End-of-Life Care

It feels very difficult to talk about patient-centric care models for lifelong health without also discussing transformative end-of-life (EOL) care. The advance directive completion rate in this country is about 33%,<sup>46</sup> which implies we avoid talking about and planning for death. End-of-life care costs in the last year of life costs are about 9% of health care spending. Mean per capita spending in the last 12 months of life is about \$80,000 in the U.S. with about 44.2% (\$35,000) of that for hospital care and about \$20,000 for long-term care.<sup>47</sup> The percentage of deaths occurring in hospitals in 2017 (about 30%) and nursing facilities (21%) represents a steady decline over 15 years; likewise, the number of deaths occurring at home (31%) and hospice facilities (8.3%) has been rising over that period.<sup>48</sup> This trend is in line with patient preferences.<sup>49,50</sup>

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Several years ago, Cleveland Clinic decided to make improving EOL care an enterprise Patient Experience metric. We initiated a process to get advance directives into the EHR, developed an advance care planning tab in the EHR, which integrated billing and conversational tools such as [The Conversation Project](#) and [Ariadne Labs](#), and 2 years later, our advance directives completion rates at main campus rose 10 percentage points, from 15% to 25%. In 2018, Cleveland Clinic went on to partner with Michael Hebb (who is noted for staging invitation-only salons and dinners where global guests from multiple disciplines and various backgrounds focus on specific themes or ideas) to design a Death Over Dinner for Health care curriculum now available for free to the public. Covid-19 pushed another collaboration on white paper called the Death, Grief, and Funerals

in a Covid Age.<sup>51</sup> We also rolled out The Pause as an enterprise-wide initiative for when patients die, which is inspired by the work of Jonathan Bartels from University of Virginia.<sup>52</sup> Based on the success of the Pause, a member of the executive team suggested that, at the daily executive huddle, we read the names of every patient who died, then pause in silence. The silence honors the caregivers and those that trusted us with their care.

During Covid-19, the Cleveland Clinic heard from patients and caregivers alike who were risking their lives, that they wanted to have conversations about advance care planning to protect their families if they died. We built advance care planning discussions into our digital engagement platforms — a feature we will continue post Covid-19 in future builds — and mobilized spiritual care to talk to patients who were interested. We are also making sure these documents can get notarized and uploaded into the EHR easily.

Others, such as Gundersen Health System, have changed EOL care by making death part of living.<sup>53</sup> And tools exist to guide the conversation, such as VitalTalk, the work of Angelo Volandes, and many more. There is no lack of resources. There is lack of measurement. Let's begin, ourselves, to measure how often patients complete an advance directive and how often we honor it.

## Reimagining Metrics and Methods for Experience Measurement

So we've covered patient pain points and the data behind them. Let's discuss today's measurement, why it's broken, and how to fix it. Since the late 1990s, patient satisfaction has been measured in the United States with the use of the [HCAHPS survey](#). CMS ties reimbursement to performance on this survey, which covers multiple domains of care, including doctor communication, nurse communication, responsiveness, and medication information. There are 29 questions on the survey, and it is given to adults at least age 18 who spend at least one evening in the hospital.<sup>54</sup>

Again, notably absent is a single question about whether a patient felt cared for — one of the most important articulated needs of our patients:

This omission is not due to a lack of work that went into the survey before it was launched in 2006; it was developed after market research for how patients judged quality in health care. Although intended to capture the experience of our patients and make it meaningfully applied and integrated into high-quality care, HCAHPS has real problems in a digital age.

“ *Grief and mental health issues have been exacerbated by Covid-19 for those who witness the trauma, death, and loss, for patients and caregivers alike. Simply stated, this means that services such as bioethics, volunteers, crisis support, moral distress teams, and especially spiritual care must be available anyhow, anytime, anywhere.* ”

For one, the data isn't timely. HCAHPS surveys may be returned within 6 weeks, after which they are not included into ratings. If feedback has to be *timely* and *specific* (qualities included in SMART goals: Specific, Measurable, Achievable, Realistic, and Timely) in order to be maximally valid to the person receiving it, then HCAHPS feedback fails. In addition, the ratings themselves are attributed to the discharging physician. So even if the experience had been with another clinician for weeks, if a new clinician takes over on the day of discharge, the scores are attributable — for the entire stay — to that discharge clinician. Although this can be messaged as highlighting the importance of teamwork and high expectations for all health care participants, the reality is that this feels inappropriate and unfair to the clinician.

Next, return rates for HCAHPS surveys is low (26.6% nationally in 2017, which is down considerably from 2008's 33.3%).<sup>55</sup> At Cleveland Clinic, our current return rate is 22%, with only 7% of African Americans returning surveys. How can we possibly say we are interested in shifting to the entire lifetime, relational experience of ALL patients when HCAHPS only captures one setting with a return rate that's a fraction of our patient interactions?

Furthermore, the HCAHPS scores themselves are influenced by more than the patient experience itself. In an internal analysis years ago, we noted that among medical patients, several factors had a negative influence of patient satisfaction ratings: coexistence of comorbid depression, severity of illness, and length of stay. We also found that patients who were more educated and over the age of 65 were more likely to return surveys, so response bias exists, and continued reliance on this methodology, widens disparities.

Lastly, the survey is too long. A 29-question paper survey takes 10 minutes to complete . . . in a world with an average attention span of 8 seconds. If patient feedback is so important, then why are current mechanisms so flawed?

The opportunity extends beyond HCAHPS. At the Cleveland Clinic, when we inventoried how many surveys we are mailing (yes, through the U.S. Postal Service), we calculated we are asking patients 543 unique questions across about 20 different surveys. The HCAHPS and [ACO-CAHPS](#) are mandated for CMS reimbursement. All the other survey types we send are not required, yet somehow, we became convinced that we need to use all of them. It's time to push back.

### *Evolving Feedback Methods*

Feedback, and its capture, is evolving. It's about time. Based on the flaws above, recommendations for future capture methodology are described in Table 2. Necessary changes include delivery of surveys by text and email, adding telehealth and digital engagement as settings, fewer questions that apply to all settings, the use of Net Promoter Score (NPS) to compare to other industries, and in-moment feedback. These changes represent a significant leap forward in patient experience methodology.

As organizations begin to work to more deeply understand the patient perspective, there is hope. Driven by competition in their own markets and desire for meaningful feedback to shape

**Table 2. How Every Component of Patient Feedback Needs to Change**

Patient Feedback	Current State	Future State
Primary Tool	HCAHPS.	Single standard patient survey Collated feedback from all sources.
Primary Question Focus	HCAHPS Overall Rating.	Net Promoter Score.
Care Setting	Inpatient.	All settings, including nonclinical and virtual.
Caregivers Included	Doctor and nurse.	All caregivers.
Delivery Mode	Mail.	Text/email.
Administration	Retrospective (6 weeks).	Real time.
Benchmark	Government.	All industry.

This table details multiple components for survey administration and its components (far left column) in current state (middle column) and a much-needed future state (far right column). Source: Adrienne Boissy, Carmen Kestranek, Cleveland Clinic Office of Patient Experience.

interventions and design, organizations and practices are exploring how to do it differently. What must be different moving forward is the methodology, the modality, and the questions themselves.

### *The Cleveland Clinic Patient Experience Approach*

If you have a positive experience in a given hospital, you are more likely to choose that hospital in the future. A 2011 study showed that a one-half point improvement in overall satisfaction is associated with a 1.2% increase in loyalty of end-of-life patients, who return for that care.<sup>56</sup> A 2018 survey of adults responsible for household health care decisions found that a recent health care experience, personally (73%) or of a family member or friend (55%), are the only factors cited by a majority of respondents as *very* or *extremely influential* in the decision to continue to use the organization for care; online physician reviews were next highest (42%), but traditional marketing campaigns (email, social media, community events, advertising) all were below 30%.<sup>57</sup> Ultimately, we are talking about loyalty and what drives it.

“*The call for all of us is to incorporate empathy into survey design and to give the time to employees and staff to attend training we say is so important.*”

Loyalty in most other industries is captured in a Net Promoter Score, which is based on a person’s response to the question: “How likely are you to recommend us to a friend or colleague?” NPS considers loyalty as having an emotional component and a cognitive component, which includes performance and price; that is, value.<sup>58,59</sup> Because early studies showed NPS was related to the repurchasing of services in 11 of 14 industries, it is an attractive experience measure rooted in to financial outcomes. NPS is also related to trust, which Covid-19 has forced us to more deeply understand.

In 2019, using facility-level, unadjusted correlation data for 2,005 hospitals, Press Ganey correlated questions from multiple surveys to “would you recommend this hospital,” according to correspondence with the author (Appendix). Thirty-five measures have coefficients equal to or greater than 0.700. Twenty-three of those are related to teamwork, safety (communication), empathy, and ease.

**Table 3. Cleveland Clinic Patient Experience Approach**

General Survey Category	Teamwork		Empathy		Safety/Communication		Ease	
Patient-Centered Promise	We will partner with you		We will care about you as a person		We will keep you safe		We will make your journey easier	
Values of Organization	Teamwork and Inclusion		Empathy		<ul style="list-style-type: none"> <li>• Safety and Quality</li> <li>• Integrity</li> </ul>		Innovation	
Active Cleveland Clinic Patient Survey Question	How well staff worked together to care for you?		Degree to which staff cared about you as a person		<ul style="list-style-type: none"> <li>• How well did your doctors communicate with you?*</li> <li>• How well did your nurses communicate with you?*</li> <li>• How often did we treat you with courtesy and respect?*</li> <li>• Degree to which you felt safe at Cleveland Clinic</li> </ul>		Ease of getting the care you needed at Cleveland Clinic	
Active Cleveland Clinic Quantitative Metric	<ul style="list-style-type: none"> <li>• % Plan of care visits</li> <li>• PAM score</li> </ul>		% Advance directives completed		<ul style="list-style-type: none"> <li>• % Doctors with communication ratings &lt; 40<sup>th</sup> percentile</li> <li>• # Safety Event Reporting System events (SERS)</li> </ul>		<ul style="list-style-type: none"> <li>• Grievance rate (per 1000 encounters)</li> <li>• % ease of tech</li> <li>• % appointments scheduled online</li> </ul>	
Highest Correlation Coefficient to <i>Would Recommend Hospital</i> based on Press Ganey questions**	Staff worked together to care for you	.803	Staff addressed emotional needs	.789	<ul style="list-style-type: none"> <li>• Nurses explain things in way you can understand</li> <li>• Friendliness/courtesy of physician</li> </ul>	<ul style="list-style-type: none"> <li>• .759</li> <li>• .765</li> </ul>	<ul style="list-style-type: none"> <li>• Wait time for tests and treatments</li> <li>• Speed of admission</li> </ul>	<ul style="list-style-type: none"> <li>• .741</li> <li>• .733</li> </ul>

Alignment of patient experience survey questions to organizational values and patient-centered promises allows us to assess our concordance with these values in our patients' eyes. Organizational strategic focus is on NPS, teamwork, empathy, safety/communication, ease with corresponding select objective quantitative metrics to add depth and evidence of supporting processes and operations. \*Today, the Active Cleveland Clinic Patient Survey Question for safety/communication category is a composite score from required and standard surveys and questions. We are experimenting with a smaller focused survey with these standalone questions after required survey windows. \*\*From Appendix. Press Ganey and HCAHPS Mean Score Correlations to HCAHPS "Recommend this Hospital." Source: Author, Press Ganey correlations from Appendix.

Safety is also not assessed on required patient surveys, which we would like to change. As discussed earlier, effective relationship-centered communication is related to safety, experience, and outcomes. We are currently assessing both better measures of communication that can apply to all caregivers and a general question of safety such as "Degree to which you felt safe at Cleveland Clinic." Safety culture surveys ask the employees and staff about safety, but being inclusive of the patient perspective will take the field to the next level.

These four categories serve as the foundation for focus areas and specific questions for patient surveys for Cleveland Clinic. In the future, these questions may be constantly refined, but the general categories are unlikely to change; in fact, when paired with objective outcomes, they will have even more power. A major gap in patient experience historically is the lack of association of the perception with objective measures of reality, of which we have incorporated a select few here. This allows us to determine whether our operations are becoming more patient centric, and ideally, that patients feel and see the result (Table 3).

For the sake of clarity, I've also mapped each category to the associated organizational values. We are working to move the organization to making a set of promises to our patients based on our

values, and those are also aligned here. I've often believed that if "you are what you measure," then our organizational values — and culture — need to be reflected in our patient surveys. (Table 3)

It is *very intentional* that these promises and categories can — and will — apply to our caregivers, not just patients.

Several years ago, a customer effort score (CES) was developed as a way to help companies identify ways that customers were burdened in interactions. CES is measured by asking the customer: "How much effort did you personally have to put forth to handle your request?" Scoring is on a scale from 1 (very low effort) to 5 (very high effort).<sup>60</sup> Over and over, we hear the message that we are making it too hard for patients to do what they need to do. In the Press Ganey correlations (Appendix), ease shows up as speed to admission and wait time assessments. So let's make it *easier* and let's measure it *asease*, ideally with branching logic that helps us dig in.

Although we will continue to meet measurement requirements, we have dramatically pivoted the organization toward the strategic focus areas in Table 2. Looking forward, these will continue to evolve and one of the impending opportunities is to pair more robust experience measurement with objective outcomes, not simply patient perspective.

In the future, as organizations gain maturity in measuring what matters to patients over their lifetime, metrics like customer lifetime value, retention rates, and share of wallet are gaining in popularity for use in health care. Each represents related concepts to loyalty and has different methodologies to assess the same *repurchasing* behavior used for NPS. The opportunity on the landscape is to begin to truly understand the experience over a lifetime relationship rather than just after a single visit. How does this come together to tell a story about the patient and what they need from us? How does any of this help us change the next touch? How do we build their trust that we will deliver on our patient-centered promises?

## **Maturity Model for Patient Experience: Back to Patient Centricity**

If we were to imagine a roadmap for patient experience, and stages of maturity that an organization might develop, it might look like the maturity model outlined in Table 4.

For each major category of patient-centered care, stages of maturity are represented, possible survey assessments are proposed, and objective, complementary metrics suggested. What is not included, but equally important, is that leadership commitment can also follow a continuum, and mature organizations have leaders with patient-centered metrics on their CEO scorecards, as well as active board member engagement in rounding and codesign.

“

*There is no lack of resources. There is lack of measurement. Let's begin, ourselves, to measure how often patients complete an advance directive and how often we honor it."*

Table 4. Patient Experience Maturity Model for Organizations

Mapping to Core Patient-Centered Categories	Category	Beginning	Achieving	Maturing	Proposed Patient Survey Questions	Quantitative Metrics
EASE: Access	Data	<ul style="list-style-type: none"> <li>• Lab releases by clinician</li> <li>• 9-5 in-office appointments</li> <li>• No patient feedback shared</li> </ul>	<ul style="list-style-type: none"> <li>• Delayed lab release</li> <li>• No cost for records</li> <li>• Internal patient ratings</li> </ul>	<ul style="list-style-type: none"> <li>• Immediate nonsensitive lab release</li> <li>• Records free and easily available</li> <li>• Publicly posted patient ratings</li> </ul>	How often did you receive the access to data you wanted, when you wanted it?	<ul style="list-style-type: none"> <li>• Y/N lab auto-release</li> <li>• Y/N fee for records</li> <li>• Y/N online ratings available</li> </ul>
	Scheduling	<ul style="list-style-type: none"> <li>• 9-5 in-office appointments</li> <li>• Local scheduling in offices</li> </ul>	<ul style="list-style-type: none"> <li>• Extended hours, walk-in clinics</li> <li>• Centralized call center</li> </ul>	<ul style="list-style-type: none"> <li>• 24-7 virtual and in-person access</li> <li>• Online scheduling</li> </ul>	Did you get an appointment when wanted?	<ul style="list-style-type: none"> <li>• % virtual visits and % ease of tech</li> <li>• % online appointments made</li> </ul>
	Portal Use	Patients call office	Phone calls and texting	Single digital doorway for organization	How easy was it to communicate with doctor's office?	% patient portal use
	Financial	<ul style="list-style-type: none"> <li>• Multiple bills after service</li> <li>• No prediction or estimation</li> </ul>	Unified bill	<ul style="list-style-type: none"> <li>• Single unified bill</li> <li>• Predictive modeling</li> <li>• Mobile pay</li> <li>• Estimates delivered</li> <li>• Real-time insurance verification</li> </ul>	<ul style="list-style-type: none"> <li>• How easy was it to pay your bill?</li> <li>• How prepared were you to manage costs?</li> <li>• Was the final out-of-pocket cost surprise-free?</li> </ul>	<ul style="list-style-type: none"> <li>• Number of complaints about billing</li> <li>• % Accuracy of cost estimators</li> </ul>
EASE: Timely	Responsive	Issues reported in traditional surveys weeks later, no follow-up	Issues reported in real time, intermittently addressed	Issues reported in real time, resolved in real time	How quickly were your concerns resolved?	<ul style="list-style-type: none"> <li>• Grievance rate (#/1k encounters)</li> <li>• Time to resolution</li> </ul>
SAFETY	Safety/Quality	Patient-Reported Outcome Measures (PROMs) or Patient Reported Outcomes (PROs) not collected	PROMs collected, but not part of care plan	PROMs/ Patient-entered data (PED) measured and included in plan	<ul style="list-style-type: none"> <li>• Degree to which you were included in care plans?</li> <li>• How well did doctors and nurses communicate with you?</li> </ul>	<ul style="list-style-type: none"> <li>• % PROM completion</li> <li>• % patient goals achieved</li> </ul>
	Safety culture	No mechanism for patient voice	Patient concerns welcome	Patients easily speak up	Degree to which you felt safe at Cleveland Clinic	<ul style="list-style-type: none"> <li>• % patient-initiated safety events</li> <li>• # Safety Event Reporting System events</li> </ul>
	Transparent risk disclosure	Bill of rights given; disclosure avoided	Minimal process for disclosure	Disclosure training required for all clinicians	Did anyone talk to you about your rights as a patient?	% disclosures per medical errors

**Table 4. Patient Experience Maturity Model for Organizations**

Mapping to Core Patient-Centered Categories	Category	Beginning	Achieving	Maturing	Proposed Patient Survey Questions	Quantitative Metrics
TEAMWORK	Best practices	No best practices	Few best practices implemented	Best practices implemented (e.g., bedside shift report, hourly rounds)	How often did we work together as a team to care for you?	<ul style="list-style-type: none"> <li>• % compliance with best practices</li> <li>• % plan of care visits documented</li> </ul>
	Patients self-manage	<ul style="list-style-type: none"> <li>• Passive member</li> <li>• No digital engagement</li> </ul>	<ul style="list-style-type: none"> <li>• Active member</li> <li>• Remote monitoring, but not integrated into EHR</li> </ul>	<ul style="list-style-type: none"> <li>• Fully engaged member, including families</li> <li>• Digital platforms for self-management, remote monitoring integrated into EHR</li> </ul>	How often did we engage/ include you in your care?	<ul style="list-style-type: none"> <li>• Patient Activation Measures scores</li> <li>• Reduction total cost, % reduction readmissions</li> </ul>
	Patients integrated in care delivery	Market research occasionally	Focus groups	Patients on safety and qual committees	As above	% committees with patient partners
	Codesign with patients and community	Few focus groups	Patients on committees	Patients and families codesign transformation	As above	% codesign projects with patients
EMPATHY	Enhance service	<ul style="list-style-type: none"> <li>• No human-centered design (HCD)</li> <li>• No hospitality services</li> </ul>	<ul style="list-style-type: none"> <li>• Occasional HCD</li> <li>• Expanding hospitality services</li> </ul>	<ul style="list-style-type: none"> <li>• Design standards for buildings</li> <li>• Concierge-like experiences</li> </ul>	How effective was our environment in creating calm?	<ul style="list-style-type: none"> <li>• % buildings designed with Human-Centered Design or with patients</li> <li>• # hospitality services</li> </ul>
	Service excellence for all staff	No or minimal training available	<ul style="list-style-type: none"> <li>• Training at onboarding</li> <li>• No ongoing evaluation</li> </ul>	Well codified programs built into performance evaluations	Describe the degree to which staff cared about you as a person	% caregivers completing training
	Emotional care available 24-7 (spiritual, bioethics, healing services)	Nonexistent	Sporadic volunteer programs	24-7 virtual/ in-person emotional care	How often did we address your emotional needs?	% decrease in stress with intervention
	Customized care	Values, Social Determinants of Health (SDOH), preferences not captured	Values, SDOH, and preferences captured, but not respected	Values, SDOH, and preferences captured, and respected	How often was care provided in ways that respected your preferences/needs?	<ul style="list-style-type: none"> <li>• % patients with SDOH addressed proactively</li> <li>• % patients receiving culturally competent care</li> </ul>
	End of Life (EOL)	EOL not discussed	Occasional references to EOL/advance care planning (ACP)	Easy to complete and import advance directive (AD)	Did we ask about your wishes for end of life?	<ul style="list-style-type: none"> <li>• % AD completion</li> <li>• % ACP billing code utilization</li> <li>• % time AD honored</li> </ul>

The Patient Experience Maturity Model for Organizations represents a continuum of patient experience maturity aligned to key components of patient-centered themes. The model is intended to prompt exploration by an organization about its delivery of patient-centered care and is not prescriptive. Rather, the model captures a multidimensional view of both subjective potential patient feedback (proposed survey questions) as well as objective operational performance metrics (relevant metrics).

Source: The author.

Based on the gaps identified in patient-centered care approaches over the past 20 years, I propose a bold new measurement approach to holistically capture the patient experience, which includes topics such as access, shared decision-making and safety, partnering with patients, empathy, and customized care. The columns are not exclusive, but rather they are meant to represent a fluid continuum. The framework is also not meant to be included or applied in its totality, but more to prompt reflection on your own readiness and maturity in multiple facets of patient centered care.

In addition, for the first time in the experience landscape, I propose pairing subjective patient input with objective metrics so that rather than chasing scores based on perception, we can simultaneously demonstrate operational achievements the truly move an organization toward patient centricity.

### *Patient Experience Evolution*

The insights of the Picker Institute and the IOM report hold true 20 years later. Our collective responsibility is to deliver on what we (and patients) have been saying matters for far too long. We have the will, the technology, and the tremendous opportunity in a post-Covid-19 world.

Organizations serious about patient experience delivery will have simplified metrics, deployed in real time via text and email, according to patient preferences, with intelligent logic built within them that enables deeper dives when necessary. We will focus on fewer questions, with more meaning, that apply to *all* settings and *all* caregivers: teamwork, empathy, safety, and ease. The experiences we survey and assess will not be constrained to an office, a hospital, a digital platform, or a singular device. We will make the shift from transactional surveys to lifelong understanding of our patients and the value we provide. The subjective metrics will be paired with the objective ones. Safety and empathy will be integral parts of patient centricity, characterized in large part by how we communicate with each other.

Post-Covid-19, with the virtual platforms and apps that have been stood up between clinicians and the patient, we often don't even *have* to touch a patient anymore, physically or emotionally. But *wemust* engineer a future wherein we do. And we must do it now. The best kept secret to exceptional care is still about human beings caring for other human beings. As Dr. Peabody pointed out nearly 100 years ago, "the secret of the care of the patient is in caring for the patient."

Together, with or without Covid-19, let's revolutionize *patient-centered care* to create *person-centered care*, a care wherein the same timeless promises we make to our patients also hold true for our own people: We will keep you safe. We will partner with you. We will make it easier. We will care for you as a person.

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[Press Ganey and HCAHPS Mean Score Correlations to HCAHPS "Recommend this Hospital"](#)

*Disclosures: Adrienne Boissy has nothing to disclose.*

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