Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

CHAPTER 1

How We Got Here: A Brief History of Patient-Centered Care

It was the worst of surgeries, it was the best of surgeries. . . . Tim and Suzi had been married for 40 years and enjoyed good health and active lifestyles. Tim played golf, was caregiver to his four grandchildren, and did regular work tending to his sizable garden. Retired, he kept busy helping other family members and members of his church community in various ways.

Neither Tim nor Suzi had much reason to encounter the healthcare industry in their more than 40 years of marriage. Their two children had been born with no complications and normal deliveries. Both Tim and Suzi saw a primary care physician and received medical screening tests and physicals recommended for their age.

But when Tim went in for his annual physical at age 62, his blood test showed an elevated prostate-specific antigen (PSA) score. It was slightly higher six months later, so his physician recommended he see a urologist. At the urologist appointment just a few weeks later, another blood test revealed that Tim's score on the Gleason scale was on the border of being considered cancerous. A biopsy showed cancer cells in 4 of the 12 samples, and the urologist encouraged Tim to have his prostate removed. The urologist pressed hard, saying that because Tim was active and in excellent health, he should make a complete recovery. Tim was reluctant,

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer
Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko
(ACHE Learn, 2025).

as his father had had his prostate removed 20 years prior, never regained normal control, and regretted having had the surgery.

Suzi questioned the urologist because she knew that the United States had more stringent recommendations for PSA testing and prostate surgery than other countries did, even though the number of deaths attributable to prostate cancer was no higher in other countries. Both Tim and Suzi expressed their concerns about Tim's father's experience. The urologist emphasized the many medical advances made in the past 20 years and explained that, with robotic surgery, he was confident there would be no problems. Tim and Suzi considered getting another opinion, but after Tim thought further about it, he decided he wanted to get it over with; he wanted to recover fully by January so that he would not have to miss marshalling at the PGA tournament in San Diego, a favorite activity of his that had become a cherished tradition.

Tim needed an electrocardiogram (EKG) and an additional blood test to get a sign-off from his primary care physician prior to surgery. He had to make these appointments on his own, all while thinking about the major surgery ahead of him. He didn't understand why another blood test was needed, as he had just had one prior to his urologist visit. During the EKG, Tim was asked when he had had a heart attack, even though he had never had one. After much discussion and further examination by his physician, he was sent to a local cardiology clinic to have yet another EKG to ensure that everything was OK prior to surgery. Finally, after further difficult testing that didn't make any sense to Tim and additional appointments, scheduling challenges, and great expense, he was assured that nothing was wrong with his heart and was cleared for surgery.

When the time came, Tim's surgeon explained to Tim and Suzi what to expect in the hospital and emphasized again that, because it was robotic surgery, Tim could expect a speedy and complete recovery. He was told the biggest inconvenience he would experience was having a catheter for seven to ten days after surgery.

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer
Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko
(ACHE Learn, 2025).

Tim came through surgery with no problems. He was up and walking right away and quickly got accustomed to the catheter. He looked forward to going home. Hospital staff members were polite, but when Tim asked questions, they often replied, “Who is your surgeon? Oh, you have Dr. Jones. Well, he likes things done a certain way.” This response made Tim wonder if his surgeon was different from most and how other surgeons did things, and it caused him some fear and anxiety. Also, depending on which nurse he asked, he received different answers to the same questions. There was no sense of teamwork or coordination.

Tim’s first week home went according to plan, and he looked forward to his first follow-up visit to have the catheter removed. Everything checked out fine, and the physician seemed pleased with Tim’s progress. But since Tim had expected to return to normal fairly quickly, and his physician had told him he was healing nicely, he became frustrated when he didn’t regain his normal urinary control. Tim expressed this concern at his three-week follow-up visit and was told, for the first time, that it could take 9 to 12 months to get back to normal. This news came as a shock to both Tim and Suzi—this didn’t sound like a “speedy and complete recovery” to them. It made them wonder what else they had not been told.

Around this time, Suzi began waking up frequently at night with what seemed to be stomach cramps. She thought she might be having a reaction to the acidic nature of all the fresh garden vegetables she and Tim had been enjoying recently. She also felt it might be stress caused by Tim’s delayed recovery. But after about a month, the discomfort became longer and more intense and felt more like menstrual cramps, so Suzi scheduled an appointment with her obstetrician/gynecologist (ob-gyn). During the week she had to wait for the appointment, her pain became even more severe, lasting several hours at a time. Her ob-gyn scheduled an ultrasound for her. While driving back to work after the ultrasound, Suzi received a phone call from the technician, who said that the physician wanted to see her the next day in her office. At

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

the visit, Suzi learned that her uterus was extremely enlarged—to 18 inches, compared to the normal uterus size of 3 to 4 inches. The increase in size concerned Suzi because, two years prior, she had had a dilation and curettage procedure to remove fibroids that were causing heavy bleeding and discomfort, and at the time the physician said her uterus was 14 inches. The consensus was that Suzi's uterus needed to be removed. Although Suzi's ob-gyn conducted a lot of hysterectomies, she wanted to consult with a specialist in a nearby city who conducted robotic hysterectomies; she wanted to see if he could do the surgery, as it would be a safer option in the event that cancer was involved.

Suzi was prescribed painkillers to help with the painful nights. A few days later, she and Tim met with the specialist and learned that the robotic procedure was in fact possible. The surgery was scheduled for the following week, and all necessary presurgical tests were handled and coordinated that day in the specialist's office. Tim and Suzi left with everything handled and scheduled for them. The only remaining challenge was managing the increasing pain until the surgery. On Sunday, the day before Suzi was to check into the hospital, her pain was so severe that she called the surgeon's office and spoke with the on-call physician. He recommended that she drive to the hospital and be admitted through the emergency department. There, Suzi was quickly set up with an intravenous morphine drip, which relieved her pain immediately. Soon thereafter, she was admitted the room she would occupy for the balance of her hospital stay. Once in her room, two nurses introduced themselves and explained that they were part of her surgeon's team. They confirmed that her surgery was scheduled for the next morning and explained that they were there to help manage the pain and prepare her for surgery the next day. That night, Suzi had her first hours of pain-free sleep in several weeks.

She came through surgery extremely well despite complications caused by the size of the uterus, and her surgeon had no concerns. Once back in her room, Suzi was up and walking and felt the best she had in over a month. Tim and her children had left by then,

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

as it had been a very early morning and a long day. Suzi's nurses said she was doing so well that she would be ready to return home that evening or the next morning. Suzi decided to wait for Tim's planned return in the morning and not make him drive an hour back late at night. Everything was completely ready for her discharge the next morning. Suzi received full explanations of what to expect and when, and she was given options whenever possible.

Suzie's experience was extremely well coordinated, and all her health providers were members of the same team—Suzi's team. There was never any delay or waiting for answers. Everyone seemed focused on helping Suzi manage her pain and return home for a restful recovery. The team handled all appointments, always taking her preferences into consideration and making her feel like she was everyone's top priority. In contrast, Tim's experience was not at all coordinated. The burden was put on him to schedule, coordinate, call, explain and reexplain, and insist that his appointments be made in time for surgery. It was his responsibility to think of and ask every question possible, as the only information shared concerned the clinical process of the surgery. Tim was given neither time nor the opportunity to explore treatment options; in fact, he was given no treatment options other than surgery.

* * *

As an industry, healthcare can be mysterious. On the outside, it gives off a cold feel. It's a world you won't have to visit much, if you're lucky and healthy. That perception is not lost on its leaders. Healthcare CEOs, experts, and consultants have banged the collective drum to become more compassionate, more convenient, and more in line with the belief that care should be centered around the patient.

The past few decades have seen a lot of activity to improve the patient experience. Numerous factors have influenced this work, including legislative action, healthcare improvement initiatives, and the formation of quality improvement organizations that have helped create ways of quantifying, measuring, and reporting

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

provider performance. Through such efforts focused on improving the quality of care, the healthcare industry has recognized that one key factor must be the patient experience, as it is intricately related to and affects overall quality.

Measuring quality began with the establishment of the Institute of Medicine (IOM) in 1970 by the National Academies of Science to help inform the nation on emerging healthcare issues. The IOM was responsible for developing the STEEEP acronym that is widely used today as a standard definition of quality in healthcare (safe, timely, effective, efficient, equitable, and patient-centered). The Agency for Health Care Policy and Research (AHRQ) was formed in 1989 under the Department of Health and Human Services. In October 1995, AHRQ launched the first Consumer Assessment of Healthcare Providers and Systems (CAHPS) program, based on the work of the Picker Institute at NRC Health. The initial focus was a multiyear initiative to support and promote the assessment of consumers' healthcare experiences in the hospital inpatient setting. The program now addresses a range of healthcare services to meet the needs of healthcare consumers, purchasers, health plans, providers, and policymakers (AHRQ 2023). The CAHPS program has two main goals:

1. To develop a standardized patient questionnaire to be used to compare results across sponsors and over time
2. To generate tools and resources that sponsors can use to produce understandable and usable comparative information for both consumers and healthcare providers

From 1995 to 2001, several other quality improvement initiatives, task forces, and sentinel event reports were initiated and published, including the two famous reports from the IOM, *To Err Is Human* (1999) and *Crossing the Quality Chasm* (2001). The latest charge for "patient-centered care" came in 2005, during a time when healthcare was coming to grips with rising costs and

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

stagnating quality of care. The term *value-based care* was still not widely used or understood. The patient-centered charge made it all the way to Washington, DC, and politicians listened.

In December 2005, the Office of Management and Budget gave its final approval for the national implementation of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) surveys for public reporting purposes. When the Centers for Medicare & Medicaid Services (CMS) began tying a portion of hospital Medicare payments to survey scores in 2007, hospitals started to pay more attention. A widespread effort was put in place to give patients a voice and to improve healthcare for patients. The first public reporting of HCAHPS results occurred in March 2008 (CMS 2023a).

From 2007 to 2016, AHRQ expanded the CAHPS program to other areas beyond hospital care, including physician clinics, home health, hospice, and outpatient and ambulatory surgery. The CAHPS program is still regularly reviewed by CMS to ensure that the survey includes what is most important to consumers.

In 2014, CMS added HCAHPS scores to its Hospital Value-based Purchasing Program, tying those results to Medicare hospital reimbursements and thus elevating the importance of the CAHPS program. In 2019, the Medicare value-based physician payment system known as the Merit-based Incentive Payment System, which includes clinician and group CAHPS measures in its reimbursement calculations, was fully implemented. The US government's increasing emphasis on value-based payments is aimed at influencing other payers in tying the amount of reimbursement to the patient experience. These moves have placed the improvement of patient experience front and center for healthcare executives and board leadership.

After more than 20 years of efforts to improve the patient experience, what do we have to show for it? Has widespread measurement of the patient experience created actionable data and real-life improvement? Has the call to consider the patient's point of view shifted minds—and hearts—to what's most important in

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

healthcare? Has an entirely new industry of patient-focused educational and training tactics staffed hospitals with newer, kinder caregivers? To answer these critical questions, we must first revisit the most prolific study of patient-centered care in US history.

THE WORK OF HARVEY PICKER

Born into a healthcare-oriented family, Harvey Picker didn't set out to change the industry—at least not initially. Picker followed in his father's footsteps and took the reins of Picker X-Ray, a leading-edge X-ray technology company that aided Allied efforts during World War II (1939–45) and saved lives with small, nearly indestructible imaging machines that could be used almost anywhere. Picker devoted three decades of his adult life to the business that bore his father's name. His wife, Jean, was a US ambassador to the United Nations, an acclaimed journalist for *Life* magazine, and a personal friend of Eleanor Roosevelt.

Picker spoke to a London *Times* reporter in 2006. According to the published article, "the couple's personal experiences of healthcare changed everything. As president of Picker X-Ray, Harvey was in constant contact with the healthcare system. And Jean had regular stays in hospitals because of a chronic and incurable infection of her neck and head" (Crompton 2006).

In his own time immersed in healthcare, Picker found healthcare highly advanced in terms of technology but woefully underperforming in the way it treated patients. This observation intensified with Jean's experiences. As Picker recalled in the *Times* article (Crompton 2006):

> I am under no illusions that my wife and I were given above average attention in hospital. But while we were there we saw how other patients' needs were badly neglected. They were left unattended on stretchers in corridors for hours. This was happening all the time in the 1960s and 1970s, in

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

> the U.K. as well as America. Now, of course, if it happens it gets far more publicity. Until the middle of the 20th century, if you became ill there were few things we knew how to cure, so patients got very personalised nursing care for almost everything, trying to pull the person through the illness. Then, with penicillin and the introduction of other medical technologies, there was a complete flip. Because you could cure people, personal care became less important and the attitude of healthcare professionals changed from looking at the person to looking at the disease. The pendulum had swung too far the other way.

In light of these experiences, Harvey and Jean Picker transferred the assets of their small family foundation to the Commonwealth Fund in 1986 and initiated the Picker/Commonwealth Program for Patient-Centered Care, which later became known as the Picker Institute (Kohler 1994). In Harvey Picker's words, "it was the first body to investigate scientifically not just what patients really wanted from healthcare but also how physicians and healthcare staff could improve the patient experience" (Kohler 1994). Harvey, Jean, and the rest of the team tackled their goal with great vigor and immediately began to interview patients firsthand.

Over the next seven years, the Picker/Commonwealth program conducted extensive academic research, including more than 8,000 interviews with patients and families, as well as focus groups composed of dozens of caregivers. This research showed that patients' preferences were too often neglected and that amenities, such as hospital food and access to parking, were given far too much significance in existing patient surveys (Kohler 1994).

The Picker Institute developed a wide range of survey tools that quickly set the standard for performance measurement in the healthcare field. In addition to its own research, Picker Institute staff members were part of a large team of investigators from across the country—joining researchers from Harvard Medical School, the Research Triangle Institute, and the RAND Corporation—who

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

worked to develop the CAHPS surveys and reports to improve public accountability and support consumer choice. The CAHPS instruments have become the national standard for evaluating care across the United States and are now required by the National Committee on Quality Assurance as well as CMS. The Picker Institute's emphasis on standardized instruments and methods of data collection helped support the creation of comparative databases that could facilitate benchmarking and spur quality improvement (Gerteis et al. 1993). As demand for Picker surveys increased, the institute lacked the capability to run large-scale data collection, processing, and reporting, so in 1994 its survey instruments were acquired by the National Research Corporation, now NRC Health (Kohler 1994).

The Picker Institute was the first of its kind in that it existed solely to advance the idea of patient-centered care. It argued that what matters most in healthcare is not what physicians or administrators think but what the patient thinks. The bedrock of this argument was the idea that for patients to truly receive the best care possible, they must be involved in the process—and partnership—of care delivery. In short order, the Picker Institute was "considered a leader in promoting patient-friendly medical care" (Hevesi 2008). This unique approach not only created reams of useful (and at the time rare) patient data but also culminated in a project known as *Through the Patient's Eyes*. This patient-centered masterwork, laid out in a 1993 best seller of the same name (Gerteis et al. 1993), concluded that patients held a high bar in their expectations of a healthcare experience and that the industry had a mountain of work to do to better serve its primary audience.

EIGHT DIMENSIONS OF PATIENT-CENTERED CARE

Out of *Through the Patient's Eyes*, the Picker Institute outlined a plan for health systems and hospitals to improve. From more than eight years of interviews and reams of patient feedback, the Picker

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

team identified the following eight dimensions of patient-centered care (Gerteis et al. 1993):

1. **Respect for patients' values, preferences, and expressed needs**
    - Respecting the values of each individual patient
    - Involving the patient in medical decisions
    - Treating the patient with dignity
2. **Coordination and integration of care**
    - Clinical care
    - Ancillary and support services
    - Frontline patient care
3. **Information, communication, and education**
    - Accurate information on the patient's clinical condition and prognosis and on the processes of care
    - Additional information to support patient self-care and autonomous patient decisions
4. **Physical comfort**
    - Pain management
    - Assistance with daily activities
    - A supportive hospital environment
5. **Emotional support and alleviation of fear and anxiety**
    - Alleviation of anxiety over physical treatment and prognosis
    - Alleviation of anxiety over the impact of the illness on the patient and family
    - Alleviation of anxiety over the financial effects of illness
6. **Involvement of family and friends**
    - Providing accommodations for family and friends
    - Involving family and close friends in decision-making
    - Supporting family members who take on the role of caregiver

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

  - Recognizing the needs of family and friends, as well as of the patient
7. **Continuity and transition**
  - Providing understandable, detailed information on medications and continuing patient needs
  - Planning and coordinating timely and appropriate treatment and services after discharge
  - Offering continuing information on access to clinical, social, physical, and financial support services
8. **Access to care**
  - Information on the location of needed healthcare services, along with appropriate transportation support
  - Ease in scheduling appointments
  - Accessible specialists and specialty services

These factors proved most important to patients before, during, and after their journey of care. Many of them, such as involvement of family and friends, were novel and underappreciated at the time. "Visitors," as family and friends were often labeled, were not considered a part of the direct care provided to the patient even though their support had an immeasurable impact on the patient's attitude, well-being, and ability to recover. The dimension of emotional support is hugely important to patients and correlates most highly with a patient's recommending an organization to others; however, this aspect of care continues to be a challenge for most organizations.

More than a quarter century has now passed since that landmark study. What has changed in that time?

CURRENT STATE OF PATIENT-CENTERED EFFORTS

Undeniably, activity, resources, and energy have been spent on the mission of patient-centered care. The Picker-inspired movement created vast amounts of patient- and consumer-provided

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

data. Over time, data sets have become faster to collect, easier to access and share, and more robust and meaningful. These data managed to infiltrate healthcare organizations all the way to the top—finally bringing the average patient's evaluation of the care experience to the CEO's desk and the boardroom. Large swaths of organizations have created initiatives to improve the care they deliver. They have broken down siloes that benefited internal departments but not patients. They have tied executive compensation and incentives to patient-provided scores. They have attempted to uncover patients' preferences beforehand and to follow up after discharge to ensure that patients are recovering as planned.

But ask anyone who has had a recent patient experience, and it's clear there hasn't been enough progress. Overall HCAHPS scores increased only about 7 percentage points from 2008 to 2015 (Papanicolas et al. 2017). The COVID-19 pandemic halted much of this progress, resulting in reduced quality of care, increased mortality, and lower HCAHPS scores (Elliott et al. 2023). National publicly reported data indicate that the pandemic set HCAHPS back almost ten years. Looking at the benchmark data (CMS 2023b) for HCAHPS surveys administered by NRC Health tells a similar story: the average overall rating in 2022 (71.1 percent) was at a level not seen since 2014 (NRC Health 2024a).

One of the most dramatic changes has been the increased cost of care. In 2001, the average American family spent about 12 percent of its income on healthcare; in 2019, it spent between 15 and 30 percent, depending on whether the family had employee-sponsored coverage or an individual plan (Kaiser Family Foundation 2019; Sekhar 2009). US healthcare spending in 2022 grew by 4 percent, reaching $4.5 trillion, or $13,493 per person, representing about 17 percent of the nation's gross domestic product (CMS 2024). Supply chain disruptions, increased labor costs, and postpandemic inflation are doubling or tripling the costs of care, depending on the service line or market. Most Americans now find themselves unable to comfortably afford healthcare. Medical bills

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

have become a leading cause of personal bankruptcy and divorce. Surprise bills have become the fodder of journalists at the national, regional, and local levels.

What do Americans think about progress? In general, most consumers are not familiar with healthcare and don't pay much attention to it until they or their family member needs it. When they do access healthcare, they come to it with expectations from other industries—food service, hospitality, financial—that they use far more often. Those industries have made leaps and bounds in improving the delivery of a consumer-friendly experience. Healthcare has not, leaving many consumers with a strong desire and incentive to stay away from it—even to their detriment.

Clearly, this widespread perspective would trouble Harvey Picker. Before he passed away in 2008, Picker was still hopeful that healthcare would improve. He often argued that improvement must come from within the rank and file of healthcare organizations themselves—and not only nurses and physicians but senior leaders, too. How and when will healthcare change? Harvey's answer, from a Picker Institute-sponsored Future of Patient-Centered Care Vision Summit in Baltimore in March 2004: "I've never seen an industry change until the fear of remaining the same is greater than the fear of change."

Outside the hospital tower, it became evident to consumers that they must own their health. Out of both necessity and stewardship of their own out-of-pocket expenses, consumers have become more aware of healthcare and are hungrier for better information and care options. Only recently, healthcare providers began to encourage their patients to take a more active role in their health. The industry began to move from volume-based care to value-based care and from being disease-focused to being health-focused.

But few people saw it coming: a global pandemic that invaded every corner of the world and challenged US healthcare organizations in nearly unfathomable ways. COVID-19 exposed the many shortcomings of the US healthcare system, including the observations of Harvey and Jean Picker. COVID cast a harsh light on the

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

lack of care coordination, equitable access to care, and overreliance on a fraying frontline. Some of the Picker dimensions were paused or outright banned (especially emotional support and the involvement of family and friends—outside visitors were no longer allowed, and COVID patients died alone and in isolation). The demands of today's healthcare consumers long preceded the pandemic, but COVID heightened their call to deafening levels. In many ways, healthcare organizations rose to the challenge, but the necessary focus on managing the COVID crisis took attention away from the progress being made on the value-based, patient-centered care journey. Now consumers hold an important memory: it can be done. Their expectations for future care will continue to trend up.

CREATING A MORE CONSUMER-FRIENDLY HEALTHCARE EXPERIENCE

On other end of value is the healthcare consumer, and they don't want to pay too much for too little. Healthcare provider organizations have only just started to realize the full breadth of information that needs to be captured to effectively create a more consumer-friendly experience. Historically, providers have done a poor job of listening to their patients and consumers. While the government mandate of HCAHPS has provided a basic level of patient satisfaction information, truly listening to the consumer involves gathering information about their experience before and after the hospital stay, not just understanding what went wrong in the hospital. Although traditional surveys capture information about a single care encounter, they don't ask about the experiences that surround it, including booking an appointment, waiting to be seen, and coming to grips with the bill—all domains that are frustrating to patients and where retail clinics tend to excel.

Consumer desire for more accessible, convenient care has tipped the balance in favor of retail healthcare. In 2019, consumers

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

were evenly split between those who felt positively about care in a retail setting and those who felt negatively. Now, about 60 percent view it positively (NRC Health 2024a). Why? To answer this question, we found that for those who have visited retail clinics in the past, 56 percent did so because it was much easier to get an appointment with them than with traditional providers (COSHC and IOM 2015). Furthermore, even if they managed to secure an appointment with a physician, almost one-third of patients reported unduly long wait times—and 20 percent said they would switch providers if they had to wait too long (Heath 2018). Also, 61 percent of patients found their bills confusing, and most of these people believed that providers were to blame (Gooch 2016; Heath 2018). It's not always the appeal of something new but rather the removal of an existing frustration that may entice patients to switch.

Patient feedback surveys focus on discrete episodes of care, which for most patients are many months or even years apart. As a result, the collection of patient data is inherently sporadic. Nearly half of provider organizations report an inadequate understanding of a patient's journey of care (Gooch 2016).

In 2007, the Institute for Healthcare Improvement (IHI) introduced the Triple Aim as a framework for optimizing health system performance. Underlying this framework is the belief that new care designs must be developed to simultaneously pursue improvements in three dimensions of care (Berwick, Nolan, and Whittington 2008):

1. Improve the patient experience (including quality and satisfaction).
2. Improve the health of populations.
3. Reduce the per capita cost of healthcare.

The Triple Aim placed even greater emphasis on patient-centered care as a central core of high-quality healthcare (IHI 2024).

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

However, we also referred to the three legs of this aim as an "iron triangle" in the introduction, underscoring the difficulties of improving all three legs in a fee-for-service healthcare system.

An important attribute of patient-centered care is the active engagement of patients in making healthcare decisions, because most medical decisions involve more than one reasonable path or option (Barry and Edgman-Levitan 2012). AHRQ's definition of *engagement* includes both activation and engagement: "Patient engagement is the involvement in their own care by individuals (and others they designate to engage on their behalf), with the goal that they make competent, well-informed decisions about their health and health care and take action to support those decisions" (AHRQ 2024). Patient engagement is a broader concept than patient satisfaction; patient engagement combines patient activation with interventions to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly (James 2013). It also involves shared decision-making in which clinicians help patients understand the importance of their own values and preferences in making the decisions that are best for them. When patients know they have treatment options, most will want to participate with their clinician in making the best choice (Barry and Edgman-Levitan 2012).

Patient engagement is one strategy to achieve the Triple Aim (James 2013). To facilitate patient activation and engage patients, an organization needs to put patients first and ensure that their care is individualized. This means treating the patient as the most important member of the healthcare team and understanding the entire journey through the patient's frame of reference. For example, an individualized approach considers how a patient with a chronic condition would like to communicate after the hospital stay. It may include providing resources such as online communities where patients with that particular condition can discuss their concerns with one another, ask questions of a physician or nurse, and participate in group education by healthcare professionals. It also ensures that the healthcare team knows about any barriers

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

the patient is facing that might inhibit compliance with the treatment plan or willingness to engage in healthy behaviors, so that the healthcare team can partner with the patient.

Ultimately, the heightened focus on healthcare quality and patient experience has helped multiple stakeholders align around the same essential goals for change, made patients or consumers more aware of the important role they play in managing their own health, and allowed patients or consumers to see themselves as vital members of the healthcare team.

Unfortunately, the United States still has large leaps to make before all consumers can receive consistent, high-quality, patient-centered care in a provider system that is easy to understand and navigate. The healthcare profession needs to stop thinking about patients or consumers only during their times of illness and consider how to interact with them during their times of wellness, too. Consumers have demanded change and will go to great lengths to get what they expect from healthcare, whether they find it in a traditional or nontraditional setting.

PICKER'S RELEVANCE TODAY AND IN THE FUTURE

In the midst of all this, one might ask, is the Picker work still relevant today? The crux of this book is to answer that question. So much has changed. Notably, the original Picker work was experience based: Organizations had to prove they boosted their performance. Picker wanted people to transcend measurement and focus on how to actually *improve* their scores. That way, progress could be quantifiably discerned on the basis of internal benchmarks.

Rather than combine existing or third-party data sets, Picker and his team believed it was important to conduct primary research with actual patients—to ask them how their experience was and why they feel the way they do. After years of success,

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

NRC Health partnered with the Picker Institute in 1994 to expand and further promote the Picker process. NRC Health adopted the Picker dimensions of care and followed the Picker process to conduct direct patient research. Since 2000, NRC Health (2024b) has received patient feedback regarding 161,693,915 encounters. Through NRC Health's current offerings, the discipline continues to keep the mission to achieve patient-centered care going after all these years.

HCAHPS was a step in the right direction because it forced the issue of patient-centered care throughout the industry and all the way to the top of health system and hospital leadership. But the bottom line is that the progress we have made has come at great cost and slow speed. If he were here today, Harvey Picker might argue that we still haven't achieved anything close to the improvements that patients laid out for us in *Through the Patient's Eyes*.

Alas, Harvey and Jean Picker aren't here to tell us what they think. But their legacy endures. Harvey and Jean had a dream to transform the healthcare world into a place where caregivers provide effective and compassionate care to everyone and experience joy in their work. That constant striving for improvement is what matters most to patients and consumers; healthcare providers need to continuously learn and seek to better themselves in order to better the patient experience.

NRC Health is striving to continue the Picker legacy. Our mission of human understanding is the next step in the evolution of patient-centered care and a way to carry Harvey's torch. We know that teaching and measuring can go only so far; hospitals and health systems must believe in the work and carry it out every day. Increasingly, that means going outside the hospital tower or physician's office and delivering human-centered care to wherever humans are. What is human understanding? It is the enablement of healthcare organizations to understand what matters most to each person they serve, and to ease that person's journey.

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

We will now take a deeper look at where we are today and compare it to where we were 30 years ago—what we've done and what we haven't, and what we've learned and what we still don't know. We will take a close look at how the Picker work still holds up (or doesn't) in today's healthcare age. And what about the future? We will look at what might be happening in healthcare in another 5, 10, or even 30 years.

REFERENCES

Agency for Healthcare Research and Quality (AHRQ). 2024. "Symposium on Patient Engagement (District of Columbia)." Accessed August 23. https://digital.ahrq.gov/ahrq-funded-projects/symposium-patient-engagement.

———. 2023. "The CAHPS Program." Reviewed April. www.ahrq.gov/cahps/about-cahps/cahps-program/index.html.

Barry, M. J., and S. Edgman-Levitan. 2012. "Shared Decision Making: The Pinnacle of Patient-Centered Care." *New England Journal of Medicine* 366 (9): 780–81.

Berwick, D. M., T. W. Nolan, and J. Whittington. 2008. "The Triple Aim: Care, Health, and Cost." *Health Affairs* 27 (3): 759–69.

Centers for Medicare & Medicaid Services (CMS). 2024. "National Health Expenditure Data: Historical." Modified July 8. www.cms.gov/data-research/statistics-trends-and-reports/national-health-expenditure-data/historical.

———. 2023a. "HCAHPS: Patients' Perspectives of Care Survey." Modified September 6. www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/HospitalHCAHPS.

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

———. 2023b. HCAHPS Update Training. Published March. https://hcahpsonline.org/globalassets/hcahps/training-materials/2023-hcahps-update-training-slides.pdf.

Committee on Optimizing Scheduling in Health Care (COSHC) and Institute of Medicine (IOM). 2015. "Issues in Access, Scheduling, and Wait Times." In *Transforming Health Care Scheduling and Access: Getting to Now*, edited by G. Kaplan, M. H. Lopez, and J. M. McGinnis, 17–31. Washington, DC: National Academies Press.

Crompton, S. 2006. "Father of Modern Patient Care." *Times* (London). Published October 28. www.thetimes.co.uk/article/father-of-modern-patient-care-kfm2qlwg5b3.

Elliott, M. N., M. K. Beckett, C. W. Cohea, W. G. Lehrman, P. D. Cleary, L. A. Giordano, C. Russ, E. H. Goldstein, and L. A. Fleisher. 2023. "Changes in Patient Experiences of Hospital Care During the COVID-19 Pandemic." *JAMA Health Forum* 4 (8): e232766. https://jamanetwork.com/journals/jama-health-forum/fullarticle/2808746.

Gerteis, M., S. Edgman-Levitan, J. Daley, and T. L. Delbanco (eds.). 1993. *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*. San Francisco: Jossey-Bass.

Gooch, K. 2016. "61% of Patients Confused by Medical Bills, Survey Finds." *Becker's Hospital Review*. Published July 14. www.beckershospitalreview.com/finance/61-of-patients-confused-by-medical-bills-survey-finds.html.

Heath, S. 2018. "Long Appointment Wait Time a Detriment to High Patient Satisfaction." *PatientEngagementHIT*. Published March 23. https://patientengagementhit.com/news/long-appointment-wait-time-a-detriment-to-high-patient-satisfaction.

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

Hevesi, D. 2008. "Harvey Picker, 92, Pioneer in Patient-Centered Care, Is Dead." *New York Times*. Published March 29. www.nytimes.com/2008/03/29/health/29picker.html.

Institute for Healthcare Improvement (IHI). 2024. "Triple Aim and Population Health." Accessed August 23. www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx.

Institute of Medicine (IOM). 2001. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press.

———. 1999. *To Err Is Human: Building A Safer Health System*. Washington, DC: National Academies Press.

James, J. 2013. "Health Policy Brief: Patient Engagement." *Health Affairs*. Published February 14. www.healthaffairs.org/do/10.1377/hpb20130214.898775/full/healthpolicybrief_86.pdf.

Kaiser Family Foundation. 2019. "The Real Cost of Health Care: Interactive Calculator Estimates Both Direct and Hidden Household Spending." News release, February 21. www.kff.org/health-costs/press-release/interactive-calculator-estimates-both-direct-and-hidden-household-spending/.

Kohler, S. 1994. "Case 83: Picker Institute." In *Casebook for the Foundation of a Great American Secret: How Private Wealth Is Changing the World*, edited by J. L. Fleishman, J. S. Kohler, and S. Schindler, 238–39. New York: PublicAffairs.

NRC Health. 2024a. *Market Insights Surveys of Healthcare Consumers*. Lincoln, NE: NRC Health.

———. 2024b. Unpublished quantitative survey data.

Papanicolas, I., J. F. Figueroa, E. J. Orav, and A. K. Jha. 2017. "Patient Hospital Experience Improved Modestly, but No

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.

Excerpted from Patient No Longer: How YOU Can Lead the Consumer Revolution in Healthcare (2nd ed.), by Ryan Donohue and Steven K. Klasko (ACHE Learn, 2025).

Evidence Medicare Incentives Promoted Meaningful Gains." *Health Affairs* 36 (1): 133–40.

Sekhar, S. 2009. "Family Health Spending to Rise Rapidly." Center for American Progress. Published September 15. www.americanprogress.org/issues/healthcare/news/2009/09/15/6699/family-health-spending-to-rise-rapidly/.

Copying and distribution of this book is prohibited without written permission.
For permission, please contact Copyright Clearance Center at www.copyright.com.