

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 sizeable 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 health-care 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,

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 due to prostate cancer was no higher in those 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 everything was OK prior to surgery. Finally, after further difficult testing that didn't make any sense to Tim and enduring additional appointments, scheduling challenges, and great expense, he was assured nothing was wrong with his heart and he 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.

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 related, 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

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 in the morning. 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, but 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, 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 re-explain, 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.

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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. For decades, 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 latest charge for “patient-centered care” came in 2005, during a time when healthcare was coming to grips with rising costs and 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 2020).

After more than a decade 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 healthcare? Has an entirely new industry of patient-focused educational and training tactics staffed hospitals with a newer, kinder caregiver? 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 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 in World War II 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 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, “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 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” (Crompton 2006).

In light of these experiences, Picker and his wife 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 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. Harvey, Jean, and the rest of the team tackled their goal with great vigor and immediately began interviewing 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 in 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 worked to develop the Consumer Assessment of Healthcare Providers and Systems (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 country 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 NRC Health (called the National Research Corporation at the time) (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 team identified eight dimensions of patient-centered care:

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**
 - Anxiety over physical treatment and prognosis
 - Anxiety over the impact of the illness on the patient and family
 - 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
 - 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 they 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. “Continuity and transition” was another underappreciated dynamic. So much of healthcare is episodic; the

patient was often expected to transition between care events and locations without much guidance, which proved to be an area of immense frustration and lasting confusion. It was eye-opening for many providers to consider these effects on those they serve. 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.

The Picker Institute's eight dimensions of care aimed to better instruct those who were committed to patient-centered care. It laid out clear, effective techniques for caregivers at every level of healthcare to improve their approach to patients. The project ultimately established a bold mission for healthcare providers across the nation to go forth and find a way to make patient-centered care a reality.

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 data. Over time, data sets have become faster to collect, easier to access and share, and more robust and meaningful. This 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 worked hard to uncover patients' preferences beforehand and to follow up after discharge to ensure patients are recovering as planned. The industry has

embraced bundled payments as a way to encourage better care, not more expensive care, for patients.

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). One of the most dramatic changes in 25 years has been the cost of care. In 2001, the average American family spent about 12 percent of its income on healthcare; now it spends anywhere between 15 and 30 percent, depending on whether the family has employee-sponsored coverage or an individual plan (Kaiser Family Foundation 2019; Sekhar 2009). Most Americans now find themselves unable to comfortably afford healthcare. Medical bills have become a leading cause of personal bankruptcy and divorce. Surprise bills have become the fodder of national media pundits.

What do Americans think about progress? Most consumers are not familiar with healthcare and don't pay much attention to it until they or a family member need it. When they do access healthcare, they come to it with expectations from other industries—food, 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 someone like 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 of the hospital tower, it has become 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 hungrier for better information and care options. Harvey and Jean Picker saw patient involvement as a key ingredient in advanced patient-centered care. Only recently have healthcare providers begun to encourage their patients to take a more active role in their health. The industry has begun to move from volume-based care to value-based care and from being disease-focused to being health-focused, but much work must still be done and everyone must be involved. It will take a village.

THE ROLE OF TECHNOLOGY

Technology is often pointed to as the salve of the patient experience. Healthcare technology in general has made leaps and bounds since the Pickers' original work. (More details on technological advances are provided in chapter 2.) Even patient-facing technology has changed. The electronic medical record (EMR) didn't exist a quarter century ago; now consumers communicate digitally with medical professionals—or even have virtual healthcare visits—and they have access to more information than anyone ever dreamt possible. The communication is also lightning quick.

But fast and easy is not how consumers would describe healthcare. Although technology has made some improvements, it has not eased the fear, frustration, and outright confusion that many consumers feel during a healthcare experience. In fact, the medical progress we have seen has created more dings and distractions in the patient room. The EMR has caused physicians' eyes to drift away from the patient and toward the screen. Transcription has replaced interaction. Technology in general has caused problems for patients trying to focus on becoming well again.

Technology is a microcosm of all the improvements made in the past quarter century. It has done immeasurable good but also caused immeasurable harm. When it's used to empower the patient and streamline the experience, the results have been impressive. When it's used as a surrogate for real human interaction, it has caused harm. Having ten different apps to manage while trying to figure out an already confusing industry is not exactly progress.

Technology could be considered a new dimension of care, but it cuts across all other dimensions. Having access to care means having access to your own medical history. It means having access to a physician when you want it, including remotely via telehealth in the convenience of your home. Involvement of family and friends means being able to text and tweet at them during your healthcare experience as you would in any other customer transaction.

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. Is there any chance those original dimensions of care still hold up? Do patients still value human interaction and efforts to secure their comfort and respect? Research conducted for this book (presented in chapter 6) demonstrates that the dimensions continue to be deeply relevant. For example, emotional support continues to be an important component of patient-centered care, perhaps even more so than it was 25 years ago. Patients still want access to care—they just want it differently today.

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 felt 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. What is most important to them? And how is that different from the actual experience? What do organizations have to do to bridge any gaps?

This approach was radically different from how healthcare organizations traditionally conducted research. Often because of a C-suite edict, department heads would get together and put the questions they themselves wanted to ask into a questionnaire. Employees and patients would be asked these questions in person. The lack of anonymity and possibility of confrontation often skewed feedback. These internal focus groups were often mere echo chambers. Picker pushed organizations to go beyond their own interests and ask patients directly, “What is important to you?”

After years of success, 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 has received patient feedback regarding 52,988,762 encounters. Through NRC Health’s current offerings, the discipline continues to keep the mission to achieve patient-centered care going after all these years.

If Harvey Picker were still alive, what would he say about healthcare today? Contributor Jona Raasch, CEO of The Governance Institute (a service of NRC Health) and former colleague and friend of Harvey Picker, says, “We are moving way too slowly. Harvey would immediately recognize we are continuing to be challenged by the same issues and problems we dealt with decades ago. Sure, there have been incremental improvements and tweaks to how we approach patients. 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. Harvey may argue 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 aren't here to tell us what they think. But their legacy endures. They brought focus to an unruly, complex, and massive industry by asking a simple question: In healthcare, who is most important? The answer—as clear as a bell—is the patient. But it is equally clear that this answer has rarely manifested itself in reality. And that's where the Pickers' lifework took aim. *Through the Patient's Eyes* became a call to action for those in healthcare who truly believe the patient is the most important person and that everything must be done with the patient in mind. 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 evolution of patient-centered care and a way to carry Harvey's torch. NRC Health's clients are adopting these practices and bringing them to life for their patients. Harvey and Jean Picker would want those improvements to reach as far and wide as possible in the vast industry of healthcare. NRC Health knows 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 of the hospital tower or physician's office and delivering

human-centered care to wherever humans are. "What Harvey and Jean set out to do was always bigger than any one individual," Raasch shares. "It's always been a collective mission. There were so many insights out of the original work—the dimensions, the 'nothing about me without me' initiative, the push for faster feedback

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.

and real-time improvement by moving from research to action. All of those things had to happen on a grand scale, and Harvey always had that vision in his mind.”

We will now take a deeper look at where we are today and compare it to where we were 25 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 25 years.

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