UNDERSTANDING SOCIETY

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In the midst of ongoing public debate about payment reform and accountability mandates, it can be easy to lose sight of the individual patient, whose total care should be central to effective, empathetic healthcare delivery. Individual health outcomes are not singularly dependent on the more arcane aspects of public policy, provider interactions, or even adherence to an exercise regimen, healthy eating, and medication management. Rather, one’s health depends on an interwoven network of individual, familial, and community factors that work in concert to influence overall well-being. While only one driver of health outcomes, patient experience can play a key role in mitigating the potentially negative effects of these other factors, as the quality of patient/provider interaction—including clear communication, and the ability for the patient to make informed and supported decisions—is foundational to quality care.

An individual’s engagement with the healthcare ecosystem is further impacted by characteristics of a provider’s facility, including parking options, accessibility for those without cars, and hours of operation. Further, in rural or underserved areas, many patients struggle to find providers who can see them quickly, or care for complex issues or comorbidities. Some patients may face difficulties with providers who are not trained to communicate a treatment plan in terms that are understandable for non-English speakers. The dynamics of a health and social ecosystem interact with one another to create a highly individualized experience for patients and the providers who seek to provide high quality care. There is not a single strategy for improving patient experience, as a driver of improving patient outcomes—rather, individuals, families, communities, government and industry must harmonize on various approaches that address commonalities that cross socioeconomic lines and put the patient front and center.

This publication brings together the perspectives of healthcare services researchers, technology innovators, and leaders in clinical organizational improvement to discuss how best to optimize delivering on the common needs each patient brings to every interaction, and to their overall healthcare management. These leaders recognize that patient experience is a complex mix of factors that determine not only an individual’s health, but also the health of the broader community. They understand that patient experience is increasingly impacted by how well technology innovation is harnessed and implemented in a clinical setting, by the level of rigor and practical application with which healthcare services research is conducted, and by the dynamic mix of factors that create high-performing, empathetic, and agile healthcare delivery teams. The authors speak to technology, rigorous research, and organizational considerations, each recognizing the backdrop that social determinants of health bring to patient experience and any effort to understand experience as a factor in outcome.

The quality of patient/provider interaction is foundational to quality care.
Abigail Sanford is interviewed about the role of patient experience in the Department of Veterans Affairs and the initiatives being rolled out to improve patient experience.

Kristine Martin Anderson discusses several key challenges that provider facilities face as they incorporate the patient’s voice into healthcare evaluation.

Omar Pedraza explores which aspects of patients' inpatient hospital care should be prioritized to improve their overall experience.

Sherri LaVela is interviewed about how patient experience relates to patient engagement, customer satisfaction, quality of care, and provider performance.

Aaron Yao and Thomas Cornwell tease out the challenges of measuring and improving patients' experiences in a home healthcare setting, where engagement with family caregivers can play an important role.

Grant Huang details the role patient experience has in improving the success of clinical trials and the effect that conducting clinical trials can have on improving patient experience.

Katie Ziemer helps us better understand what kind of expectations inform patients' assessment of their experiences, with important implications for how we use this information to address discrepancies in care.

Ipsos believes that research needs to inform continuous improvement in healthcare, as well as account for the context of social determinants. As healthcare has adopted continuous feedback loop principles from the retail industry, there has been at times an over-rotation toward instant data at the expense of a balanced approach to collecting multiple data points over time. Beyond point of service feedback, a deeper analysis of patient experience data identifies facility design, provider recruitment, training, and engagement, communication, and business process concerns that are common across industries and geographies. Indeed, highly functional facilities use evidence-based research as well as human-centered design principles in order to effect change across these major areas of concern. Similarly, highly effective providers deliver not only evidence-based, high quality care, but also communicate empathy and consider the patient’s needs in the context of his or her community.

In building on the work that has already been done, a number of questions remain regarding how best to understand and measure the patient experience as well as use the results to support quality improvement. Below, we present brief abstracts of each article in this edition of Understanding Society.

1 Zachary Lewis describes Ipsos’ framework for measuring patient experience and using the results to enhance healthcare delivery.

2 Aysha Keisler and Katie Ziemer examine how consumers use patient experience data when selecting providers or hospitals, an issue at the intersection of patient experience and consumer-driven healthcare.

Alan Roshwalb demonstrates the importance of accounting for types of patients and services offered when organizations use patient experience data to evaluate their sub-units or individual providers.

A deeper analysis of patient experience data identifies concerns that are common across industries and geographies.
Paramount to the questions of how best to measure patient experience and how to make use of those measures is a more fundamental question: Why does patient experience matter? There are three principal schools of thought to address this question:

1. **To ensure that patients remain satisfied and loyal customers.** From this perspective, patient experience is a healthcare-sector version of customer experience, wherein an individual’s experience matters because the organization or business wants them to continue being a customer.

2. **To achieve better long-term health outcomes.** In this view, patient experience is seen as a significant determinant of health outcomes that organizations should attend to in order to improve the overall health of the population they serve.

3. **As an end in itself.** From this viewpoint, patient experience matters in and of itself, because healthcare institutions that abide by the principle of “do no harm” should leave patients feeling that they have been treated well.

Although these perspectives are not mutually exclusive, the specific measures...
taken and the way data are used can vary depending on which of these lenses is being used. Whether the ultimate goal is to increase patient loyalty, improve health outcomes, or ensure patients are treated respectfully, it is essential to understand aspects of the healthcare experience that matter to the patient and to connect them to the processes that institutions and providers use to deliver care.

Ipsos’ framework for measuring patient experience and for using the resultant findings to underpin improvements in delivery has been designed with the flexibility to adapt to all these priorities. In practical terms, our focus has been on improving care as a service in and of itself in addition to treating it as a means to improving population health.

As we look at what to measure, our efforts should start with understanding patients’ experience from their perspective. What are they hoping to achieve when they enter the web of doctors, nurses, clerks, technicians, pharmacists, and administrators that is the healthcare system? What are their expectations? What barriers can impede them from realizing their objectives and having their needs addressed? The journey mapping approach, adapted from customer experience research, offers a useful tool for identifying the important stages of a patient’s experience, along with the points that can cause pain or frustration on the one hand, and delight or reassurance on the other.

At the same time, it is essential to recognize how these journeys can vary based on a patient’s personal characteristics (e.g., health literacy, self-efficacy), needs (e.g., management of a chronic condition vs. a single episode of care), and circumstances (e.g., social determinants of health). The revolution in health informatics, incorporating not only electronic health records but “wearables” and other sources of data from “the Internet of things,” allows such information to be collected unobtrusively and economically. The patient’s self-report collected by means of a survey can thus be focused on the subjective experiences throughout the journey.

Assessing the experience from the patient’s perspective, while absolutely essential, is insufficient for integrating measurement into a system that can learn, adapt, and improve that experience. The patient journey must be mapped against the processes, personnel, and infrastructure that healthcare institutions apply to deliver care. The tools and training available to a doctor upon encountering patients, the procedure a clerk follows when checking patients in, the rules for family visitation in hospitals, the systems used for scheduling appointments, and the checklists followed to ensure a successful surgery can all affect the patient experience, and must be integrated into the patient journey map.

Having identified aspects of the patient experience that should be measured and connected to a healthcare institution’s systems and staff, the next task is to collect data. We work with our clients to determine the optimal approach, based on the structure of the system and potential ability of patients to respond through various channels. The fundamental requirement at this stage is to obtain, with as little burden on patients as possible, sufficient information to evaluate performance at every level of the institution where care is delivered. In an inpatient setting, doing so may involve measuring the performance of individual departments within the hospital; in an outpatient setting it may mean measuring the performance of each individual provider.

Once such performance measures are obtained, the task lies in communicating them clearly at the level where action can be taken, and pairing them with the tools to support such action. We focus on providing clear, timely, targeted feedback to decision-makers:

- **Clear:** Survey results are being presented to decision-makers, not researchers, and we recognize the importance of giving those decision-
makers a snapshot of the data that lets them see clearly, based on ratings and comments, how patients are experiencing care. In addition, this information must be put into context so that providers and facilities are evaluated based on their performance and not the composition of their patient population, which is outside of their control.

• **Timely:** Putting data into decision-makers’ hands quickly is not just about fixing problems faster; it also means ensuring that these problems are still fresh enough in memory so that they can be understood in detail and corrected. The judicious use of hot alerts and quick detection of changes in trended data are thus pivotal for an effective measurement program.

• **Targeted:** Providers, managers, and administrators must balance multiple competing priorities at any given time; therefore, it is important that the right information gets to the right people and includes specific action items. As a result, reporting tools must balance the presentation of customized, top-priority findings with the ability to dive deeper into the data and understand the factors that underlie issues that are detected.

Even the clear presentation of results to decision-makers may be insufficient to bring about systematic improvements in patient experience. To realize their full potential, the reporting of patient experience measures must be augmented by action-planning tools and tailored guidance on how to address deficiencies. A useful approach for empowering decision-makers to address issues identified by the research is **ticket-based action-planning**, a key hallmark of the “closed-loop” enterprise feedback management (EFM) tools employed to address customer experience across many sectors. However, utilizing EFM tools to manage patient experience is far more complex than it is for managing customer experience in industries such as travel and hospitality. For health delivery organizations, improving patient experience is intertwined with other equally important considerations, such as the patient’s long-term health and privacy requirements. Addressing a bad patient experience requires more than a call to an unsatisfied customer, paired with a refund or credit to be applied in the future. It often requires the same kind of institutional change that is required for reducing hospital-acquired infections or improving medication reconciliation. An effective system thus needs to augment these tools by connecting decision-makers with **tested and proven templates for improving patient experience** that can be adapted to their circumstances and the particular needs of their patients.

As interventions are developed, adapted, and implemented to improve patients’ care, changes in their experiences are measured as part of the system. This process allows administrators, managers, and providers to assess the success of various initiatives and document what works and what doesn’t. Based on the data, these initiatives can be introduced at scale as appropriate if they are found to be effective, and adapted or removed if they are not. In this way, the Plan-Do-Study-Act model that has been so successful at quality improvement across a range of healthcare issues is embedded in a **data-rich positive feedback loop for patient experience** and contributes to a growing body of knowledge about how such data can be used to deliver experiences that make patients healthier and more satisfied.

Addressing a bad patient experience requires more than a call to an unsatisfied customer.
Systematic measurement of patient experience serves multiple purposes. In addition to contributing to financial payment in value-based payment programs, the U.S. Federal government seeks transparency in patient experience ratings so that consumers can make informed decisions regarding their healthcare. The Centers for Medicare and Medicaid Services (CMS) provide patient experience ratings for hospitals across the country on government-hosted websites, such as Hospital Compare (https://www.medicare.gov/hospitalcompare). In addition, private service review websites and applications such as Yelp (www.yelp.com) allow consumers to post ratings and reviews of the same healthcare transactions. Between these websites or applications and others (e.g., Healthgrades, Zocdoc, information from Consumer Reports), a wealth of information on hospital performance is now available to consumers. Moreover, the types of ratings range from symbolic scores (e.g., star ratings) to numeric scores and text reviews from patients.

As behavioral scientists, we wanted to understand how consumers interpret different types of hospital ratings from other patients and whether the ratings influence their choices. We undertook a study to explore three research questions:

1) Does the type of rating (star vs. percentage) influence hospital choice?
2) Does the source of the rating (private vs. government) influence hospital choice?
and 3) Do consumers with low health literacy or difficulty in understanding health information differ when interpreting patient experience ratings from those with high health literacy?

We presented fictitious hospital reviews to a representative sample of 1,005 U.S. adults from Ipsos’ online panel. The first review contained a star rating that was either high (four out of five stars) or low (two stars) and either provided by the U.S. government’s Hospital Compare or by the private Yelp source. The second hospital review presented a percentage score that corresponded to the top 10%, top 25%, bottom 25%, or bottom 10% of scores nationally. After each review, respondents were asked how likely they were to use the hospital if in need of hospital services and the degree to which the review would affect their choice of hospital.

**Star ratings drive intention to use a hypothetical hospital, but negative ratings exert greater influence than positive reviews.**

Not surprisingly, consumers are significantly more likely to want to use a four-star-rated hospital than a two-star-rated hospital ($F[1,1001]=215.1$, $p<.001$). However, the source of the review does not matter much: low star ratings from Hospital Compare and Yelp elicit the same response. Respondents were also just as likely to use a hospital with a high rating from Hospital Compare as they were to use one with the same high rating from Yelp. Interestingly, consumers appear biased to weigh negative information more than positive information in hospital choice. Consumers are more likely to report that their choice of a hospital would be affected by a low rating than by a high rating ($F[1,1001]=31.0$, $p<.001$). In addition, consumers are biased to weigh Hospital Compare ratings slightly more than Yelp ratings ($F[1,1001]=4.4$, $p<.05$).

**Numeric percentage ratings are difficult to interpret in isolation.**

Unlike star ratings, patient experience ratings displayed as a percentage score have little impact on patients’ decision to use a hospital. Consumers are significantly more likely to use a hospital when it is ranked in the top 10% as compared to when it is ranked in the bottom 25% ($t=-3.0$, $df=501$, $p<.01$) of hospitals nationally. However, there was no significant difference between the top 10% and the bottom 10%, which suggests that respondents do not know how to interpret such percentage scores without benchmarks to inform them what “good” and “bad” scores are. These findings are also in contrast to the difference in likelihood observed between high and low star ratings. Moreover, in contrast to the negative bias observed with star ratings, likelihood to report that percentage scores affect one’s choice of a hospital does not vary greatly depending on whether the percentage is fairly high (top 25%), fairly low (bottom 25%) or very low (bottom 10%).

**Respondents report that they trust a federal hospital review website more than a private hospital review site. However, their choice of hospital suggests that they do not differentiate between these sources.**

Consumers trust CMS Hospital Compare ratings (40% report high trust) significantly more than Yelp ratings (31% report high trust) ($t=9.9$, $df=1004$, $p<.001$). This is consistent with the finding that consumers are more likely to report that their
choice of a hospital would be affected by Hospital Compare ratings than by Yelp ratings. However, when presented with reviews, respondents’ likelihood to use the hospital does not differ depending on whether it comes from one source or the other. In other words, greater trust in Hospital Compare does not translate into a greater likelihood to use its ratings. Consumers’ stated values of how much they trust the public (government) and private sources of patient experience ratings do not align with their actions.

Star ratings have a greater influence on those with high health literacy.

For star ratings, consumers with high health literacy tend to have a more extreme response to the ratings than those with low health literacy. Those with high health literacy are more likely to use a hospital with high ratings (four stars) and less likely to use a hospital with low ratings (two stars) than the low health literacy group ($F[1,997]=5.0$, $p<.05$). This finding holds true for both Yelp and Hospital Compare ratings.

Consumers with low health literacy do not use numeric percentage ratings optimally.

When shown percentage ratings, consumers with low health literacy are actually more likely to use a hospital if it is ranked in the bottom 10% than if it is ranked in the top 10% of hospitals nationally ($F[3,997]=3.8$, $p=.01$). The opposite is true for those with high health literacy: they are more likely to use highly-rated hospitals, as would be expected. In addition, for the low health literacy group,
Those with low health literacy do not use numeric percentage ratings to make optimal hospital choices, which is potentially harmful to health outcomes.

**Conclusion**

Overall, consumers appear to find it easier to use star ratings to choose their hospitals than numeric percentage ratings. This is especially true for those with low health literacy who interpreted percentage ratings in the opposite manner as would be expected. Hospitals and review websites should consider turning percentage scores into star ratings or finding another way to make percentages easier for consumers to understand. In addition, education campaigns could help increase consumers’ health literacy, thereby enabling them to make a more well-informed choice. Although consumers report greater trust in federal hospital review websites, private hospital reviews carry just as much weight when consumers are actually choosing a hospital. It may be beneficial to educate consumers on the difference between federal review and private review websites, including the bias that may be present in private websites.
How Good is My Doctor?
A Perspective on a Fair Comparison

Introduction
“I looked up my doctor, and she scored an 89.” “Really? My doctor only scored an 85. I should see yours instead!”

A well-known use of patient experience ratings is to give consumers information to assist in selecting their healthcare professionals. Scores are also widely used by health plans, clinics, and physician groups in deciding on compensation, pay-for-performance, quality improvement interventions, contract extensions, and termination. Good or bad patient experience ratings can impact providers in a number of consequential ways—not only how much prospective patients will seek them out, but also whether or under what conditions they will be accepted into various health plan networks.

Despite their importance, patient experience rating scores are often reported and evaluated on a scorecard without taking context into account. However, context can often change how a score is perceived and evaluated, and without it, the evaluation can be unfair. Here is an illustration: A physician practices internal medicine and sees patients for routine checkups and sick visits. This physician, as is usually the case in internal medicine, has an ongoing relationship with many of these patients. In general, patients who have an established relationship with their physician tend to give them higher ratings. Therefore, this physician is likely to receive higher scores from internal medicine patients.

The same provider works periodically as an urgent or emergency care physician, seeing acutely sick or injured patients. These patients often have to wait to see the physician since they do not have an appointment, and they generally do not have an ongoing relationship with the physician. Thus, the patients in urgent or emergency care would likely give this provider lower scores, which would pull down the physician’s overall ratings.

Here is how things become more complicated. Two physicians see some of their patients in their office and some at a walk-in urgent care (UC) clinic. As shown in the first figure, they both have identical scores of 90% for their office visits and of 80% for their UC visits. However, as shown in the second figure, the composition (or “mix”) of their respective patients is different: Physician 1 sees 90% of her patients in her office and 10% at the UC clinic whereas Physician 2 sees 50% of his patients at his office and 50% at the UC clinic.
When the overall scores are calculated for both physicians, Physician 1’s score is 89% and Physician 2’s score is 85%. Physician 1’s score is a full 4 points higher than Physician 2’s score of 85% even though each physician scored the same for each department. The difference is solely due to their mix of patients. Not taking into account their respective mix of patients, Physician 1 is rated as “a better doctor” than Physician 2.

To be fair, the rating should factor in the context in which both operate. This is why we believe in the employment of benchmarks that bring in context.

**Ipsos’ Point of View for a Fair Scorecard Benchmark**

Benchmarks allow for comparing and rewarding performance, but they must meet several standards to be effective and accepted:

- **Transparency**—The construction of the benchmark must be explainable and understandable by the users of the information. Black-box approaches without a clear and tractable process can cause distrust and uncertainty among the providers and network managers.

- **Statistical efficacy**—A benchmark must have a sound statistical basis that is reliable, consistent, and allows for statistical testing.

- **Fairness**—Contextual variables that can unfairly influence a measure ought to be controlled, e.g., the mix of patients in the example above.

There are two possible directions to take benchmarks and make them fair. One is to adjust the benchmark to make it comparable to the score; the other is to adjust the score to make it comparable to the benchmark.

Ipsos’ Fair Scorecard Benchmark (FSB) approach is to adjust the benchmark rather than the score. Conceptually this is very straightforward. It tells the provider what the scores of other providers would look like if they had the same composition of patients. Ipsos’ Fair Scorecard Benchmark (FSB) identifies groupings where scores are different, such as specialties, age ranges, or health status. It creates \( k \) estimation cells, and calculates the percentage of the provider’s patients in each cell and the cells’ scores based on all patients. The FSB is the weighted average of these percentages and scores such as given in this formula \( j \):

\[
\sum_{k} P_{j,k} Y_{k}
\]

\( P_{j,k} \) – Percentage of patients for provider \( j \) in cell \( k \)

\( Y_{k} \) – Population score for cell \( k \)

The FSB’s formulation is common, so variances and statistical testing is available. It uses the current data, so the FSB values are current. It does not use a complicated model, so anyone with access to the data can replicate their own score and the benchmark. The Fair Scorecard Benchmark method has transparency, has statistical efficacy, and is fair.

By contrast, an example of adjusting scores to match the benchmark is the Centers for Medicare and Medicaid’s (CMS) reporting of Hospital Consumer Assessment of Healthcare Providers & Systems (HCAHPS) hospital scores. HCAHPS uses a complex model based on non-current data. CMS publishes a description of their model, so it is possible for someone to calculate their own score. However, they do not publish the model’s underlying statistics to allow for direct statistical testing.

Often, benchmark systems lack at least one key component. They may lack documentation or their modeling may use non-current data resulting in estimates that may not be accurate for current data. Additionally, statistical testing may be biased without the model’s underlying components; or the adjustments just don’t appear to be fair. In these cases, they do not meet the needs for transparency, statistical efficacy, or fairness.
Case Study

Below, we present data adapted from one year’s worth of patient satisfaction evaluations for a managed healthcare system. The system is comprised of 20 healthcare clinics in a midsize metropolitan area. Data were collected from 51,339 patients for approximately 600 providers. The average across all patients was 84.50. As shown in the table below, patient rating scores by the 17 specialties vary widely. Scores for physicians treating urgent care and emergency patients are approximately six points lower than the average, while geneticists score seven points above the average.

Scores of five providers from lowest to highest are shown below. Each one has a different specialty, and some see patients from a mixture of specialties. Their scores range from 82.7 to 89.2. Provider 1’s score is below the overall unadjusted mean, but it is above their Fair Scorecard Benchmark. The gap is the difference between the provider’s score and the FSB. Provider 1 has the greatest gap—the highest score relative to its FSB. Provider 5 has the highest overall score, but the negative gap indicates that he is performing below his peers in Podiatry. These results with their gaps show how scores without context are not as meaningful as when there is context.

<table>
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<th>PROVIDER</th>
<th>TOP 2 BOX RATING</th>
<th>FAIR SCORECARD Benchmark</th>
<th>GAP</th>
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<td>78.16</td>
<td>4.54</td>
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<td>89.2</td>
<td>90.45</td>
<td>−1.25</td>
<td>Podiatry</td>
</tr>
</tbody>
</table>

Context can often change how a score is perceived and evaluated.

Conclusion

The Fair Scorecard goes a long way in answering the question, “How good is my doctor?” because it provides context to a provider’s score. Some approaches adjust the provider’s score to make every score look alike, but those approaches often use non-current data, use a complex algorithm, and present difficulty in conducting statistical tests. The FSB approach provides context, uses current data, is easy to calculate, and is easy to explain. Patient experience is just one place where the FSB approach is useful. It has also been applied in the hotel industry (hotel properties’ customer experience scores based on leisure versus business travelers mix), automobile dealerships (sales, warranty repairs, versus pay-for-service repairs), and franchise pizza restaurants (in-restaurant dining, take-out, versus home delivery).
Abigail Sanford is the acting Deputy Director of the Veterans Patient Experience Program for the Department of Veterans Affairs. In this role, she leads the strategic organizational change for the VA-wide Patient Experience Program including development and delivery of improvement initiatives, strategic communications, and stakeholder relationship management. We sat down with Abigail to learn more about the Veterans Patient Experience Program, referred to as “VA PX,” which is a directorate of the Veterans Experience Office (VEO).

What is the Veterans Experience Office?

VA established the Veterans Experience Office with the mission of enabling VA to be the leading customer service organization in government so that Veterans, their families, caregivers and survivors choose VA. As Secretary Shulkin has said, “It is critical that we create a seamless Veteran experience across the entire organization. VA must proactively engage Veterans and their families to ensure their voices are heard.”

VEO’s Veterans Patient Experience Directorate is partnering with the Veterans Health Administration (VHA) under the leadership of acting Under Secretary for Health, Dr. Carolyn Clancy, to improve the patient experience in VA healthcare facilities. Many VHA facilities have effective patient experience programs, but there is not one definitive best practice for all of VHA to replicate. One of our missions has been to define, design, and deploy an enterprise-wide program to improve patient experience. At the onset of the program, we spent nearly three months conducting significant research both within VA and with non-VA health systems to really understand what patient experience is. We wanted to learn what patient experience means in non-VA care, and what is being done to improve it. We also wanted to know what it means to VA internally, and how we could create a standard approach to patient experience to improve consistency across the enterprise. “The Veteran’s perspective is not the only focus of this initiative. There are system improvement issues being addressed by teams of very talented and dedicated staff across VA, but it is the perspective that matters most in meeting our mission,” explained Chief Veteran Experience Officer, Dr. Lynda Davis.

How does patient experience in the VA compare to patient experience in the civilian sector?

We have done a significant amount of research and benchmarking. We uncovered great insights because the private sector has been doing this for a decade and a half. The private sector has had many external motivating factors to improve the patient experience, which the VA has not been exposed to. This includes competing for customers for retention and the reimbursement model using Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) scores. Across the board, we’re seeing patient experience as a high priority in non-VA private sector and health systems. Basically, what we have are two completely different universes of healthcare. The VA has been sheltered from some of those outside factors, so it hasn’t had the same incentives to improve patient experience. Our office was charged with developing ways to improve patient experience. However, to implement enterprise-wide initiatives, we have also had to get organizational buy-in from our stakeholders in the Veterans Health Administration (VHA). Even if leadership says, “Hey, go
take a look at this and improve it," there are 147 facilities and over 300,000 employees, so it’s a massive change effort. We have been talking with our stakeholders internally to figure out how this is all resonating with them. We have essentially been pounding the pavement with our stump speech, sharing the value of a comprehensive patient experience program with specific messaging for facility leadership or other relevant program offices. Simultaneously building the program and initiatives to improve patient experience, we have been promoting the value of embracing and adopting a standard patient experience approach across the enterprise.

**How have you been getting buy-in for patient experience within the VA?**

It’s important to acknowledge our primary mission: We should improve the experience for Veterans because it’s the right thing to do for Veterans, their families, and their caregivers. Veterans deserve not only the best clinical outcomes, but also consistently exceptional experiences while receiving care. Of course, this resonates with many VA employees and leaders, but we know that running hospitals and clinics is difficult work. Therefore, we also communicate some of our other expected outcomes from this program, which include many operational benefits. For example, we have specific solutions focused on improving leadership and employee engagement. One solution, which we are calling “WECARE Leadership Rounding” (see below) has been shown to decrease nurse turnover. It can cost up to $60,000 to replace a nurse in terms of time spent on search and training. Even though we don’t have the same financial models as the private sector and non-VA care, it’s still a resource issue for us to meet our mission. UCLA has a similar leadership rounding tool they call “CICARE” as part of their comprehensive patient experience efforts. Since implementing patient experience measures, UCLA has seen their HCAHPS scores improve in a significant and sustained way, which is huge. Showing how improving patient experience also engages the leadership, engages the employees, reduces turnover, reduces absenteeism, and reduces workers compensation claims resonates with all our facility directors. In addition, reducing no-shows is a big deal for the VA, because access is one of our biggest problems. If we’re scheduling appointments 30 days out and we don’t have or use techniques that the private sector is using, like appointment reminders, we’re going to have more no-shows. Appointment reminders that give patients the opportunity to confirm or cancel can help open up appointment slots for somebody else. If we can improve the experience from the time a person arrives at a facility and parks their car to the time they get in the clinician’s exam room, it actually shortens appointment time and enables the providers to focus on what the patients are there for. Patients get frustrated and anxious when they can’t find a place to park, they don’t know where the appointment is, and then they have to wait 15 minutes in the waiting room. The provider then has to spend five or ten minutes focusing on those issues instead of focusing on the reasons why the patient is there. We tell this to our internal stakeholders and show them that even the simple details that seem trivial have an impact on the things that matter, like our availability of resources to treat more Veterans and making our appointments more available.

What initiatives does the VA currently have to improve patient experience?

1. **WECARE Leadership Rounding**

WECARE Leadership Rounding is based on the CICARE program in the UCLA health system where the hospital leaders—medical center director, the associate director, and chief of staff—get out of their office for at least an hour and they ask employees and Veterans...
questions about patient experience. This has had a huge impact on patient experience because it gets the leaders out and talking to patients. It helps them connect with employees, give kudos to those who are doing a good job, and better understand the issues employees are facing. Leadership Rounding connects leaders directly with issues that they can fix right away. If they can’t fix them right away, they can track and follow up on the issues. In the VA, facility leaders are required to do Leadership Rounding a minimum of 15 times per year. It really sets a tone that highlights the importance of patient experience in the facility.

2. Own the Moment Customer Experience Workshop

Hand-in-hand with Leadership Rounding, we’re also teaching customer experience behaviors to the providers and staff. Leaders are looking for those behaviors, and it gives employees the opportunity to demonstrate their customer experience skills. The purpose is to empower employees to deliver that experience in their everyday interactions.

3. Standard Phone Greeting

We’re implementing a standard phone greeting which provides staff the opportunity to set the tone for patient experience. Every time an employee picks up a Veteran-facing phone line, they will use a four-part reading or they say hello, good morning, or good afternoon. They name the facility, the department, and themselves, as well as offer assistance. It sets the caller at ease. Calling the VA could potentially be a nerve-racking experience. Patients may wonder, “Did I call the right place? Are they going to be able to help me? Do I have to schedule an appointment or get test results?” We’re talking about people’s health here. It might seem simple but, believe it or not, we don’t have a standard phone greeting now. We have to start where we are and set the foundation so that we can build upon it.

4. Red Coat Ambassadors

The Red Coat Ambassador Program is a greeter program whereby every VA facility has greeters and volunteers at main entrances and other places throughout the facility wearing a red vest. These ambassadors are trained to engage with people, provide information, help Veterans get to their appointments, and put them at ease. It also provides a standard look and feel—you walk into any VA, see the red coats, and know that those are the people there to help you.

5. Standard Name Badges

Some of the feedback we got from Veterans is that they have trouble reading staff names on the I.D. cards. This new badge has the staff member’s first name in large letters, their hometown, and the reason why they chose to work at the VA. Listing the person’s hometown is something Disney World and Westin hotels do because it’s an automatic opportunity to engage. For example, if you see that you’re from the same place, it instantly creates rapport. Listing why they chose to work at the VA is a daily reminder to the employee and an outward sign letting the Veteran know why they are working here.
Patient experience measures shot out of the cannon when CMS added HCAHPS scores to the Hospital Value Based Purchasing program in 2006. By 2008, hospitals were accountable publicly, and soon financially, for the opinions of their patients. A decade later, demand for patient experience measures has expanded to include both additional dimensions of satisfaction such as timely access to care and new experience areas such as patient-reported outcomes.

Consumer groups are increasingly demanding development of patient-reported outcome measures (PROMS) to get at the ultimate question—is healthcare meeting the expectations of our patients and families? Inserting the
Patient Experience: Putting the Patient Front and Center

surveys that were designed for research, which can be costly and burdensome to administer. Patient satisfaction surveys are increasingly automated, but they are siloed to reflect individual interactions with the healthcare system and not a holistic view of the treatment. As a result, important elements like care coordination remain difficult to capture. Functional status assessments which assess important topics like mobility, pain, and mental health can be critical to following patients to determine a patient’s need for care or support, are largely unavailable. Technology today allows patients to be “followed” without visits, and analytic capability could easily allow triggers to suggest to patients that they see a doctor. However, technology is not used for this purpose and data is sparse.

3. Progress in payment models that favor longitudinal views of care is slow—Despite national focus on payment reform and hype around alternative payment models, there remain very few incentives for providers to manage the patient holistically. Payment models that include some form of capitation or patient assignment to an ACO remain limited. The clear majority of care is delivered in a fee-for-service (FFS) payment model. Even in alternative payment models that pay for episodes or bundles of care, the bundling is done with back-end processes to add together FFS claims to get a perspective on the full episode of care. In today’s healthcare system, few care teams would be willing to hold themselves financially responsible for a patient’s lack of functional status improvement. But without accountability for the full experience, who is motivated to invest in technology to improve the capture of the functional status data, patient compliance, or the quality improvement planning and execution? Given the current delivery and payment models, we need increased incentives to collect patient experience data, establish the baselines, and learn about what can be changed. Perhaps an old-fashioned and much maligned process measure that requires collection of functional status data for the 90 days surrounding select surgeries would be the right place to start the journey? At a minimum, getting the patient’s voice inserted into care delivery and assessment of care is in desperate need of a new road map. This additional focus would make the collection of robust valuable patient experience measures attainable in healthcare.

1. Basic information to support quality improvement programs is missing—Patient experience measures generally lack basic statistics like baselines and expected ranges; they also lack knowledge related to the improvability of the measure or which interventions result in improvement or sustain improvement in healthcare. For patient satisfaction data, we observe regional variability in scores. It is not certain if this variability is related to demographics that influence expectations or rather related to performance. How do we separate these effects? Is the same threshold achievable across populations? How much functional status gain should we expect pre- and post-knee replacement? What variables should we use to risk-adjust functional status gain, and how do we ensure that we are separating patient risk factors from provider performance?

2. Healthcare providers are limited in their use of technology to understand customers—Healthcare is behind other industries in its efforts to collect consumer experience data. It is common to receive a web survey seeking experience data after hotel stays, flights, or even visiting vacation planning websites. The surveys are short, include intelligent logic, and may even offer the opportunity to make your comments public. In many cases, guests get a response from a hotel property manager regarding their report of a bad experience within days of submitting the survey. Most healthcare experience data are captured through surveys that were designed for research, which can be costly and burdensome to administer. Patient satisfaction surveys are increasingly automated, but they are siloed to reflect individual interactions with the healthcare system and not a holistic view of the treatment. As a result, important elements like care coordination remain difficult to capture. Functional status assessments which assess important topics like mobility, pain, and mental health can be critical to following patients to determine a patient’s need for care or support, are largely unavailable. Technology today allows patients to be “followed” without visits, and analytic capability could easily allow triggers to suggest to patients that they see a doctor. However, technology is not used for this purpose and data is sparse.

There remain very few incentives for providers to manage the patient holistically.
Leaders of healthcare organizations are facing a growing imperative to improve patient experience as it becomes a major component in defining and measuring healthcare quality. Patient experience ratings are now built into performance-based reimbursement, board certification and licensing, and practice recognition programs.\(^1\) As patient experience continues to become an integral part of the quality improvement process, healthcare organization leaders are challenged with implementing patient experience improvement efforts in the face of competing priorities and limited resources.

Given the multifaceted nature of patient experience, where should healthcare organizations focus their efforts to have the largest impact? Determining the aspects of healthcare that matter most to patients can help organizations focus their resources on improving processes that are most likely to enhance the overall care experience.

Studies consistently highlight the importance of provider communication and interpersonal relationships in improving overall care experience.\(^13\),\(^14\),\(^15\),\(^16\) Specifically, researchers stress the importance of making the patient feel respected,\(^17\) allowing adequate time to properly discuss health issues,\(^18\) offering clear medical instructions,\(^19\),\(^20\) showing empathy,\(^21\) and expressing genuine interest in the patient’s health.\(^22\) Indeed, interventions that target improvements in provider communications have led to improvements in patients’ overall care experience.\(^23\),\(^24\) These findings underscore that to improve patient experience, providers should promote effective communication to make patients feel cared for and heard.
Though research seems to agree on the importance of provider communications and interpersonal relationships on overall care experience, there may be subsets of the patient population that have different values for what constitutes a good healthcare experience. Healthcare organizations that specialize in niche patient populations or treatments may need to focus their efforts on improving aspects of care besides communication in order to improve their patient experience ratings. To contribute to our understanding of whether the drivers of patient experience remain the same across patient populations and care types, we sought to understand whether the drivers of care experience within the military community were consistent with research findings in the civilian population.

Little is known about the drivers of care experience within the military community, which may differ from those seen in the civilian population, given the unique culture and environment associated with military service. For instance, military members can experience changes in geography, changes in status within the service, and changes in service branch, which all have the potential to impact their experience with healthcare. As military members have access to comprehensive medical care through the military health system, the opportunity exists to assess whether these unique circumstances impact their care experience, by analyzing patient experience data collected from military treatment facilities.

The Defense Health Agency (DHA), with support from Ipsos, conducted an analysis of data collected from approximately 33,000 military inpatient users that received care from November 1, 2014 through March 31, 2015. Results are reported in the 2015 TRICARE Inpatient Satisfaction Survey Report of Findings. As part of the study, the authors conducted a drivers analysis to identify the factors that shape inpatient satisfaction among the military community.

An instrument based on the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) was used. The researchers sought to understand the extent to which global measures of patient experience, which includes a patient’s overall rating of their inpatient experience (the “Overall Hospital Rating” measure) and their willingness to recommend the hospital to others (the “Recommend the Hospital” measure), were driven by patient experience with specific aspects of care. These include factors such as provider communication and the cleanliness of the hospital environment. To do this, logistic regression was applied, wherein the global measures were treated as outcome variables and the remaining HCAHPS measures that reflect specific aspects of care were treated as predictor variables. The coefficients of these logistic models were converted into driver importance metrics to aid in interpretation and numerical comparison.

Driver importances represent the “percent of total impact” explained by each driver included in the model (regardless of the direction of the effect), expressed on a 0-100 scale, where the sum of all driver importances is 100. Importances values are displayed on a bar chart for ease of visualization and comparison of their net impact on a given outcome measure.

Results show that nurse communication, doctor communication, and the quality of the patient’s care transition experience from the hospital to their home are among the strongest drivers for global measures of overall patient experience in the military setting. This result was observed when the data were analyzed in aggregate as well as when the data were separated by (a) the type of hospital (a military treatment facility or a civilian hospital contracted to provide care to military users) and (b) the type of hospital.

The period of transition from hospital to home represents a crucial time for ensuring the patient understands their care plan and avoids unnecessary readmissions.
care received (primarily medical, surgical, or obstetrics care).

The finding that communication is important to overall care experience is consistent with what is reported in the civilian literature, suggesting that effective communication is valued across patient types and settings.

The quality of care transition was also an important driver of military patients' overall ratings of their care. The period of transition from hospital to home represents a crucial time for ensuring the patient understands their care plan and avoids unnecessary readmissions. The addition of care transition questions in patient experience surveys has been relatively recent; therefore, few studies have explored the relationship between care transitions and patients' overall experience ratings. However, the data from this study suggest that the quality of care transition from the hospital to the home can leave a lasting impression and represents an important aspect of patient care.

Taken together, findings from the literature and the DHA drivers analysis suggests that provider communications and interpersonal relationships are among the aspects of care most important to a patient. That provider communications remain so important in our analysis after examining drivers by facility and care type suggests that effective communication is a critical aspect of the patient care experience regardless of where or why the care is being received. It is important to remember, however, that patient experience is a multifaceted construct. No single aspect of care should be targeted for improvement at the expense of another. As the DHA study shows, other aspects of care, such as care transitions, may still play an important role in a patient's overall experience. But if a healthcare organization is looking to improve their experience ratings, they should look toward ensuring that provider communications are effective in making patients feel cared for, listened to, and respected.
What do you consider as patient engagement, and how is patient engagement positioned in understanding patient experience?

Patient engagement within the realm of patient experience is necessary but insufficient; so, you can have patient engagement but it doesn’t necessarily determine if you’re going to have a better patient experience. To address patient experience, you must provide people the opportunity to engage and give feedback and input. This means including patients in decisions about their health, healthcare management, and overall care plan. Patient engagement also includes involving patients (and their families, where applicable) in opportunities such as hospital committees, research planning and teams, and advisory committees. With regard to patient experience, I believe that patient engagement is one piece of many that should be used to achieve and maintain optimal patient experience.

How is patient experience and satisfaction in healthcare different from satisfaction and experience in other service-based sectors?

This is a very difficult question to answer. On a basic level, there are a lot of similarities in patient experience and patient satisfaction in healthcare compared to other service-sectors—you provide a service, you have a consumer, and your outcome is satisfaction. While both sectors are interested in being the consumers’ choice for repeat visits and referrals to friends, the motivation behind the outcome differs in healthcare. Time is also a major component. Healthcare is an ongoing, continuous outcome whereas in other sectors, such as the travel industry, the service provided is usually completed in only one transaction.

The motivation behind the outcome of healthcare is the lifelong relationship, well-being, and health delivery that meets the patient’s goals. In healthcare, happiness of the consumer is important; however, happiness sometimes isn’t the equivalent of the most effective care delivery. The motivation for optimizing consumer experience in healthcare should lie in better health and well-being of the patient.

Is patient experience a valuable indicator of quality? How is patient experience positioned in quality improvement efforts?

This is the million-dollar question. On the one hand, patient experience is the most valuable indicator of quality. Can we say that a patient received good quality of care if their experience was poor? This ultimately depends on how we are defining quality. Patient experience measurement is challenging if quality is measured or reported solely in quantitatively-based terms (e.g., good blood pressure control) or by following guideline-recommended care without accounting for patient contextual factors. Consideration of contextual factors to accurately measure patient experience in quality improvement (QI) efforts should be prioritized, noting that this is difficult to measure and hard to
align with performance-based indicators. In future QI efforts, it would be optimal to capture and link qualitative measurements with clinical and health measures documented in the patient medical record.

What three major lessons have we learned in the past about improving patient experience?

First, improving patient experience requires a change in culture throughout the organization beyond the surface level. Delivery of an optimal patient experience requires commitment and compassion at multiple levels. Second, leadership must be on board. Leadership not only has to champion the initiatives leading to provision of good patient experience, but they should make it clear that they support patient experience indicators as acceptable measures of good healthcare delivery. Leaders should foster staff engagement by encouraging providers and staff to try novel approaches and risk-taking to optimize patient experience and deliver the best healthcare. Finally, to improve patient experience, we must establish a common understanding of the value of patient experience, how it will be measured, and how patient experience will be associated with performance measures.

An open-minded provider can pave the way for improving patient experience, just as a resistant-to-change provider can limit the integration of patient experience approaches.

Has the emphasis on patient experience compromised clinical and effective healthcare practices? If so, how?

I am a huge proponent of patient experience and patient preferences driving care; but, the reality is that sometimes the provision of care driven by patient goals to provide optimal patient experience is not consistent with Clinical Practice Guideline-driven care. As a result, it is critical to engage in shared decision-making to facilitate a more collaborative relationship between patient and provider to achieve the best attainable outcomes that matches the goals of both.

Is the burden of patient experience disproportionately placed on physicians?

I would not use the term “burden of patient experience.” It really should be about providing the patient with what meets their needs; having this mission in mind takes the guesswork out of improving patient experience and should, perhaps, be less burdensome for providers. Because care has been provider-driven and prescriptive for so long, it truly is the responsibility of providers to accept the change in momentum to less provider-driven and more shared decision-making. An open-minded provider can pave the way for improving patient experience, just as a resistant-to-change provider can limit
the integration of patient-experience approaches that deviate from traditional provider-driven approaches. Aligning patient experience to provider performance is one of the biggest challenges. If providers do not feel that the leadership of their organization values this idea of optimal patient experience as an important measurement, then providers are going to go back to their algorithm-based and traditional provider-driven approaches. Leadership prioritizing patient experience is crucial to provider buy-in. It is also the patient’s responsibility to be engaged in their care. This is difficult for some patients. For example, older patients feel like they are talking back to their provider if they question their provider’s decisions. As I mentioned before, shared decision-making is necessary for patient engagement, which is part of patient satisfaction and experience.

**What greatest challenge do you foresee in measuring patient experience?**

Lack of consensus on what and how to measure patient experience continues to be a challenge. This makes practitioners hesitant and impedes implementation of innovative approaches to improve patient experience. We also need to understand how we measure the sustainability of patient experience. This is not a new concept, but it continues to be an important point for us to address for patient experience and patient satisfaction.

**What three main data analytic tools should we leverage to better understand patient experience?** **Do you see big data playing a role in our understanding of patient experience?**

If you look up an academic paper on patient experience, the paper may only focus on HCAHPS which is mainly focused on patient satisfaction, but patient experience is a bigger concept—patient experience is not solely based on satisfaction measures. Patient satisfaction can be captured in a Likert scale, but capturing patient experience is more expansive and would benefit from mixed methods. Open-ended narratives are important. Some traditional qualitative methods are ideal at getting in-depth information from the patient’s point of view. Participatory approaches, such as guided tours and standardized patient studies, are also key information gathering techniques. One may use observation and/or audio-recorders to help capture real-time data to help understand contextual factors and things that matter most to patients; for example, what’s going on at home that could be interfering with the patient being able to achieve their healthcare goals.

Findings from studies using participatory methods revealed that sidewalks and curb sides near the VA needed to be modified to accommodate individuals using assistive devices such as wheel chairs. Upon learning that the distance between the parking lot and facility entrance was problematic for some patients, multiple VA facilities implemented a valet system to improve the experience for patients and offer overall better patient-centered care delivery. Mixed methods that include a qualitative component would help unveil patient-level contextual factors that impact patients’ ability to get to their appointments, such as time and transportation limits. Mixed methods can also help in identifying factors related to the environment of care that impact the patient experience, such as wayfinding signage, noise levels, and privacy. Although qualitative and participatory methods are time-consuming and laborious, the depth of knowledge is great and the challenge lies in getting it linked to patient medical record data in a meaningful way.
In the past, it was common for physicians to visit patients at home. The number of medical home visits has declined dramatically during the 20th century in the middle- and high-income countries.\textsuperscript{28,29} Because of the emergence of advanced healthcare technologies and medical specialization,\textsuperscript{30} patient care moved to physician offices, health clinics, and hospitals. Facility based care can't meet the needs of frail homebound seniors, who cannot access it. In the United States alone, there are three to four million older community-dwelling adults that have three or more dependencies in Activities of Daily Living and one million are bedfast.\textsuperscript{31,32,33} The vast majority of them would prefer to stay in their own homes as long as possible rather than move to an institution.\textsuperscript{34} They often suffer from multiple morbidities and functional impairments.\textsuperscript{35,36,37,38}

Without timely, essential primary and palliative care, frail, elderly patients often receive highly fragmented care. This results in increased patient and caregiver suffering, decreased provider satisfaction, and escalating healthcare costs from ambulance trips, emergency department visits, hospitalizations, and additional post-acute care.\textsuperscript{35,36,37,38} The number of these patients will increase dramatically in the next two decades.\textsuperscript{39,40,41} In 2050, the population aged 65 and over in the United States is projected to be 84 million (21% of the total population), almost double its population of 43 million in 2012 (14% of
By 2050, the population aged 80 and older will nearly triple, and the number of people in their 90s and 100s will quadruple. Many other middle- and high-income countries (China, Japan, Germany, UK) have a similar aging trend. Thus, many more frail patients will experience difficulty accessing office-based primary and palliative care.

Home-Based Medical Care (HBMC or house call) is a team-based model that ensures these patients receive needed primary care and palliative care, improves the overall care experience and care coordination, and is less costly. In the U.S., about 5,000 primary care providers made 1.7 million private residence visits to Medicare fee-for-service beneficiaries in 2013. It is also an emerging model in many healthcare systems, including Japan, Taiwan, and China. In the primary care at home model, patients ideally receive comprehensive longitudinal primary care and comorbidity management at home from an interdisciplinary professional team of physicians, nurse practitioners, physician assistants, nurses, social workers, and therapists. Providers can order in-home diagnostics and treatment with mobile technology such as lab tests, EKGs, X-rays, ultrasounds, IVs, and more. The palliative care at home provides care for people coping with serious, often life-limiting illnesses and focuses on offering holistic relief from sources of distress in the physical, psychosocial, and spiritual domains.

There is evidence that HBMC improves patient and family member satisfaction. HBMC patients more regularly receive end-of-life care that is consistent with their goals of care. For example, at an HBMC practice HomeCare Physicians in Wheaton, IL, end-of-life wishes are discussed early and often to best meet patient desires. In 2015, the practice had 230 deaths. Of these patients, 80% died at home and 76% were on hospice care. The majority did not spend any time in the hospital during their last three months of life. In contrast, 70% of Americans say they would prefer to die at home, but only 33.5% do. Because most patients of quality HBMC programs die at home, quality house call programs also decrease hospital mortality rates.

Quality care at home and improved patient experiences are associated with reduced healthcare costs. Medical house calls for three months post-hospitalization cut hospital readmissions for elderly congestive heart failure patients by more than half. The Independence at Home house call demonstration program authorized in ACA realized a remarkable $25 million overall savings in the first year—an average of $3,070 per beneficiary. The beneficiaries in the demonstration program had fewer 30-day readmissions, hospitalizations, and emergency department visits. The largest house call program in the U.S. generated over $3.6 million in savings for their Accountable Care Organization (ACO) program in Performance Year 2, representing 3.75% of the total cost savings achieved under the entire national ACO program. The Veterans house call program decreased total costs by 24%, amounting to over $9,000 savings per veteran, 59% reduction in hospital days, and 89% reduction in nursing home days.

Unfortunately, most elderly patients who could benefit from HBMC currently do not receive the service because of a shortage of providers. Currently only about 15% of the nation’s home-limited patients receive home care medicine. Similar shortages of home care physicians are observed in other healthcare systems. For example, there are about 20 million home-limited patients in China, but less than 1% of them have received long term primary and palliative care at home, and there aren’t any full-time house call programs. There is a need to increase home-based medical care programs and the workforce through developing financing models and training.
Clinical trials have led to major advances in medicine over many decades and are the hallmark for new treatments and policies aimed at improving health and preventing disease for millions of people worldwide. Many may be familiar with clinical trials from examples such as the groundbreaking work behind the Salk vaccine that helped nearly eradicate polio in the United States (U.S.), or more recent efforts supported by federal agencies, industry and disease-focused foundations. People may not, however, be as aware of the role and impact that Veterans have had in these life-changing studies in the U.S. Specifically, Veterans
returning from World War II who had tuberculosis were participants in the first cooperative clinical trial for this disease. That trial served as a foundation for later widespread activities that provided rigorous evidence for clinical practice. Since that time, it is no exaggeration to say that countless numbers of patients have contributed to the many breakthroughs that have resulted in our greater health and well-being.

Veteran-focused research
The success of clinical trials directly depends on the patients who voluntarily participate in them. More recently, there have been increasing efforts focused on patient engagement and experiences in clinical trials. Within the U.S. Department of Veterans Affairs (VA), there is continued recognition that Veterans are not only the reason for why clinical trials are conducted but why they succeed. The Cooperative Studies Program (CSP) is one major organization within VA that specializes in clinical trials, and we are no different in keeping Veterans as a primary focus of our work. CSP conducts a broad range of trials for major physical and mental health issues that affect these individuals, including spinal cord injury, posttraumatic stress disorder, depression, and suicidal attempts, as well as other medical conditions like heart disease, cancer, and diabetes to which they—like the general U.S. population—are susceptible. In fact, several practices underlying American medicine today are based on work done by CSP over nearly seven decades. In part, the reason for this is that we continue to examine ways that put our Veterans first, and this includes enhancing their patient experience.

The success of clinical trials directly depends on the patients who voluntarily participate in them.

Among key activities are ones focused on recruitment and providing opportunities to enroll in studies, considering what is required to participate in a trial, and making quality and safety precedent. It’s no secret that recruitment for research trials is challenging. General barriers for patients consist of following protocol requirements as part of participation, time commitment, and even the fear and stigma of “experimentation” and concerns about safety. While CSP is not immune to these challenges, we have taken several steps toward assuaging their impact through the design and conduct of our clinical trials. Some of these activities are innovations that take advantage of the ability to conduct trials in the nation’s largest integrated healthcare system.

Improving recruitment—and experience
Recently, CSP has placed an even greater emphasis on participant recruitment, including how patient experiences can influence and affect the activities for a clinical trial. Among our best practices are Human Rights Committees (HRCs) that involve gathering perspectives from various representatives, including Veterans. HRCs are charged not only with evaluating the ethical and safety aspects of a CSP study, but also including Veteran experiences and perceptions in the proposed design of a study. Our Network of Dedicated Enrollment Sites (NODES) is another program that scrutinizes both how we design our research studies and how patients perceive their experiences. In addition, to help with more directly involving clinicians who treat patients and enabling them to participate in a “learning healthcare environment,” CSP initiated its Point of Care Research (POC-R), which combines research with clinical care. This means that patients who are already receiving care from a doctor may simultaneously be offered the opportunity to participate in a relevant trial at the point of care. This is a more streamlined approach from the current model in which a patient must first be determined to be eligible for a study and next referred to a study investigator to receive more information. The POC-R model not only makes participation easier and more accessible for patients, it also allows us to compare two or more available treatment methods while capitalizing on the VA’s electronic medical record system. The intent is to minimize disruption to the doctor or patient volunteer, and we expect that...
results from POC-R studies will be available much more quickly for use in clinical care.

We have other initiatives that are in developmental stages emphasizing ways to bring the trial to the patient. One example involves determining how to deliver study medications directly to trial participants rather than having the burden of going to their local VA pharmacy or investigational unit to retrieve them. This innovative approach is being explored by our Presidential award-winning CSP Clinical Research Pharmacy Coordinating Center. A “distributed enrollment” concept is also seeking ways to enroll cancer patients who may not be close enough to a VA hospital, but who may still have an opportunity to participate in a trial that offers new treatments through another facility.

Quality-driven with a personal touch

All of these activities occur on a quality-driven foundation, something that CSP centers have achieved by meeting an internationally recognized standard known as the International Organization for Standardization 9001. Attaining these standards requires a particular focus on customers and emphasizes a continual improvement culture that makes patient experience a priority. To take this a step further, CSP is also implementing a risk-based monitoring strategy that helps to identify potential areas for attention before they become problematic. Each of these efforts continues to involve a strict adherence to general clinical practice (GCP) guidelines. Ultimately, they are directed toward helping us to build trust among all of our stakeholders, particularly our Veterans.

Finally, we are acutely aware that what we do isn’t possible without our Veteran volunteers, so their experience is paramount—before, during, and after a research study. We believe that part of that experience lies in something very simple: saying “thank you.” To this end, we created our Helping to Enhance Research Outcomes through Exemplary Service (HEROES) program, a practice through which we directly acknowledge and thank our Veteran volunteers for their time and commitment. Not only does this demonstrate our appreciation, it also lets them know that their contribution is part of something bigger that will benefit many more people.

Better experience, better medicine

Clinical research is the backbone of good medicine. As we’ve seen historically, it’s the patient volunteers who have made some of the most significant treatment and prevention strategies a reality. This type of research has always been an important element of the larger VA healthcare mission, and our Veterans are central to this work. CSP is part of this overall effort to continue to improve the patient experience in our studies and beyond. It is why we look for new ways to focus on the Veteran experience and to implement ideas as part of our ongoing commitment to them and the nation in seeking even better medicine for the future.

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Parallel to its growing acceptance as a marker of the quality of healthcare, patient experience has become a major area of focus for all actors throughout the American healthcare system: providers, payers, and regulators have been busy designing, implementing, and promoting myriads of initiatives to optimize the experience of patients. However, while “improving patient experience” has become a mantra, there is no escaping the fact that the concept itself is highly subjective. What qualifies as a “good” or “bad” experience very much depends on the patient’s expectations. If an experience meets or exceeds expectations, an individual will be more satisfied with the experience, whereas if an experience
falls below expectations, the individual will be dissatisfied. Hence there are limitations to looking at individual patients’ ratings of their experience with a provider on a given metric as an indicator of that provider’s actual performance.

In order to have a better understanding of the relationship between patients’ experience and expectations, our team at Ipsos conducted a study aimed at: (1) getting a deeper understanding of American patients’ expectations for their healthcare; (2) exploring whether and how these expectations differ by demographic and individual characteristics; and (3) comparing these expectations with widely used data on U.S. patients’ reported experience.

In August 2017, our team at Ipsos designed and conducted a national survey of 1,010 U.S. adults from Ipsos’ online panel about their expectations when seeing their primary care physician. We then compared these expectations with aggregate ratings from the national Consumer Assessment of Healthcare Providers and Systems (CAHPS) Clinician & Group database. The CAHPS database informs how U.S. patients assess their actual experiences with providers on various aspects of care, such as getting timely appointments.

What do patients expect?

The survey shows that, when it comes to healthcare, American patients’ highest expectations are related to how providers communicate with them. Large majorities expect primary care providers to always show respect (74%), listen carefully (69%), and explain things clearly (66%). Patients also expect office staff to always be courteous and respectful (73%).

Conversely, expectations are lowest for getting timely appointments, care, and information from primary care providers—only 37% of respondents expect to always get an appointment for a check-up or routine care as soon as they need it.

Do different types of people have different expectations?

Expectations vary according to gender, age, and health literacy. Specifically, men, younger adults, and those with low health literacy have lower expectations than women, older adults, and those with high health literacy. Education and race do not significantly impact expectations.

These findings have several implications. First, men and younger adults see the doctor less often than women and older adults, which may color their expectations. If someone rarely goes to the doctor, they may not know what to expect or not expect very much. Second, when people have low expectations, it doesn’t take much to generate high satisfaction. As such, high satisfaction could be an indicator of low quality care which just happens to exceed low expectations. Preliminary evidence suggests that those with low health literacy receive lower quality of care. Many other characteristics not explored in this study may also affect expectations, such as a person’s illness severity at the point of care.

Do patients’ experiences meet or exceed their expectations?

For every area, patients’ aggregate CAHPS experience ratings are significantly higher than survey respondents’ expectations. The areas showing the widest gaps between CAHPS scores and patient expectations are getting timely check-up appointments and the provider spending enough time with the patient. While only 37% of those surveyed by Ipsos expect to always get appointments as soon as they need it for a checkup, 72% of patients in the CAHPS database report that it is always the case with their provider. Only 56% expect their providers to always spend enough time with them, but 85% report that it is the case with their provider.

The smallest gap pertains to talking about prescription medication at each visit. Providers talked to patients about their medication only slightly more often than people expected.
Given that patients receive better care than they expect, we would assume that patients are highly satisfied with their care. This is supported by the CAHPS data, which found that 82% of people in the U.S. rated their provider as the “best provider possible” (CG-CAHPS 2016 Adult 6-Month Survey 3.0).

Conclusion
The current study presents a first step in exploring the relationship between expectations and actual experiences, but more research is needed to fully delineate this relationship. Theoretically, deficient care could still result in high satisfaction ratings if expectations are low enough. However, research has yet to empirically validate this. Specifically, the patient journey should be mapped so that expectations, experiences, and satisfaction can be delineated over time for the same individuals and objective measures of quality of care should be incorporated.

Overall, expectations that are too low or too high can have negative effects. Expectations that are too low risk becoming a self-fulfilling prophecy of deficient care. Expectations that are too high result in disappointment and low satisfaction. Our study suggests that people have relatively low expectations for their healthcare experience. Educating patients about the kind of high quality experience they should have can help them develop higher, and perhaps more realistic, expectations. This is especially the case for men, younger adults, and those with low health literacy. The more patients understand about the kind of care they should be receiving, the more they can become active consumers of healthcare rather than passive recipients.

<table>
<thead>
<tr>
<th>Patient Experience and Patient Expectation Scores*</th>
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<tbody>
<tr>
<td>Gap Between Patient Experience and Patient Expectation Scores*</td>
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</table>

All gaps were significant at p<0.05.

*Higher scores indicate that CAHPS scores were higher than expectation scores. Top box (“Always”) percentages from 2016 CG-CAHPS Adult 6-Month Survey 3.0. Top Box Scores were compared to basis panel expectation scores.
References and Footnotes


5. Yelp example: Greenville Hospital received four out of five stars by patients according to Yelp, a privately-run website that lets people rate businesses they’ve used. Hospital Compare example: Greenville Hospital received two out of five stars by patients according to Hospital Compare, a website run by the US government that posts patient rating of hospitals.

6. The hospitals and reviews presented in the study were entirely fictitious.

7. Percentage score example: [83%, 78%, 67%, OR 61%] of patients who provided feedback gave City Hospital a rating of 9 or 10 on a scale from 0 (lowest) to 10 (highest). The rating is provided by Hospital Compare, a website run by the U.S. government that posts patient ratings of hospitals.

8. Note that we presented respondents with percentage scores in isolation, whereas Hospital Compare presents state and national averages or ratings of other hospitals alongside percentages. Thus, the impact of ratings given on Hospital Compare may differ from our observations.

9. Trust in Yelp and Hospital Compare questions: How much trust would you place in patients reviews from these websites? (a) Hospital Compare, described as “a consumer-oriented website that provides information on how well hospitals provide care to their patients.” Patients are asked to complete a survey about their experience at the hospital. The site was created through the efforts of the Centers for Medicare & Medicaid Services (CMS), part of the US government. (b) Yelp, described as a service “To connect people with great local businesses.” Yelp posts reviews and ratings about businesses from individuals that have used that business and went to the website to provide feedback. The site was created by former PayPal employees Russell Simmons and Jeremy Stoppelman.


11. Hospital CAHPS


27 A Likert scale asked participants how much they agree or disagree with a particular statement, usually on a 5-point or 7-point scale.


50 https://www.cahpsdatabase.ahrq.gov/ CAHPSIDB/Public/CG/CG_Topicscores.aspx

51 National Ambulatory Medical Care Survey: 2014 State and National Summary Tables


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