



# PATIENT ENGAGEMENT & HEALTHCARE VALUE

A White Paper from the Center for Healthcare Innovation's 2016 Healthcare Executive Roundtable

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# BACKGROUND

This white paper focuses on examining healthcare value based on the expert insights from the Center for Healthcare Innovation's Healthcare Executive Roundtable held on October 13th, 2016 in New York City and other key trends and market forces. The roundtable identified specific ways in which healthcare stakeholders can enhance patient engagement, such as building relationships based on mutual trust and open communication with patients. Additionally, this white paper explores how patients can optimize their degree of engaging healthcare professionals. Furthermore, healthcare organizations (HCOs) that partner with patients, leverage existing health technologies, and draw on external experiences will have created an environment that engages the patient to be a good steward in managing their health.

This white paper attempts to:

- Define core concepts such as value and trust in healthcare
- Map out the patient engagement value pathway
- Make recommendations to boost patient engagement in a consumer-driven future

Healthcare is currently facing significant regulatory, structural, legislative, and financial changes, as well as a paradigm shift that is placing the patient at the forefront of the decision-making process. As the healthcare landscape transitions to a more consumer-driven and patient-centric model, organizations must adapt to this changing ecosystem. This white paper aims to not only outline the connection between patient engagement and value, but also to identify actionable strategies which stakeholders can benchmark their organizational alignment.

# VALUE

## How is Healthcare Value Defined?

Value in healthcare can be difficult to define. Yet, it is essential that there is consensus on its definition when one begins to think about patient engagement. While it is easy to define value using a simple cost-benefit equation, this view is quickly losing traction, as patients and their families need to be at the forefront of any value definition. From the patient perspective, value may be defined as the quality of life afforded by healthcare services. For example, while the cost associated with Hepatitis C drugs might be high, eliminating the disease increases quality of life and avoids the need for liver transplantation. For patients, these benefits outweigh the costs of the drug for the individual. From a societal standpoint, the curative properties of the drug result in shorter transplant lists, fewer years of lost productivity, and avoiding preventable deaths.

Given this, defined broadly, value in healthcare may be the benefit afforded to patients, their families, and society. This definition takes value a step further than health outcomes. It includes concepts previously beyond the scope of business decisions, such as patient experience and population health, while still deriving from the fundamental principles of costs and benefits. Weaving the patients' points of view into the decision-making process earlier allows the definition of value to better align with patient concerns.

“While it is easy to define value using a simple cost-benefit equation, this view is quickly losing traction, as patients and their families need to be at the forefront of any value definition.”

# PATIENT OWNERSHIP

## Patient Engagement Definition & Goals

As healthcare moves from the tacit curing of illness to maintaining a state of total well-being, patient engagement becomes a critical factor. An engaged patient is one who actively participates as a member of the care team outside the hospital or clinic walls. To foster an environment in which patients take ownership of their own care, provider organizations must start recognizing that patients are partners in the care delivery process. This partnership primarily serves to link healthcare decisions with patients' life plans, goals, and experiences. While a collaborative treatment plan is essential to engage patients with their care, provider-driven strategies are not the sole source of engagement. There are certain characteristics of engaged patients that are independent of provider motivation.

## Characteristics of Engaged Patients

The “Patients as Partners” model identifies three main characteristics of engaged patients: (1) continuous learning, (2) assessment, and (3) adaptation.<sup>1</sup> Patients who are effective partners in their own care are primarily those who strive to continuously gain scientific and medical know-how about their conditions and treatment plans. This continuous learning helps them understand the organizational constraints of care delivery and makes them more effective participants of the care delivery team. In turn, providers can leverage patients’ experiential learning while deciding which treatment plan to follow. This mutual understanding builds patients’ confidence, competence, and efficiency in managing their own care.<sup>2</sup> Additionally, a newer concept of shared decision making, in which providers and patients make decisions together, is gaining momentum in the 21st century healthcare landscape. Continuous learning also serves as an effective tool in empowering patients in evaluating the quality and appropriateness of their care. Next, assessment is a critical component of a care plan that aligns with patients’ goals and is only possible through gaining factual knowledge related to the condition. Finally, based on their assessment, patients can adapt their care by deciding on a personal plan of action to reconcile the differences between the care they receive and the care they want.

## Implications for Providers

Given the characteristics of an engaged patient, there are three key strategies providers must utilize to maximize partnerships with patients and their families: (1) welcoming patient and caregiver voices, (2) building relationships of mutual trust, and (3) personalizing value offerings.

First, patient and caregiver voices, needs, and perspectives must be included throughout the patient experience. Providers must strive to determine a care plan that caters to the expectations of patients by being intentional in listening to them and their caregivers. To foster an environment of open communication, providers can make use of both structural tools like surveys and focus groups, as well as direct questions during every encounter. Providers can also use existing feedback mechanisms such as WEGO Health, a platform of patient thought-leaders, influencers, and activists. By providing a convenient method to access and incorporate patients’ opinions into the care delivery process, WEGO streamlines the care continuum.

The second focus area is building trust between patients and providers. Only through open channels of communication that aim to harbor relationships based on trust can providers expect to have participation from patients. Therefore, maintaining trust in long-term relationships is as important as building it with new patients. Some concrete tools such as Open Notes, which allows online access to personal health information, can aid this process. Other strategies that build a relationship of mutual trust include treating patients with care and respect and getting to know them and their families on a more personal level. This practice is similar to financial planners getting to know their clients’ retirement preferences to make the most fitting decisions on their behalf. Furthermore, providers must pay attention to the health literacy level of their patients and tailor their language so as to make health-related information

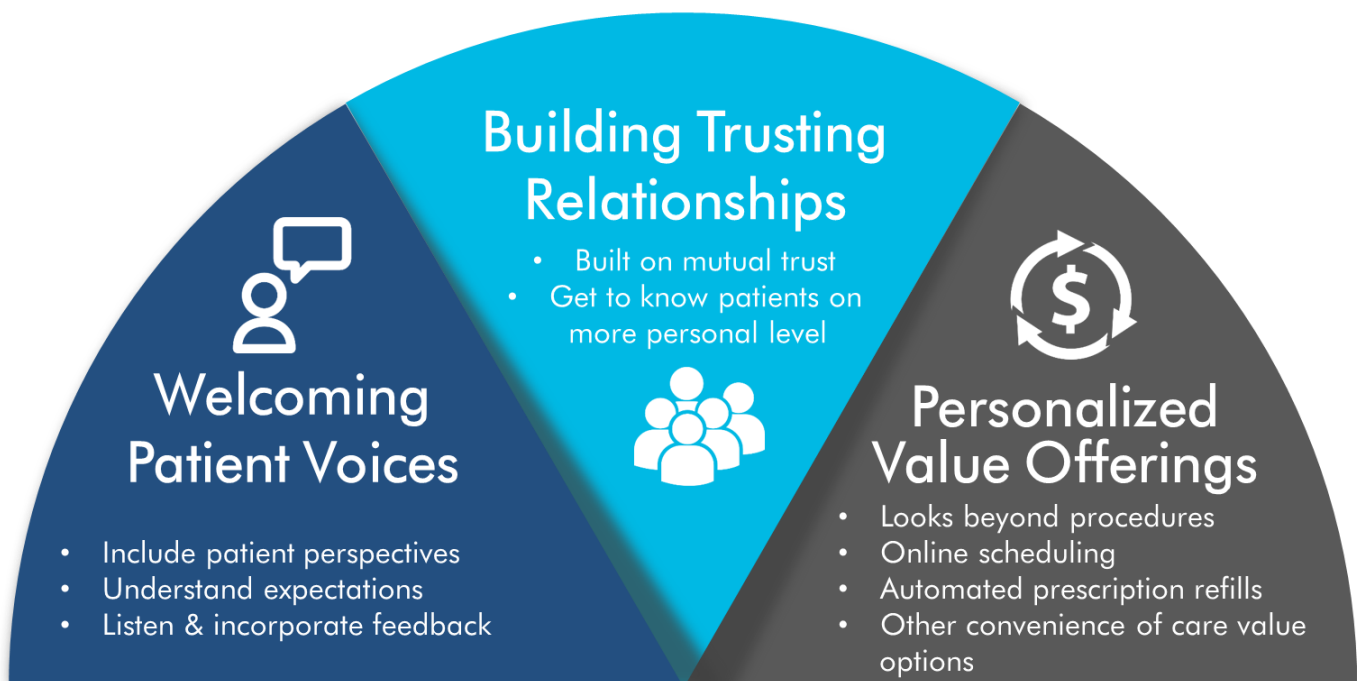
“There are three key strategies providers must utilize to maximize partnerships with patients and their families: (1) welcoming patient and caregiver voices, (2) building relationships of mutual trust, and (3) personalizing value offerings.”

digestible by the general public. It is important for physicians and healthcare professionals to ensure they are communicating in a way that patients understand and answer any lingering questions and concerns from patients and their families.

The third strategy is personalizing the value offering of healthcare by adding value beyond health outcomes. As healthcare moves towards a focus on total well-being, providers should look beyond the medical service provided to patients and focus on other aspects of health. One such aspect is social determinants of health, including a social support system. Research shows that “people who get less social and emotional support from others are more likely to experience less well-being, more depression, a greater risk of pregnancy complications, and higher levels of disability from chronic diseases.”<sup>3</sup> Other factors that determine a patient’s wellbeing are economic status, mobility, and unidentified risk indicators such as drug abuse and mental illness. Only through taking into consideration a person as a whole can providers expect patients to be engaged with their own care.

Overall, a full collaborative partnership with patients in their own care is essential to maximizing patient engagement. While providers can undertake concrete programs and interventions to boost participation, the fundamental drivers of engagement are patients themselves. Engaged patients learn about their illness, assess the treatment they receive, and adapt their care plan to suit their own needs and goals. In turn, providers can cultivate an environment of engagement through (1) including patient and caregiver voices, (2) open communication and building trust, and (3) personalizing value. Engagement is a bi-directional relationship that requires effort from both providers and patients to achieve the right care for the right person.

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# TECHNOLOGY

## What Role Does Technology Play?

Leveraging technology to optimize patient engagement in healthcare can be broken down into two functional categories. The first category includes applications that enable real-time communication between two parties, connecting patients with providers and/or providers with one another. The second category includes the dissemination or collection of information. In this latter functional group, technology is used for infrastructural capabilities of healthcare organizations, such as the Electronic Medical Records (EMR) and the Patient Activation Measure (PAM), or as web-based interactive self-help content.

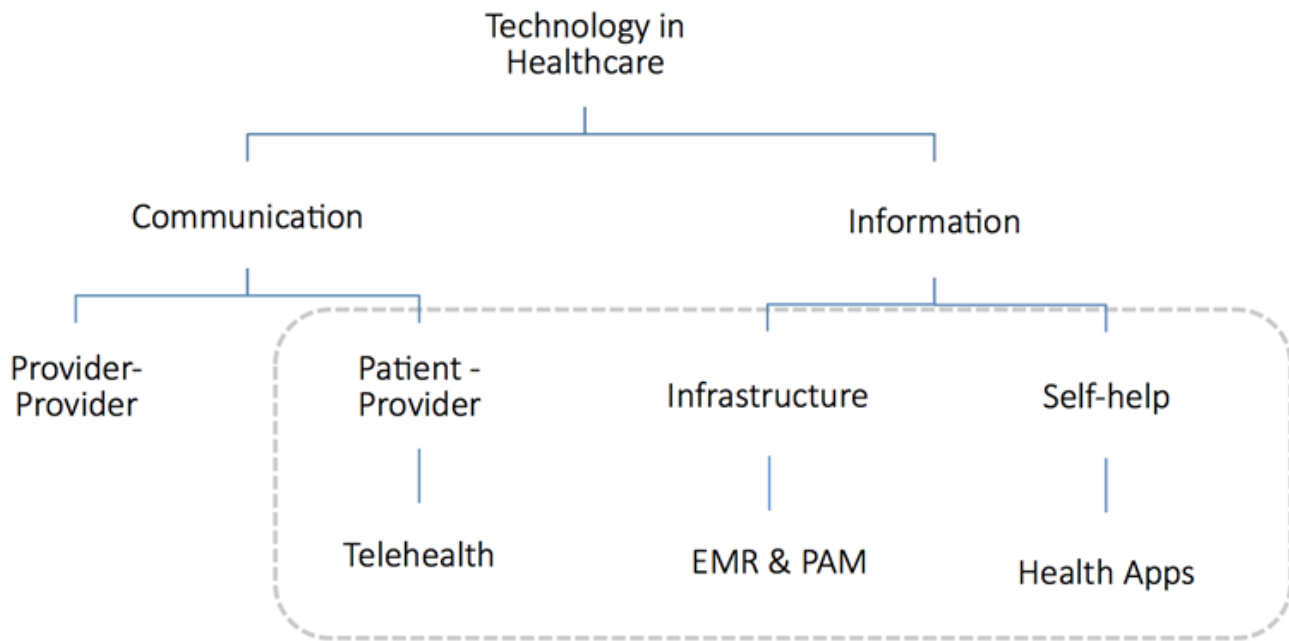
Most use of technology in healthcare can be categorized under these two functional groups and four sub-groups: provider-provider communication, patient-provider communication, self-help, and infrastructure. One common thread among the different categories is the ultimate goal of optimizing the patient experience. While all categories deserve a section of their own, we will investigate those areas that most directly relate to patient engagement: patient-provider communication, patient self-help, and infrastructure.

## Patient – Provider Communication

One of the most direct ways in which technology helps boost patient engagement is through telehealth. Telehealth includes all applications that enable communication between patients and providers in a virtual arena. This broad definition includes all services offered by providers to engage patients outside of the traditional hospital, clinic, or office environment. Some common examples are virtual face-to-face appointments with providers on a secure platform or a secure messaging service that offers instant access for follow-up questions. Lower transactional costs in communicating with providers opens up additional access points and increases the likelihood that patients will be more engaged with their care. Studies show that the more frequent communication a patient has with their provider, the more likely they are to have improved health outcomes.<sup>4</sup>

A similar telehealth example is Johns Hopkins Medicine's "Hospital at Home" program, a model for patients who are in need of healthcare services but are stable enough to be treated at home. A caregiver visits patients for the treatment, and monitors them via telehealth in subsequent days. By keeping a constant line of communication open between the patient and the provider in the convenience of the patient's home, JHM has been able to achieve greater engagement at a lower cost, and those treated through the Hospital at Home program had significantly higher satisfaction with lower costs than those in traditional hospital care.<sup>5</sup>

"Studies show that the more frequent communication a patient has with their provider, the more likely they are to have improved health outcomes."



## Self-Help Platforms

While telehealth enables patients to access healthcare services with greater convenience and increased frequency, technology also allows patients to take ownership of their care through self-help platforms. Online self-help can take the form of health literacy websites, applications, and platforms linked to wearable devices. By having information and data about their own health easily available and accessible, patients are more likely to feel empowered to take ownership of their care.<sup>6</sup>

One platform that allows patients to keep track of lifestyle habits and health data is Apple's Health app. Through this app, users can keep track of metrics like physical activity, sleep cycles, and diet. The health app also allows users to record health data such as lab results, medical records, and vitals. The Health App can be used through smartphones or wearable devices that make real-time data tracking even more convenient. Such applications are relatively inexpensive tools for patients who own smartphones and are used extensively by physicians to supplement clinical treatment plans. Recent studies show that using platforms that combine personal health data management with e-learning and virtual support programs (such platforms are called "Interactive Health Communication Applications") significantly improves clinical and behavioral outcomes.<sup>7</sup> Providers are encouraged to partner with these data sources to continually expand their analytical understanding of a patient's health status and thereby supplement decision making in the care process.

"Recent studies show that using platforms that combine personal health data management with e-learning and virtual support programs significantly improves clinical and behavioral outcomes."



The benefits of telehealth applications can only be achieved if patients know how to use the prescribed tools properly. Asking a patient to use an app and expecting them to figure it out on their own may be counterproductive. Healthcare organizations that encourage the use of self-help applications should also ensure patients understand how to use the technology functions. Ochsner Health System provides a great example of a hospital offering guidance in healthcare apps and devices to their patients. With their “O Bar” initiative, Ochsner has created a point of service for all questions related to healthcare technology, similar to Apple’s Genius Bar in concept and design. At the O Bar, patients can consult a technology specialist and get first-hand demonstrations on the use of health applications as well as various wearable devices such as the Fitbit and wireless home monitors.



View of O Bar

Patients and physicians who want to learn about healthcare applications and wearable devices can receive personal education at this desk modeled after the Genius Bar

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Ochsner Health System

A 2013 survey of 2,000 patients with chronic illnesses revealed that patients were more likely to fill a prescription for a health application than for a prescription drug.<sup>8</sup> In response, Ochsner has developed a prescription system for the O Bar, where patients are recommended by their physicians to receive personal education about health apps or wearable devices. This practice ensures that apps can be effectively used as complementary tools to clinical treatment plans.

Overall, technology can be a valuable tool to supplement clinical treatment plans and empower patients to be more engaged in their own care. However, HCOs and providers that recommend health applications must also ensure that patients can comfortably use the technology. Help desks can be an important resource not only for patients but also for physicians who feel they need additional education on technology use in healthcare.

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## Engagement Scoring

Technology also plays an important role in patient engagement as a monitoring tool for healthcare providers. One such tool that helps providers stratify the engagement levels of their patients is the Patient Activation Measure (PAM). Developed in 2004, the Patient Activation Measure is an analytical tool to measure the level of engagement patients feel towards their own healthcare.<sup>9</sup> A well-respected measure for engagement, PAM is determined by administering surveys to patients, asking them about frequency of exercise, diet choices, and disease-specific practices such as logging blood sugar levels for diabetes patients. By cross-referencing these criteria, the Patient Activation Measure produces an engagement score for each person, estimating their likelihood of actively pursuing their treatment plan.

By determining and monitoring a patient's PAM score, provider organizations can have an accurate picture of the engagement levels of their patient population. This information can help with strategic decision-making by establishing targets for increased case management efforts to boost engagement. Depending on the results of a PAM survey, a hospital can decide to focus on the patients in a specific line of service who have statistically lower engagement than those in other treatment groups.

# BUILDING TRUST

## How Do Trust Barriers Impact Engagement?

One critical factor limiting patient engagement is the lack of trust patients feel towards providers and the healthcare industry in general. In the current healthcare landscape, asymmetrical knowledge between physicians and patients often results in a linear relationship with physicians making the majority of healthcare decisions. Also, drug pricing and healthcare executive compensation add further distrust to the healthcare industry.

For patients to become more involved, both providers and patients must build mutual trust. HCOs should strive to educate patients instead of statically providing information so as to empower them to take ownership of their own healthcare. This might be best accomplished by bringing healthcare outside of the provider setting to local communities. Some non-traditional partnerships such as those with faith-based leadership may lead to a nurturing, trusting relationship with patients that extend beyond the boundaries of the hospital.

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# THE BIOPHARMACEUTICAL INDUSTRY

## How Can the Biopharmaceutical Industry Engage Patients?

As discussed, patient engagement has been defined as interactions between healthcare organizations and patients designed to provide more positive experiences that result in higher standards of care for patients with improved satisfaction and outcomes.<sup>10</sup> The value of patient engagement is no more apparent than in the pharmaceutical industry, especially since regulatory and industry changes impact the ecosystem (e.g., the proliferation of social media, outcomes-based contracts). Incorporating patient feedback to address their needs is a critical dimension of value in conversations related to product development.<sup>11, 12</sup>

Capturing and integrating patients' and caregivers' input requires a shift from the more traditional product focus of pharmaceutical marketers. However, the benefits of understanding patients' and caregivers' needs and behaviors and incorporating them into product design results in a superior product. As Ed Miseta, Chief Editor of Clinical Leader stated, “increasingly, it appears better engagements with patients and consumers may be the crucial link for pharma companies to achieve better and more efficient outcomes.”<sup>13</sup> Such patient and caregiver engagement needs to begin in the early stages of drug development

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all the way through to commercialization and beyond. As such, the drug development process can anticipate, and deliver, on the needs and wants of patients and caregivers (e.g., adherence, formulation preference). Such momentum can be seen by the Food and Drug Administration (FDA), as they are engaging with patients like never before.<sup>14</sup>

A recent example of the FDA's inclusion of patient voices arose during the approval process of a drug to treat a common form of childhood muscular dystrophy, called Duchenne muscular dystrophy. While clinical trials showed promising results, the study sample consisted of 12 patients and had no control group. Due to insufficient scientific evidence, the agency's expert advisory panel recommended against approving the drug. However, passionate and well-organized patient advocate groups communicated the benefits of the new drugs during deliberations. The FDA eventually heeded patients' demands and approved the drug.<sup>15</sup> This process was a prime example of engaging patients in discussions related to their own care and well-being.

## CONSUMERISM BEST PRACTICES

### What Examples Can be Drawn from Other Industries?

Slowly, the healthcare industry is beginning to adopt solutions from other industries where customers experience higher levels of trust towards organizations. For example, there is much to be learned from Southwest Airlines' success with wait times and the relationship Disney has with its "guests." By allowing passengers to choose their seats, Southwest has become a turnaround champion, needing only 25 minutes to turn around a passenger jet compared to the 35 minutes to an hour required by its competitors.<sup>16</sup> Another industry leader, Disney, also uses novel approaches to set itself apart. In Disney World, visitors are not customers, but "guests." From the minute they step onto the campus, guests are completely immersed in the experience. Both facilities and staff contribute to this immersive experience, making people's time in Disney World truly one of a kind. While these organizations are not traditional partners for healthcare organizations, there are lessons to be drawn. By studying leaders of different industries, HCOs can identify practices that differentiate these organizations and significantly improve the service provided to patients.

"The healthcare industry is beginning to adopt solutions from other industries where customers experience higher levels of trust towards organizations."

# CONCLUSION

In conclusion, as the U.S. healthcare environment continues to shift from volume to value, a patient-centric approach becomes more important than ever. Healthcare value will continue to evolve to include the benefits that patients derive beyond successful outcomes. Providers are challenged with creating environments conducive to engaging patients with their own care. Engaged patients are partners in their own healthcare and a part of the care team outside the walls of the hospital. They continuously learn about their own health, assess the care they receive, and take an active part in deciding on the best approach to managing their wellbeing. To foster a setting that encourages patients taking ownership of their care, providers must include patients' voices to create personalized value and establish relationships based on mutual trust. While the relationship between providers and physicians might be the primary avenue to encourage a partnership, hospitals, health systems, and integrated delivery networks must also take critical steps, such as aiming to leverage existing technologies that enable patients to become partners in their care. A part of the shared responsibility also lies with the pharmaceutical industry. Engaging patients in discussions related to new drugs and treatment ensures that patients' needs are prioritized over other concerns. As a whole, the healthcare industry must look outwards for best practice examples that will help better address the needs and goals of patients.

## KEY INSIGHTS

1. Only patients can ultimately determine their own level of engagement with their care, although providers can adopt policies and practices to create environments conducive to engagement.
2. Patients should be viewed as valuable partners in their own care. They have experiential knowledge that is valuable for healthcare teams and patients ultimately play the largest and most influential role in their own care.
3. Provider organizations can obtain mutual benefit by investing in technologies that promote better communication between patients and providers, as well as infrastructures to structurally analyze patient engagement levels.
4. The pharmaceutical industry should give credence to patient voices represented by patient advocacy groups. Only through including these stakeholders in discussions can they best serve the interests of patients.
5. Leaders in different industries have perfected the art of catering to their customers' needs. Healthcare as an industry should look externally for best practices in products and services that answer customer needs, and in building relationships that last.

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The Center for Healthcare Innovation is an independent, 501(c)(3) research and educational institute that helps patients and providers increase their knowledge and understanding of the opportunities and challenges of maximizing healthcare value to improve health and quality of life. We aim to make the world a healthier place. CHI encourages and enables meaningful and executable innovation that aims to address existing and ensuing healthcare dynamics through communication, education, training, symposia, reports, and research. By bringing the best and brightest healthcare leaders from all over the world together to share their ideas and expertise, CHI creates a unique opportunity to address and improve healthcare value, which we view as a function of quality, access, and cost. For more information, please visit [www.chisite.org](http://www.chisite.org).

## Healthcare Executive Roundtable:

The Center for Healthcare Innovation organizes an annual healthcare executive roundtable, which is an expert, cross-sectoral, collaborative discussion designed to help healthcare stakeholders optimize engagement, communication, and collaboration. The roundtable is limited to a smaller and more intimate group of senior healthcare executives discussing key issues impacting healthcare. For more information, please visit [www.chisite.org/education/healthcare-executive-roundtable](http://www.chisite.org/education/healthcare-executive-roundtable)

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