

Human Understanding: Digging Deeper with the Board

The Governance Institute spoke with Susan Edgman-Levitan, PA, Executive Director of the John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital, Co-Chair of the Mass General Brigham Patient Experience Leaders Committee, and Lecturer in Medicine at Harvard Medical School, to discuss how her organization has applied Human Understanding to their work. Prior to this role, Ms. Edgman-Levitan was the founding President of the Picker Institute. She is also a Senior Fellow at IHI and a member of the IHI Lucian Leape Institute. She has been a principal investigator on the AHRQ-funded Consumer Assessments of Healthcare Providers and Systems Consortium since 1995. Below are the highlights of our conversation.



The Governance Institute (TGI): Looking back at your work with the Picker Institute, how has the idea of patient-centered care expanded at our nation's healthcare organizations today?

Susan Edgman-Levitan (SEL): That work has expanded a great deal. The concept of patient- and family-centered care has evolved into *person-centered care*, which connects with the Human Understanding work at NRC Health: how we understand and help to improve all of the issues that impact someone's ability to manage and improve their care.

For us, the concept has expanded in four primary ways:

1. We are focusing on a deeper understanding of social determinants of health (SDOHs) and how we can support not just the patients we serve but also the communities where they live.
2. We are working to change the clinical paradigm from "what is the matter with you?" to "what matters to you?" We want to understand where we have common ground to support our patients' efforts to manage their chronic conditions. We also want to signal that "what matters to you matters to us" as we strengthen the trust our patients and communities have in us.
3. We are working to better understand what matters to our staff, which is even more critical since COVID. If we aren't taking care of our staff, they can't take care of the patients we serve. This includes hiring the right people, orienting them to the values of our organization, and how we hold them accountable to those values. It's about understanding the "why" for our staff—why do they choose to work in healthcare and in

|| One of the things I'm most excited about is that we are now starting to implement NRC Health's Human Understanding Program, taking a programmatic approach to focus on what matters to patients before, during, after, and outside of care."

—Susan Edgman-Levitan

the Mass General Brigham (MGB) system. We also know that helping people connect with the passion and commitment that motivated them to make a difference in healthcare is critical to reducing burnout. Our research has shown that the singular commonality of high-performing patient- and family-centered organizations is being a great place to work. That is critical for leaders to galvanize behind.

4. We have launched a multi-million-dollar effort, United Against Racism, to address the impact that racism has on MGB patients, employees, and the broader community. We believe that systemic racism is a public health issue. This effort includes initiatives to increase the diversity of our boards, leadership, clinicians, and staff. We are also focusing on policies and workstreams to address the structural racism that results in inequitable care. This includes translating our patient portal into eight different languages, increased access to interpreters, enhanced access for all patients, and improving our community health outcomes.

TGI: How would you describe the ways Human Understanding is different from typical patient experience activities such as CAHPS surveys?

SEL: It gets at the culture of the organization and how that impacts the way we are delivering care to our patients. It connects the "why" for our staff with how we partner with patients to understand their needs. From there, we learn at a much deeper level the interventions and strategies that make sense to the patients, and that is where we focus our implementation.

Patient experience surveys are excellent at revealing problems, but they don't tell us the solution. We have patient advisory councils that focus on how patients define the problems and what solutions they would propose. For boards and leadership—this process saves so much money. If you leave us to our own devices to design an intervention to address a problem, it is usually too complicated, too difficult, too expensive, and likely to be wrong. Patients tell us exactly what they need, and they will often tell us that two-thirds of our solution doesn't matter to them.

To do this, we use a human-centered design process that many organizations are adopting. We bring together doctors, nurses, practice managers, other care team members, and patients to define the problem and potential solutions, from everyone's perspectives. It is most important to define the problem accurately. Then we whittle the solutions down, vet them again from the same multi-disciplinary perspective, and then test and implement. We have found this to be incredibly effective.

TGI: How can we make a more direct connection between patient experience, Human Understanding, and quality outcomes?

SEL: Healthcare leaders and board members are often confused about what we mean by patient experience. They sometimes still think it's about the food and parking. We design the CAHPS surveys to query people about the aspects of care that are essential to high-quality care, *through the eyes of the patient*. They focus on the aspects of care that contribute to better outcomes: communication about their diagnosis and medications, coordination with their care team, access to care when they need it, and getting the information they need to manage their own conditions. From this perspective, it makes sense that patient experience scores are directly related to outcomes. This perspective is also the fundamental underpinning of the Human Understanding approach that NRC Health is driving.

My CAHPS colleagues conducted a study with the VA on patients admitted for a heart attack.¹ They looked at the technical quality of care as well as patient experience data from their hospitalization through follow-up ambulatory care. They measured symptoms, mental health, patient experiences, and overall outcome measures. The only predictor of how well a patient would be doing one year post-discharge was the patient experience scores. More research continues to link clinical quality, staff engagement, and outcomes with patient experience results.

NRC Health also makes it easy to review patient experience data by race and ethnicity. If these data are not easily accessible, it is difficult to achieve overall quality targets—many of which are tied to reimbursement. The largest disparities exist for our Black and LatinX patients. Because we stratify the data, we can see where the problems are and then develop targeted interventions to address those patients' needs. Designing culturally sensitive and affirming interventions is also where partnering with patients to help design care becomes even more critical.

TGI: Board members at acute-care hospitals are facing the challenge of how to get away from a hospital-centric structure and make more impact in the outpatient setting. Can you give some examples of how to apply Human Understanding in the inpatient vs. outpatient setting?

SEL: In the inpatient setting, surgical services have always done better than medical services. They have well-defined teams and workflows; they know what their role is; there are well-defined algorithms for what is supposed to happen each day. Patients and families are often prepared for what will happen in the hospital before they arrive. They know what to expect, what equipment they will need, how long the stay will be, and what their home care will entail. Medical patients are very different—usually older and sicker, with unpredictable lengths of stay. In many organizations, they are cared for by a hospitalist who doesn't know them. To foster more coordinated care and trust, our primary care doctors make social calls to their patients in the hospital, so the patient knows that their doctor is informed and consulted. We are also educating patients about the role of the hospitalist, why they are an expert in inpatient care, why that is important, and how that person is communicating with their ambulatory doctors. Just providing this information to patients has helped increase HCAHPS scores. Many of our hospitalists hand out business cards with their cell phone number on them. We also ask family members to bring photographs or other things about the patient to give the care team a sense of who the patient is and what matters to them. Finally, we have our hospitalists shadow primary care doctors, so they have a better understanding of the primary care doctors' role and relationships with their patients.

In the primary care setting, we are working to understand how to better engage patients. We have a set of engagement questions about the most important things to them, and usually it is medication, diet, and exercise. Doctors don't talk about these things very much, but they are critical to chronic disease management. Doctors who do a better job of this get higher overall ratings from their patients.

Primary care providers need training support. We are also working to understand how different problems or conditions can be addressed by different visit types. When is a telehealth visit sufficient versus when must a patient be seen in person? We are also working to create better teamwork and support to address the needs of our clinical staff. When is a pharmacist important? How can community health workers support patient engagement and chronic disease management or substance use recovery?

TGI: What are the most important things the board and leadership should be doing (or not doing) to help the organization implement Human Understanding?

SEL: Having patients on the board is critical—people who can bring the patient lens to the discussions. We have patients, family members, and parents on our boards and several committees. They bring invaluable perspectives that often change our approach. Lay board members who are community leaders do not always represent these perspectives, so it is important to identify people who are committed to providing the views of patients.

Second, boards need to see patient experience and safety data regularly, with an engaged quality/safety committee that can dig deeper. Safety and experience often go hand in hand. Boards need to be educated about how to interpret the data so they understand what they are looking at and what questions are important. Organizations that take this seriously start every board meeting with both a positive and negative patient story, to illustrate their positive impact as well as their challenges. It sends a message that patients really are at the core of what we do and why we are here.

TGI: How are you applying Human Understanding to efforts around SDOHs?

SEL: In 2008, Massachusetts passed universal coverage (health insurance) legislation, which also required that every hospital create patient and family advisory councils. I wish every state did this. Every initiative we start begins with

1 Mark Meterko, et al., "Mortality among Patients with Acute Myocardial Infarction: The Influences of Patient-Centered Care and Evidence-Based Medicine," Health Services Research, October 2010.



the councils—what they think, how they can inform the design and implementation, and how we will communicate it to the public. With SDOHs, we did a lot of qualitative research with patients to learn how to explain why we are asking personal questions such as if a patient feels safe at home or can afford their medications. Helping patients understand why we are asking, what we are going to do with the information, and what kinds of support they will be receiving, is a game changer.

TGI: How do you gather this information from people in the community who aren't yet patients?

SEL: We have deep relationships with certain communities where we are the dominant provider. In Chelsea, which is a small community with the highest number of patients with chronic conditions across our state, we created Healthy Chelsea. It is a community group that includes the leadership of the MGB Chelsea Community Health Center, the police chief, the school board chair, the mayor, the town administrator, and the head of probation services, among many others. We share

our SDOH data with them, so they know where they have housing or education challenges. We have similar relationships like this in other communities. Even though we don't provide care to everyone, the work those organizations do affects everyone who lives there.

In Chelsea they learned that there was a high incidence of trauma in children who had witnessed any kind of violence. When an incident occurs, a social worker on call is paged, who comes to meet with the children involved along with a police officer who is specially trained. The intent is to provide emotional support and to minimize people being afraid of the police. Young children who are part of this program get to know the police officer and social worker over time. Many of these children grow up and decide they want to be a police officer or doctor because of the support they received through this program.

TGI: What is your post-COVID outlook—where do we need to go with Human Understanding?

SEL: Everyone is dealing with massive staff shortages and burnout. Human Understanding is critically important to moving our organizations forward. At MGB, we are engaging with the primary care practices that have been hit hardest by COVID, through a focused series of events culminating in a retreat. The purpose is to help them think positively about the future. We interview staff and doctors and ask, what are the strengths of your practice, and what are the challenges? What is your vision for your practice in the future? We use that to create a draft vision for the practice that we share during the retreat.

We start the retreat with a "why" exercise: why are they there, why are they working in healthcare, what does it mean to them, why is it important, and why are they working in this practice? They discuss these questions for an hour in a small group of people they don't normally work with. This helps them get to know each other better, which improves communication and teamwork. It also shows the clinical staff how committed all staff are to making a difference for their patients. Then we do an "I Care" training: communication, advocacy, respect, and empathy. We use real NRC

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Health experience data and comments to show where they are doing well and where they have challenges. We also ask them to define what these behaviors look like—what does good communication, advocacy, respect, and empathy look like to you? We take them out of their comfort zone, so they look at things from a different lens. They come up with work plans and we help with process improvement support so they can develop and implement new workflows.

TGI: What do you feel are the important takeaways for boards from this conversation?

SEL: Boards need to focus on defining the values of the organization and how everyone will be held accountable to those values. Their focus on the patient's experience, clinical quality, and safety is as critical as their focus on financial outcomes. They also need to prioritize the resources to make sure these things can happen. They should be vigilant about promoting high-quality care and patient experiences backed up by reliable evidence as opposed to assuming that empty marketing campaigns will be enough.

They also can help by supporting regular evaluations of employee engagement and culture surveys—there is evidence that those that score well on culture surveys perform well on patient experience and outcome measures. Boards don't always understand the connection between how we take care of our staff and how we take care of our patients. It's a critical connection that fosters deep Human Understanding and successful healthcare organizations.