URMC Taps Advisory Councils to Close the Equity Gap for Deaf and Transgender Patients

By Audrey Doyle

University of Rochester Medical Center has a long history of developing targeted patient and family advisory councils, or PFACs, to create a welcoming and responsive health system for all patients. So it was only natural that system leaders turned to this engagement strategy to better meet the needs of two often-marginalized groups: individuals who are deaf or hard of hearing and those who are transgender or gender-diverse.

For both groups, performance on Press Ganey patient experience surveys and other resources indicated suboptimal care experiences. For the deaf and hard of hearing, the issues included misconceptions about deafness and American Sign Language (ASL) and a lack of ASL interpreters. For transgender/gender-diverse patients, the issues included conscious and unconscious biases they'd experienced from clinical and nonclinical staff.

To better understand the unique needs and perspectives of these patients and their families, leaders formed the Deaf and Hard of Hearing Patient and Family Advisory Council in 2018 and the Transgender and Gender-Diverse Patient and Family Advisory Council in 2019. "These groups struggle with disparities in health care, and we were unintentionally letting them down," said chief patient experience officer Jackie Beckerman, who will co-present a session on URMC's Behavioral Health, Deaf, and Transgender PFACs at Press Ganey's 2020 Virtual National Client Conference. "No one understands their needs better than they do. Through these councils, they can tell us what they need for a positive care experience and let us know how we can deliver it."

AT A GLANCE

- University of Rochester Medical Center (URMC) formed patient and family advisory councils dedicated to the needs of deaf and transgender individuals to understand the health care disparities these groups face and develop tactics to improve their access to and experience of care.
- By educating clinical and nonclinical staff on misconceptions about deafness and unconscious biases they may have toward transgender individuals, leaders are eliminating avoidable suffering and building patient–provider trust.
- Toolkits and easier access to ASL interpreters are facilitating communication with the deaf and hard of hearing, while removing gender markers from patient identification wristbands and patient-facing documentation is ensuring a more inclusive environment for transgender/gender-diverse patients.

Addressing the Communication Needs of the Deaf

Patient and family advisory councils have been key contributors to quality improvement efforts at URMC for more than 20 years. Leaders formed the organization's first council at Strong Memorial Hospital (SMH), the flagship facility of its clinical enterprise, UR Medicine. This was followed by separate councils dedicated to the needs of behavioral health, NICU, pediatric, and cancer patients and families.

URMC's Deaf PFAC is among the first of its kind in the country, according to Beckerman. It includes members of local advocacy and community groups, deaf and hard-of-hearing patients and family members, and deaf and signing staff, with additional representation from URMC's Patient Engagement Committee. During two-hour monthly meetings led by Beckerman and a deaf co-facilitator, the members discuss disparities and roadblocks the deaf and hard of hearing encounter in health care generally and at URMC specifically and advise leaders on how best to address them.

According to Beckerman, the meetings have been eye-opening. "We've learned so much, from the basics on," she said. For example, staff often used the term *hearing-impaired* when discussing hearing loss with patients and families, not realizing this is offensive to deaf people. "Deafness isn't an impairment, but that's how it's described on the problem list [the document that states a patient's health problems] and it's the term many providers were trained to use," she said. To remind employees not to use the term, leaders created a screensaver instructing them to use *deaf, deaf-blind*, or *hard of hearing* instead. The screensaver also reminds employees to ask deaf patients and families how they prefer to communicate instead of assuming they can read lips.

Many clinical and nonclinical staff also weren't well-versed in ASL and other modes of communication. For instance, many didn't know ASL doesn't mirror spoken English, but rather, is a distinct language that uses visual cues and has unique grammatical rules. This means people who only know how to communicate through ASL may not read, speak, or understand English. Staff also didn't know that when a patient or family member asks for a deaf interpreter, they want an interpreter *who is deaf*, not an interpreter *for the deaf*. As Beckerman explained, a deaf interpreter works with an ASL interpreter who can hear; the ASL interpreter relays messages from hearing individuals in the room to the deaf interpreter, who relays the messages to the deaf individual.

Leaders addressed these communication issues through education and training. They also created a toolkit for every hospital unit that includes a laminated "communication alert" which patients and families can use to let caregivers know whether they need an ASL interpreter or a deaf interpreter, as well as a card listing ASL interpreter service contact options. For COVID-19 screening purposes, the toolkit includes a laminated sheet that uses questions and graphics patients can point to in order to describe their symptoms. In addition, clear face masks are now available on each unit.

Through the meetings, leaders also learned of personnel/staffing needs. For instance, many deaf family members arriving at URMC hospitals after hours had difficulty getting help if no one was at the information desk; although a sign on the desk gave a number to call for assistance, they couldn't use the phone if they had difficulty communicating verbally. Leaders also learned that access to ASL interpreters was an ongoing problem as the organization continued to grow. There were times, for instance, when ill patients had to wait several days to be seen in a URMC clinic because an interpreter wasn't readily available.

To resolve these issues, leaders were able to hire additional ASL interpreters (including two deaf interpreters). To avoid scheduling conflicts, patients can request an interpreter when they schedule their appointment, and the request is automatically sent to Interpreter Services. In addition, a text message line is now available around the clock for urgent interpreter needs. Leaders also worked with schedulers to ensure that information desks at hospitals throughout the system are staffed around the clock.

At press time, the Deaf PFAC was working with URMC to create an educational video series in ASL for the organization's website. The first video in the series, set to go live in mid-November, will explain the system's COVID visitation policy, screening process, and safety updates.

Creating a More Inclusive Environment for Transgender Patients

In developing the Transgender PFAC, leaders faced challenges around member recruitment. Transgender people are often disrespected by the medical community, which causes them to distrust doctors and hospitals and avoid seeking care, Beckerman explained. So even though the Rochester, New York, area has a sizable transgender population, recruiting members for the Transgender PFAC hasn't been easy, she said. "Our hope is that by working with our transgender and gender-diverse community, we will start to gain their trust and ultimately eliminate these disparities."

Currently, the Transgender PFAC consists of six transgender individuals, six parents of transgender teens, and one person who is gender-diverse. A transgender staff member facilitates the meetings, which are held monthly for 90 minutes, with Beckerman as co-facilitator.

Although this council has only been meeting for about a year, members have already helped institute some important changes that have resulted in a more inclusive environment for transgender patients. Following are some examples.

- Gender markers were removed from patient identification wristbands and patient-facing documentation. URMC's electronic health records system was also changed to override default pronouns.
- Upon learning that staff sometimes inadvertently misused patients' pronouns or used their "deadname" (i.e., their name given at birth), the council created an educational screensaver that reminds staff to ask patients what name they go by and what their pronouns are, and not to use the term *preferred name*, as this is unacceptable to the transgender community.
- URMC created a new rooming policy. Previously, to avoid making any patients feel uncomfortable, staff would often assign transgender patients to a private room, which sometimes meant these patients spent extra days in the ED waiting for a room to become available. Now patients are assigned to the first free room. If it's a semiprivate room, they're placed in accordance with their gender identity.

With these changes in place, the Transgender PFAC is now being asked for feedback on how the council is working. They're also being asked for input on upcoming initiatives. For instance, URMC is in the process of renaming its Women's Health Clinic to be more inclusive of transgender men who may still need services the clinic offers; once a name has been decided, it will go back to the PFAC for their input.

Next Up: A Focus on Data and Diversity

To capture more feedback from transgender and gender-diverse patients, the health system plans to customize its Press Ganey patient experience surveys with questions specific to this patient population. Leaders also plan to explore the possibility of incorporating video into the survey process to gather feedback from patients who only communicate in ASL.

Beckerman is also working to bring more diversity to all the PFACs. "We'd like them to include deaf and transgender patients of color; we'd like a deaf patient to be on the Transgender PFAC and vice versa." In addition, URMC is exploring the creation of a Diversity, Equity, and Inclusion advisory council that would be a subcommittee of the system's flagship advisory council.

"There's still so much work to be done," Beckerman said. "But by continuing to listen to the patient voice, we can keep making improvements that will have a lasting impact."