As a patient advocate, I wasn’t sure what to expect when I attended the Institute for Healthcare Improvement (IHI) seminar, “Person- and Family-Centered Care: Transforming the Patient Experience.” I arrived to find a room full of people who came together from all over the world to talk about how to engage patients and their families in the design and delivery of healthcare. Having spent five years as a caregiver, I know patients can be a part of improving the care a loved one receives. So now, I work to examine how technology can be introduced in the healthcare journey. I came looking for answers on how to engage technology such as electronic health records and health information exchange with patients and caregivers to meet the triple aim of healthcare of better care, at lower costs, with better outcomes.

Patient Family Advisors described how their experiences shaped them to becoming a valuable part of a healthcare system. They not only described the challenges they faced, they also shared their lessons learned in a way that were easy to apply to any situation. The patient voice was heard throughout the event from an IHI staff member’s description of how she became involved with IHI after a battle with breast cancer, to the musician who serenaded us during lunch with the song he wrote for his dying wife to take her mind off the side effects of chemotherapy, to the gentleman who poignantly recounted how he had been pushed by the red coated valets at the Cleveland Clinic just like the gentleman in the Cleveland Clinic Empathy video. The patient voice was heard in every aspect of the event.

So what happens next? For me, it is to provide the business case for patient engagement while my clients work to meet their reporting requirements. One example is incorporating bedside huddles to allow patients and family members the opportunity to be involved in the conversation. There is valuable information that can be retrieved from electronic health records as long as it is entered accurately. During bedside huddles, documentation being placed in the electronic health record can be verified by the patient and/or family. There is value in having patients involved in the design and roll out of patient portals. They can help us identify what personal health information patients would be most helpful in engaging them in their own healthcare. Patients and families can help ensure better quality patient generated data is entered into personal health records. Better quality data entered into a health information exchange, allows the patient to have the right information when and where they need it no matter where they are in a healthcare setting. When good quality data is available about a patient, healthcare organizations can use the data to create information which can be used to lower costs and help drive better outcomes. Electronic health records and health information exchange can be used as the great equalizer to provide health equity for all.

- Teresa Younkin, Patient Advocate, Danville, PA