GUEST OPINION

People at the Center

Sharon F. Terry, MA*

It is high time that the benefits that have accrued to other fields, industry, and especially consumer-centered services are applied to healthcare. All sorts of technological advances have catapulted consumers into a new era, whether it is ride sharing, shopping, or entertainment. Healthcare often has appeared insulated from transformation through consumer pressure enabled by technology. It appears to be too much of “whack-a-mole” system—pressure applied in one area results in less than desirable manner.

I am most interested in healthcare transformation from the grassroots up, and as such, in how artificial intelligence, telemedicine, telehealth, wearables, and other technologies will enable real people to have an effect on one of the most essential systems in their lives. How can these technologies, which have transformed other areas of individuals, families, and communities’ lives, give people the tools to take charge of their health, and to manage their sicknesses?

Rather recently, regulatory bodies such as the Food and Drug Administration have begun to require Patient Focused Drug Development and Real World Evidence. Although this is a fabulous focus, a focus on real people in real life situations, for the biotech and pharma companies, it is not easy to gather or analyze this information.

I envision a world in which people get to use complex technologies to transform health with less and less friction. By this I mean that the technologies are transparently part of individuals’ lives where they live, eat, work, play, and pray. Using them requires no extra lifting. And they are obviously being used, not soaking up data with no notice, and especially without concern for the needs of the individual and/or community.

Right use of advanced technology should enable the most important questions that communities have to surface. What matters most to people should become apparent. And then the technologies should answer these questions in real time, with real participation of people as partners in research, not as subjects of research that does not address their greatest concerns, their needs.

I built an engagement system ~24 years ago to help people with pseudoxanthoma elasticum (PXE) share what they know about living with that disease. My kids had just been diagnosed with PXE. At first it was a simple questionnaire, built after listening to those living with the condition told me what information they needed. Many other advocacy groups wanted the same capability, and so, with others who had the same goal, we developed the Program for Engaging Everyone Responsibly (PEER). PEER was an early system to capture Patient Reported Outcomes (PRO). The healthcare system now respects PRO in a grown respect for the lived experience of the real expert in health—people who struggle to stay healthy, and/or work to mitigate the effects of their own disease. Together with LunaPBC, we have now upgraded PEER to enable communities to engage their members, prioritize research questions, and integrate many kinds of data, including PRO, electronic health records, wearables, and genomic information. As we built this, and as we continue to refine it, we have never lost site of the fact that people’s skin is literally in this game, and they have to remain central. For us, never selling these data, allowing access to it to facilitate maximal data sharing only as the participants see fit, has been critical. And sharing the benefits with people, in this case through shares in the company, is essential to us.

Personally, I look forward to exploring healthcare transformation through technology as we struggle to continue to keep people and their needs at the center. I advocate for transparency about what we are about. I demand that we focus on what matters to people. I require that we keep people involved from start to finish, never subjects always partners. I am curious about how much we can accelerate discovery if citizen scientists have access to data. And I am compelled to find ways to share the benefits accrued to the investigators and inventors with the people from whom they gather data. Finally, I will always consider it immoral to hoard the data that come from people and their communities. The technologies themselves, as

Genetic Alliance, Washington, District of Columbia.

*Address correspondence to: Sharon F. Terry, MA, Genetic Alliance, 4301 Connecticut Ave NW, Suite 404, Washington DC 20008-2304, E-mail: sterry@geneticalliance.org

they are built and refined, must facilitate data sharing to ever accelerate solutions to suffering.

I am excited to see how *Healthcare Transformation* can contribute to our understanding of these burgeoning technologies, provide a platform to increase sharing of intelligence and advances, and provide a forum for the intersection of all of the stakeholders.

About the Author

Sharon F. Terry, a member of the *Healthcare Transformation* Editorial Board, is President and CEO of Genetic Alliance, an enterprise engaging individuals,

families, and communities to transform health. Genetic Alliance works to provide programs, products, and tools for ordinary people to take charge of their health and to further biomedical research. As a citizen scientist and mother of two children with a genetic condition, she codiscovered the ABCC6 gene, developed a diagnostic test, and conducts clinical trials. She is the author of 150 peer-reviewed articles, of which 30 are on clinical PXE studies. She is coinventor of the Program for Engaging Everyone Responsibly (PEER) and is a member of the NIH “All of Us” Research Program Advisory Panel.