A new approach to patient engagement

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For many teens, the move from paediatric to adult care presents a difficult transition period. To better address the unique challenges for paediatric type 1 diabetes patients, the transition age team at London Health Sciences Centre wanted to put a patient advisory group in place. After a year without success in recruiting members, the team, led by LHSC paediatric endocrinologist Dr. Patricia Gallego, decided to look for an alternative approach to engaging patients.

If other transition-age programs at LHSC were already doing something successful in terms of patient engagement, could they model something similar in this area of care?

“The Mental Health Care transition age pilot project really caught our attention as a unique approach to working with a similarly aged population,” says Tracy Robinson, Strategic Patient Oriented Research Associate at Children’s Hospital at LHSC. “We thought it might make sense to look at creating a comparable engagement experience for our teens.”

One of the key features of the mental health program was partnering with mindyourmind. Working with young people aged 14-29 to co-create interactive tools and innovative resources to build capacity and resilience, the non-profit organization mindyourmind exists in the space where mental health, wellness, engagement and technology meet. Leveraging a unique design studio model, young people have the opportunity to work directly with facilitators, content experts and designers to brainstorm, design and develop tangible projects. The goal of all design studios is to promote wellness, reduce stigmas around mental health and increase access to community supports, both professional and peer-based.

“Think focus group, but more interactive technologies and with the outcome of producing an actual product. The design studio really added the coolness factor that we didn’t have in-house,” notes Robinson. “It also came with the important benefit of providing a neutral space away from their parents and care providers where they felt they could more freely share their thoughts, opinions and experiences.”

To create the type 1 diabetes design studio, LHSC and mindyourmind enlisted the help of a peer mentor, Kayla Brown, who had been steadily building a social media community of fellow type 1 diabetes peers through a personal blog and Facebook. Leveraging her T1 Empowerment Facebook group to recruit individuals for the design studio, coupled with the offer of a small honorarium, a group of eight individuals aged 17-23 came together in March to discuss what they felt they actually needed in terms of support during the transition to adult care.

Through the design studio process, the group established that what they needed most was tools that would help them to begin conversations with their health-care providers about relevant topics and a social media-based peer mentor community where they could continue conversations about how to deal with day-to-day challenges. Topics like how to overcome feeling embarrassed to administer insulin in front of new friends because of the stigmas sometimes associated with needles and injection devices are more credible coming from someone with lived experience.

The end result was the design and production of business- and postcard-sized invites that contained a number of quick prompts to help patients start conversations with their health-care providers, and each other, about care transfer. Participation in the peer conversation through the hashtag #GrowingWithT1D was also encouraged.

“We’ll be handing out these cards to patients in our teen clinic who are between 15 and 17 years old,” says Robinson. “We hope this is just the beginning of a continued conversation, and while we don’t know exactly what role we might play in this peer mentor community just yet, we are excited to tap into the great feedback from this group and use that to make changes to our transition-aged program to better serve the needs of our patients.”

More information about the diabetes group design studio is available on the mindyourmind website.
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