KHSC CEO's Research Brief

Patient engagement in research

October, 2018

Traditionally, patient contributions to research have been restricted to the role of "research participant" or "subject." Today the emphasis is on "patient engagement" in research: that is, meaningful and continued collaboration, in which patients and families become partners and are actively engaged in all stages of a research project.

As the examples below show, giving these groups a voice during the research process ensures that studies focus on patients' priorities, leading to better patient outcomes and bringing about positive change in the lives of people in the Greater Kingston area.

Dr. Dawa Samdup - Exergaming and autism spectrum disorder
Through patient and family engagement, a small group of local families is helping Dr. Dawa Samdup, a developmental pediatrician at the KidsInclusive Centre for Child & Youth Development (Hotel Dieu site), to study the effectiveness of a novel exergaming program to increase physical activity and fitness in children with autism spectrum disorder (ASD). This pilot project involves five children aged 9-12 and their parents, and will take place in the children's homes, where they will play specially designed exergames using a recumbent bicycle. The research team, with input from the families, will assess the children before and after exergaming in cardiovascular fitness and health-related quality of life. These children and their families will also provide input on how to design the next, larger study, and on broader issues, such as whether the exergaming program should be offered in schools or camps.

"Patient engagement in research really informs what I do," says Dr. Samdup. "I see the patient and the family as a whole. It's not just doing diagnostics; it's about quality of life, and how the family is affected in the community."

Dr. Amer Johri - Metabolic syndrome
Dr. Amer Johri, Director of the Cardiovascular Imaging Network Queen's (CINQ) lab at Kingston Health Sciences Centre, recently completed the first large-scale study of the effects of L-Carnitine, a nutritional supplement, on patients with metabolic syndrome. Left untreated, metabolic syndrome greatly increases the risk of many chronic illnesses such as diabetes and heart disease. Study patients were then asked to help develop the next phase of this research. These volunteers shared their experiences with this condition at focus groups, and offered suggestions about where future research efforts should be directed.

These patient perspectives helped to target future research and programs aimed at metabolic syndrome, Dr. Johri says. "For example, an important theme that emerged from this population was the need for earlier detection and prevention of heart disease related to metabolic syndrome. Patients expressed that while secondary prevention was critical, equally important was prevention of disease, and primordial prevention of disease risk factors. This emphasis now informs the rationale for our program using novel imaging biomarkers, such as point-of-care ultrasound, to study and detect this disease earlier and more accurately."

Creating a community of practice

KHSC is working towards embedding patient engagement into research practice. Lisa McAvoy, Research Facilitator for the W.J. Henderson Centre for Patient-Oriented Research, is KHSC's staff representative on the CAHO Community of Practice in Patient Engagement in Research. She is one of several local participants who have taken the Ontario SPOR Support Unit's Master Class and she is now working with a patient representative to create a Patient Engagement in Research Advisory Committee.

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