

# Patient advisors revolutionize research



Matt Owen and Dr. Karen Coleman

**F**ifteen years ago when Matt Owen was a freshman psychology major in college, he had a “psychotic break from reality.”

“I started having hallucinations that altered my mind in a way that dealing with everyday life became challenging,” he said. “It changed the course of my life.”

Times were rocky for a while, including more than a year of being homeless. But with medication, therapy, and self-awareness, Owen has been able not only to turn his life around, but to help others. Now 33 and studying for his nursing license, he does that by helping guide behavioral research at Kaiser Permanente.

Owen serves 2 roles for Kaiser Permanente. As a patient advisor, he helps to guide physicians and health care professionals as they plan and

improve programs. As a patient stakeholder, he helps investigators keep the patient in mind when conducting their research.

“The reason I’m a patient stakeholder is because it is very therapeutic. It is a nice way to contribute to the psychiatric field, to actually produce something valuable using my experience,” Owen said. “It has been very enriching to see how a behavioral health care system works and to contribute to that as much as possible.”

## Patient involvement in research at KPSC

Kaiser Permanente Southern California has long relied upon patients for their experience and wisdom to help shape medical policies and programs. Currently, patients participate in 2 regional committees. One addresses general

medical policies and projects. The other, on which Owen serves, focuses specifically on behavioral health. The patient advisors report to and advise the region's quality improvement leaders.

In the last few years, the idea of engaging patients to also help improve research has become more popular. R&E research scientist Karen J. Coleman, PhD, MS, began working with patient stakeholders 8 years ago while evaluating bariatric surgery outcomes.

More recently, she has worked to create an infrastructure for patient engagement in mental health research with funding by the Patient-Centered Outcomes Research Institute. The award is designed to integrate patients into the Mental Health Research Network, of which KPSC is a part.

### Openness to patient input is increasing

"In the past, researchers may have hesitated to engage patients in research discussions because they may not have known how to address their specific needs for research," Dr. Coleman said. "But today, more researchers see the benefits of patient engagement, to help frame better research questions and better understand the results."

Dr. Coleman is exploring the potential for 3 different levels of patient engagement:

- A co-investigator level, in which a patient becomes a citizen scientist, involved in conducting and writing the research
- An advisory board, in which scientists work with patients on the board periodically to develop, test, and disseminate research ideas
- A larger population-based patient group that could help scientists understand if their ideas resonate with the needs of patients



Dr. Kristi Reynolds

### Patients can give critical tips to researchers

Kristi Reynolds, PhD, MPH, recalled inviting a patient with a blood-clotting disorder to be part of the research team studying anticoagulation medications. The team had planned to use mail and phone calls to survey patients about how anticoagulation medications affected the patients' quality of life.

Dr. Reynolds, director of R&E's Division of Epidemiologic Research, said the patient helped the researchers develop the survey and put the questions in an order that made more sense from a patient's point of view.

"He also suggested that we offer the survey through email, which turned out to be very important for the study," Dr. Reynolds recalled.

The email response rate was so high that the team was able to conduct additional surveys and compare response rates between mail, phone calls, and email.



Dr. Huong Nguyen

"Email had the highest response," Dr. Reynolds said. "It really saved us money and helped us to reach more patients."

### **Some researchers see patient engagement as a necessity**

Huong Q. Nguyen, PhD, RN, is a researcher whose work focuses on chronically ill adults and older adults. She said she engages patients in research out of pure necessity.

"We can't design interventions for patients, families, and caregivers if we don't talk to them, right?" she said. "You can't just design interventions in a vacuum and expect them to automatically love what you create."

The first R&E project that Dr. Nguyen worked with patient advisors on was the Walk-On! Physical Activity Coaching project from 2014 to 2018. It was designed to determine the effectiveness of a 12-month physical activity coaching program for people with chronic obstructive pulmonary

disease, or COPD. She had 3 advisors initially during the proposal phase, which was then expanded to 8 advisors when the study was funded.

"Those advisors were instrumental in helping me pull together the proposal," she said, "from detailing what that program looks like to how it would actually meet the needs of people living with COPD."

### **Patient advisors become invested in projects**

The advisors spent 4 years on the project, working on different aspects of the research. They helped refine study materials and create a patient-friendly consent form. Dr. Nguyen and the research team were able to engage about 25% of the patients with COPD that they approached.

"They were definitely sad when the study came to an end, because they saw each other as

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*“My experience has allowed me to touch other peoples’ lives in a way that is meaningful to me, at least. I hope it’s meaningful to them.”*

– Matt Owen, patient advisor

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support,” Dr. Nguyen said. “They also wanted to continue to stay engaged and contribute to research.”

The Walk-On! paper was published in *JAMA Network Open* in August 2019. Dr. Nguyen is currently working on a study about palliative care that uses palliative care caregivers as the advisors.

Sometimes there are challenges. Patient advisors might experience some disappointment when suggestions aren’t implemented due to Institutional Review Board (IRB) rules meant to stringently protect research subjects. Other times a proposed intervention is dependent on factors they can’t control, such as the willingness of doctors and nurses to implement a certain practice, Dr. Nguyen said.

“More often, I think, they make connections, make contributions, and benefit from the work,” she said.

### **Owen’s psychiatrist recommended him for patient advisor role**

Matt Owen, the patient stakeholder in Dr. Coleman’s research, said that the experience has been rewarding.

After learning to take care of himself, Owen looked for ways to help others. He was hired to be a peer counselor to others with mental



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health challenges. Four years ago, his psychiatrist recommended him for a patient advisor role at Kaiser Permanente. About a year ago, he became a patient stakeholder, and is working on a research project studying how peer counselors might benefit mental health patients.

“Working as an advocate has allowed me to help others in a way that is meaningful to me, and hopefully to them,” he said. “I want to see people get better and make the moves that they need to live a more fulfilling life.”

Owen said he’s tried to give as much input as possible to the peer support project because it is something he knows so well.

Also, he added, “I think that the experience of using our own challenges and own experiences to help someone else out is one of the best things we can do.”