A collection of articles featuring projects highlighted at the 2017 PCORI Annual Meeting
What does patient-centered research look like in the field? How do patients and other stakeholders engage in projects? These stories provide a glimpse into the workings of projects highlighted at the 2017 PCORI Annual Meeting. Hear from researchers what it’s like to partner with patients and other stakeholders, and from patients about being part of a research team. Learn how research done differently can make a difference for patients, caregivers, clinicians, researchers, and others.

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Improving Health in the Mississippi Delta through Powerful Engagement

Barbara Young is a survivor. The lifelong Mississippi Delta resident beat cancer four times in a place where healthcare resources are scarce. When she was first diagnosed with breast cancer, in 1987, Young and her husband were raising three small children. She was also working two jobs and running a cake-baking business from home. “I thought I was just tired from working two jobs; I didn’t know I had cancer,” she says, “I had all the warning signs, but I didn’t understand them.”

Young says a lack of information and resources in the small town where she lived made decisions about the most appropriate cancer treatment difficult. After choosing a mastectomy, Young developed cancer in her other breast. In the years following treatment of that tumor, she went on to have uterine cancer and stomach cancer. “The pain from stomach cancer was unbelievable,” she says, “I couldn’t do anything. I couldn’t even brush my teeth.”

During her treatment, she received a call from Freddie White-Johnson, MPPA, of the local cancer outreach program, the Mississippi Network for Cancer Control and Prevention, a program of the University of Southern Mississippi. That changed her life.

Young says White-Johnson’s daily calls and the information she provided motivated her not only to continue with treatment but to become involved in health outreach, using her experiences to educate others about preventing cancer and to help those facing the disease. Today, she is a community health advisor in the cancer network and Fannie Lou Hamer Cancer Foundation, which is using a Eugene Washington PCORI Engagement Award to advance breast and prostate cancer prevention, diagnosis, and treatment, and encourage the community to participate as partners in research. PCORI’s support of the network received recognition in proclamations from a city—Greenwood, Mississippi—where the award team has been active, as well as from the state legislature and the lieutenant governor.

Freddie White-Johnson visits the home of a man who is experiencing prostate cancer symptoms. In addition to giving him information about cancer screening, she noticed he had no heat and brought him an electric heater. (Photo courtesy of Freddie White-Johnson)
“When I was first diagnosed, we didn't have access to computers and other technology. Our local health department was the only source of care. Right now, we still don't have a lot of access,” Young says. “Before you talk about cancer, you've got to talk about other needs.”

Where Hardships Are Common
The financial, educational, and healthcare challenges of Mississippi Delta residents can be as vast as the Delta itself. In this region that stretches over northwest Mississippi, 30 percent of families live below the poverty line, with some groups affected more severely than others. For example, 10.2 percent of white families live below the poverty line, versus 41.7 percent of black or African-American families. In the state, 18 percent of those over age 25 lack a high school diploma, higher than the national average of about 13.3 percent.

The Delta faces other social problems including high rates of teen pregnancy and incarceration, and many people who lack sufficient food and clothing. Some residents have no indoor plumbing.

According to the US Centers for Disease Control and Prevention, the number of new cases of cancer in Mississippi are highest for prostate and breast cancer. The story of prostate cancer in the region is particularly stark. The new case rate in black or African-American men in Mississippi is almost twice as high as the new case rate in black or African-American men nationally.

Health care can be hard to come by, and not just because some people lack insurance. The area has few healthcare providers, transportation is difficult, wait times are long, and appointments may be brief. For example, a Delta ob-gyn with a nurse practitioner may see 50 to 60 patients a day, White-Johnson says.

So, a simple phone call from her or a member of her team can make a world of difference.

From a Movement to an Empowered Community
Although Delta residents may be unfamiliar with the Mississippi Network for Cancer Control and Prevention, Freddie White-Johnson is a well-known name. She almost single-handedly created a community cancer outreach movement under the most unlikely of circumstances.

In 2005, she founded the Fannie Lou Hamer Cancer Foundation, which uses private and public funding to support cancer awareness and prevention activities and works to improve the daily lives of those affected by cancer. Volunteers often run the activities, many of them from the Mississippi Cancer Network, an organization for which White-Johnson now serves as the program director.

Run by community members for community members, the network focuses on education, outreach, and advocacy related to cancer, with an emphasis on breast and prostate cancer. Since its beginning, the network has trained more than 1,000 community members as community health advisors.

The network selects as potential advisors people who already make a difference in their communities by helping others. Trained advisors teach community members about breast and prostate cancer, including warning signs, symptoms, and the importance of screening.

The community health advisors meet community members wherever they are—at churches, recreation centers, shopping areas, and even fire stations. They provide food and bring activities to occupy families’ youngest members, so that parents are free to learn. They also hold health fairs, distribute literature, and recruit people for cancer screenings. After these events, advisors follow up with community members who have never been screened even though guidelines suggest they should have been.

“When people learn, they do better. Once we change mindset and attitudes, you are going to start seeing behavior change,” White-Johnson says.

White-Johnson and community advisors also call and visit homes of those living with cancer. They provide transportation to medical appointments and help patients compile questions to discuss with their doctors. They even help take care of some patients’ most basic needs, which can include providing food, heat, and clothing, and teaching proper hygiene.

The PCORI Engagement Award allowed White-Johnson and her team at the University of Southern Mississippi to expand their more than a decade’s worth of work helping those in the Delta by developing a training curriculum for advisors. The project's other leader, Carol Connell, PhD, RD, a professor of Nutrition and Food Systems at the University of Southern Mississippi, says that to develop the training, the team conducted interviews with advisors to understand how they do outreach, particularly about cancer. The team then met with a community advisory board to discuss the findings.

“There are so many people still out there in Mississippi in 2017 who don’t have any direct support or health resources. There are men who don’t even know what a prostate is. There’s so much work that still needs to be done.”

—Freddie White-Johnson
From these interviews, the team learned that the community members contacted by community health advisors did not understand the concept of research and were deeply concerned about exploitation. They thought that becoming research participants would make them guinea pigs, says White-Johnson. By the end of the award, in April 2017, the team had created a training program that addressed the community’s concerns.

**A Life Dedicated to Helping ‘People Like Us’**

White-Johnson once was a community member in need of help, like those she serves today. She grew up poor on a cotton-and-soybean plantation; neither of her parents completed high school. In 1977, when she was 17, her father was diagnosed with stage IV lung cancer. At the time, her family had never heard of cancer and had no health insurance.

“He was treating what was cancer with Epsom salts and warm water and gargling,” White-Johnson says. “The pain got worse to the point that finally my mother said he had to go to the doctor. They ran tests and told us immediately that it was lung cancer.”

Just before he died, her father gave her advice: “The world owes you nothing. If you want anything out of life, you are going to have to work for it. Go to school and get an education. Then come back and help the people like us.”

“That’s what I’ve done,” White-Johnson says. She earned a master’s degree in public policy and administration and became a program director at the University of Southern Mississippi. It’s where she created the Fannie Lou Hamer Cancer Foundation to offer support to the Delta. When she approached the university in 2004 about launching the foundation, she envisioned building a nonprofit foundation as large as Susan G. Komen for the Cure.

Funding from the university, local, statewide, and national organizations, such as the Sunflower County Board of Supervisors, and the Mississippi Partnership for Comprehensive Cancer Control of the State Department of Health, helped the foundation get off the ground. Some people said her ideas were just too ambitious for the area and its resources.

“I was afraid of failure at first, but I wanted to see if the foundation could give people a different perception of true community engagement and community-based participatory research,” White-Johnson says.

Enthusiasm was high when she held her first informal meeting about developing the foundation. Around 75 people attended, including staff from the University of Southern Mississippi, researchers, community health advisors, community leaders, healthcare providers, and representatives from social and welfare agencies. However, no one wanted to lead the foundation. So, White-Johnson stepped up to take charge.

In 2010, when some of the early funding ended, the university chose to independently continue the network, now called the Mississippi Network for Cancer Control and Prevention. White-Johnson’s foundation supports the network with supplementary funding. Additional funds came to the university in 2015 with the PCORI Engagement Award.

“There are so many people still out there in Mississippi in 2017 who don’t have any direct support or health resources,” White-Johnson says. “There are men who don’t even know what a prostate is. There’s so much work that still needs to be done.”

White-Johnson adds, “I love doing what I do, being that voice for the underserved that makes a difference and gives many people who are in need a ray of hope.”

With the training curriculum developed through the PCORI Engagement Award, the network can teach more community members how to find answers to their questions and get more involved in their own health care. The advisors can also learn to more effectively support community members, as White-Johnson has always done.

“Freddie just sees a need. She didn’t see that I was 97 pounds or that I had lost all of my hair,” Young says. “She just saw a human being who needed help and
Tackling Chronic Pain While Reducing Opioid Use

Betts Tully has lived with pain since the mid-1980s. “I had a car accident; I had degenerative disc disease; I’ve had two operations on my spine,” she says.

Tully is one of tens of millions of Americans living with chronic pain, which is pain that occurs at least half the time for at least six months. As one of the most common causes of long-term disability, chronic pain costs the United States an estimated $600 billion yearly in healthcare expenses and lost productivity.

For years, Tully managed her pain with very low doses of opioid drugs. But when her chronic pain began to worsen in 2000, she visited multiple pain clinics seeking solutions, repeatedly increasing her dose of opioids. She ended up taking oxycodone, a strong opioid, in a dose far greater than the level that should trigger caution, according to 2016 Centers for Disease Control and Prevention (CDC) guidelines.

“By June 2001, I was a total zombie,” Tully says. “I’d worked all my life. I’d been an elected official in my hometown. I’d owned businesses. But now, I was someone walking around the house in a robe, not able to drive, not able to think, not able to do anything.”

She spent years recovering from medically induced addiction and learning to manage her pain without opioids. Now, she’s a patient partner on a PCORI-funded study that compares outcomes at pain clinics that either have or haven’t implemented an opioid risk-reduction program. Early results show that the program has been successful: it decreased patients’ average opioid dose.

PCORI’s research portfolio tackles the challenge of chronic pain on many fronts. PCORI has funded 49 comparative clinical effectiveness studies addressing chronic noncancer pain management or opioid use. Fifteen focus on use of opioids in treating chronic pain, and three others assess opioid use in the context of substance abuse.*

“Chronic pain is one of the biggest conundrums facing medicine,” says Michael Von Korff, ScD, an epidemiologist and health-services researcher at Group Health Cooperative in Seattle, which has recently become part of Kaiser Permanente and changed its name to Kaiser Permanente Washington. He leads the PCORI-funded study of the opioid risk-reduction program in clinics. “We had an important opportunity to see whether a health system initiative could help patients in pain without overrelying on opioids.”

WORTH THE RISKS?

Opioids, taken as prescribed, can help control some short-term pain, but there’s disagreement about whether they work over the long run and, if they...
do, whether their benefits outweigh the risk of addiction. “There aren't any long-term studies to tell you whether opioid use is safe and effective for chronic pain,” says Von Korff. “But the practice of prescribing them took off. By 2014, 3 percent of all US adults were receiving long-term opioid therapy.”

This extensive prescribing of opioids has contributed to an alarming rise in inappropriate use, outright abuse, and overdose. Since 1999, prescription-opioid sales have quadrupled, according to CDC. And, in 2015, opioid overdoses caused 33,000 deaths.

For many years, Von Korff had studied the risks of prescription opioid use. His and others’ research suggested that chronic pain patients using prescribed opioids were risking overdose. What's more, his research indicated that higher doses increased overdose risk.

In 2010, Group Health started a risk-reduction initiative to lower the highest opioid doses among its patients, while more closely following all its patients on opioids. The initiative also included individualized care plans created by physicians and patients, along with a requirement that each patient get opioid prescriptions from only one physician.

In addition to the clinics it runs, Group Health contracts for patient care at outside clinics, where the risk-reduction program isn’t required. Von Korff realized that by comparing treatment at Group Health and the outside clinics, he had the perfect opportunity for a natural experiment on the initiatives’ impact. “We want to find out whether our program is the right response to the opioids problem,” he says.

With PCORI funding, he started the study, with Tully and eight other patients with diverse perspectives and experiences as advisors, to compare health outcomes among 1,600 patients using opioids long term. Outcomes measured include patients’ ratings of their pain and psychological well-being, and their perceptions of the opioids' benefits and risks.

The researchers are also studying electronic health records—from 2006 to 2014—of 33,000 long-term opioid users. The team will assess the risk-reduction initiative’s impact on opioid-related problems, including overdose and car accidents.

The study is ongoing, but initial results show that the average daily opioid dose declined more at Group Health clinics than at the clinics without the initiative. What’s more, the fraction of patients being treated for pain taking daily doses of more than 120 milligrams of morphine or its equivalent fell more dramatically at Group Health than at the other clinics, the team reported in 2016.

Not all the measures showed a difference, however. Last November, the researchers reported no difference in motor vehicle crashes when comparing patients taking chronic opioids from Group Health clinics and clinics without the initiative.

**A Right to Science-Based Treatments**

After her recovery, Tully became concerned about overprescription nationwide. “Patients have a right to safe, effective, and science-based treatments,” she says. She teamed up with a doctor to form the advocacy group Physicians for Responsible Opioid Prescribing. Through that group, she met Von Korff.

Tully and the other patient advisors helped select what the study measures. “For injuries, we were originally going to look just at hip and pelvis fractures,” Von Korff says. “But our patient advisory committee said, ‘We know people who have had falls, and you should be looking at a much broader range of injuries, like twisted ankles or concussions.’ We dramatically expanded the range of injuries we're looking at.”

Patient advisors' diverse experiences have helped throughout the study. “Opioid use is a very controversial area, so different patients have different points of view,” Von Korff says. “There isn’t a patient point of view.”

Tully agrees. She now takes no opioids but, she says, “there are some patients advising the project who struggle, saying, ‘If you took my pain meds away, I'd be in bed crying all day.’”

Another patient, Max Sokolnicki, says that the advisors have provided “very, very honest opinions,” and he's glad the researchers are listening. Sokolnicki developed chronic foot pain in 2002 after a hip replacement damaged a nerve. He’s taken strong
opioids but disliked the side effects. Now, he uses a spinal cord stimulator, a device that sends mild electric current to the spine, to manage his day-to-day pain. He saves strong opioids for his occasionally more serious pain.

Regardless of their individual experiences, Tully says, the patient advisors agree that the study is powerfully important. She emphasizes the lack of available research to inform evidence-based practice. “You have to know what you’re dealing with and be aware of the risks, as well as the benefits, of opioids,” she says.

*As of publication on pcori.org May 9, 2017

Helping Patients with Chest Pain Make Decisions in the ER

One day in 2011, Michel Demers experienced chest pain, headaches, and dizziness. He immediately got worried, thinking of his father, who had died at 50 from a heart attack.

As a stay-at-home dad, Demers had two small children to look after. He called his wife, Annie LeBlanc, PhD, a Mayo Clinic researcher. The two scrambled for childcare and then went to the emergency department at Mayo Clinic. Demers underwent numerous tests and received excellent care but still wasn’t sure how sick he might be.

Demers recalls feeling very anxious: “I was thinking, if they have to do so many tests, maybe I have a very big problem.”

Physicians wanted to monitor him overnight and run more tests the next day, but the couple worried about the cost of an overnight stay and about care of their children. Demers spoke mostly French—the family had recently moved from Canada—so LeBlanc was uncomfortable leaving him on his own.

“I started asking questions,” LeBlanc says. “I said, ‘Can you tell me his risk of a heart attack in the next month?’ And it was very uncomfortable. It really felt like we were asking too much.”

After about an hour and a half, a doctor told the couple the tests had come back negative: Demers was not having a heart attack, and his chest pain probably was caused by stress. Three hours into the visit, the two decided—against doctors’ recommendations, they note—to go home rather than stay overnight.

“We were getting the best of care,” LeBlanc reflects. “It was just not the care that we needed or wanted.”

Now, Demers and LeBlanc are patient and caregiver co-investigators of a PCORI-funded project that has tested a way to better inform patients about their care options and heart risks when they are being treated for chest pain in emergency departments. The study involved patients, like Demers, for whom tests had ruled out a heart attack and who were at low risk of heart attack.

Led by Erik P. Hess, MD, MS, an emergency medicine physician and researcher at Mayo Clinic, the study tested use of a decision aid: a single sheet of paper that explains patients’ risk levels for future heart attacks and their options for further testing—whether in the hospital or later in a doctor’s office.

The study results, recently published in *The BMJ*, were striking. Patients who used the decision aid in conversations with ER clinicians were less apt to decide to stay overnight for additional testing, and they faced no additional heart problems in the weeks that followed, as compared with patients who received only usual care.

Patients who used the decision aid also emerged with greater knowledge of both their heart risk and care options, and they got more involved in decisions about their care.

**A Major Health Burden**

Chest pain accounts for around 6.5 million visits to US emergency departments every year, according to the Centers for Disease Control and Prevention. But the vast majority of these visits do not end up being heart attacks.

Emergency physicians run tests to rule out a heart attack or unstable angina, a serious condition in which the heart doesn’t get enough blood flow. These tests miss about 1.5 percent of cases, and they don’t do a good job at predicting whether a patient will experience a serious heart problem in the coming weeks.
When a person comes to the emergency room with chest pain, doctors often want to run many tests. A decision aid may improve communication and decision making. (Courtesy of Erik Hess)

“The dilemma is how you manage patients who are at low risk for a cardiac event in a way that’s safe and doesn’t introduce undue burden on the patient,” Hess adds. Perhaps too often, he adds, doctors tend to be extra cautious and recommend that patients stay in the hospital for monitoring or undergo additional tests, such as stress testing or coronary computed tomography angiography. “There’s frequently a mismatch between the intensity of evaluation and patients’ risk,” he says.

Another issue is insufficient communication, Hess adds. “Patients don’t want to be left in the dark,” he says, but the rapid pace of emergency departments can mean that doctors might not have time to discuss patients’ future heart disease risks with them, or they make recommendations for further evaluation without taking patient preferences fully into account.

LeBlanc agrees. “In the ER, the level of stress and anxiety in patients is so high. You can’t begin to have discussions until they understand where they are in terms of risk,” she says.

**Easing Communication under Stress**

Coincidentally, LeBlanc herself is doing research on shared decision making. But during Demers’s ER visit, she did not think about patient involvement in healthcare decisions.

“When I was in the ER with Michel, there was not an ounce of the researcher in me,” she says. “I sat there and apologized for asking questions.”

Shortly afterward, LeBlanc mentioned the experience to Hess. He soon asked the couple to join him in developing a proposal for PCORI-funded research on decision making in ERs and, after the project was approved, to help design the decision aid.

The tool is a single printed page with tailored information for patients. Demers and LeBlanc recommended using easy-to-understand wording, bulleting topics, and limiting the amount of text.

A doctor first applies an online tool that uses test results and characteristics such as sex and age to calculate a patient’s risk of upcoming heart problems. Then, the clinician goes to a collection of decision aids and prints out the piece of paper corresponding to that risk.

At Demers’s and LeBlanc’s urging, the first thing the page says is that the patient’s test results are negative for a heart attack. An easy-to-understand diagram illustrates a patient’s risk of heart attack in the next 45 days.

The aid also lays out a patient’s choices: further testing in the ER, following up with another doctor, or having the ER physician make the decision about next steps. The research team intends for the decision aid to
help clinicians and patients discuss risk and treatment options, not to replace those conversations.

**Promising Results**

“Clinicians using our decision aid engaged patients more in the decision-making process, effectively transferring knowledge of individual risk and treatment options,” Hess says.

In the study, the research team randomly assigned 898 patients in emergency departments at six hospitals to receive either usual care or that care supplemented with the decision aid. All of the patients were considered low risk because they had tested negative for heart problems.

After their visits, all the patients filled out a survey assessing their knowledge of their own risk and treatment options. It also asked how they felt about the ER experience, such as their trust in the clinicians who treated them and satisfaction with the decisions they made.

Then, 45 days later, a research team member called each of the patients to find out whether they had gone on to experience any major heart problems, Hess’s team reported in *The BMJ*.

Largely because of conversations with Demers, LeBlanc, and other patients and caregivers, the study placed greatest emphasis on determining whether patients who used the decision aid emerged with greater understanding of risk and treatment options. “What really matters is that the patients’ information needs are met,” LeBlanc says.

In addition to learning more, those patients who used the decision aid felt more confident in their decisions, whether they stayed for further testing or went home.

And just 37 percent of patients who used the decision aid decided to stay at the hospital for further testing, compared with 52 percent of patients who received only usual care. The fewer patients choosing additional testing did not translate to more heart problems in the following days.

The choice to avoid more tests in the hospital could be a boon to emergency departments, Hess says. “The patients are not in there as long, so you can open up a treatment bed. Overcrowding and increased waiting times have been shown to decrease the quality of care.”

The clinicians, as well as the patients, learned more when the decision aid guided conversations. “The physician becomes aware of where a patient is coming from, of the nonmedical factors that affect a patient’s decision making,” Hess says. “It can provide a more meaningful interaction.” In the study, using the decision aid made the clinician-patient interaction take just an average of 1.3 minutes longer.

The next step for the project is to test the decision aid with more patients. But it may be put to use in some emergency departments before those trials are complete. The Mayo Clinic is planning to make routine use of the aid, as are at least two of the other emergency departments that participated in the study.

“What really matters here is that patients’ needs were met when they used the decision aid,” LeBlanc says. “The challenge is: how do you make it a standard of care? That’s where we are right now.”

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During National Minority Health Month each April, we highlight PCORI’s large portfolio of research addressing disparities in health and healthcare. PCORI has awarded $192 million to fund 70 research projects on addressing disparities.* One of these projects takes on colorectal cancer, for which early detection clearly saves lives: 90 percent of people whose colorectal cancer is early stage at diagnosis live for at least five years, but only 14 percent of people whose cancer has spread to other parts of the body survive that long. Screening rates differ between groups of people, with Hispanics/Latinos falling behind whites.

The US Preventive Services Task Force recommends routine screening for colorectal cancer starting at age 50. The two most common tests are a colonoscopy, repeated every 10 years if findings are normal, and a stool blood test, required once a year. People need to do one or the other, not both.

A coalition of cancer organizations has set a goal of an 80 percent screening rate by 2018. Currently, the national screening average is 66 percent, and the average among Hispanics/Latinos is only 47 percent.

We spoke with two members of a research team that is testing a method to increase screening among Hispanic Americans. Ronald E. Myers, PhD, of Thomas Jefferson University is the principal investigator of the study, and Myra Piña, MD, of the Fé Foundation of the Hispanic Chamber of Commerce of the Lehigh Valley is a member of the study’s patient and stakeholder advisory committee.

We also provided information about, and access to, both of the tests. Importantly, we also asked people which test they preferred and how likely they were to do their preferred test. That allowed us to help them develop a screening plan that they would be most likely to follow.

Myra Piña: The navigators are able to reach out to the patients and make them feel that they weren’t under pressure. They explained in such a caring way that the person came to their own decision about following the screening plan. The navigator worked hard to create a helping relationship with the patient on the phone.

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<td>Professor, Director of Division of Population Science, Thomas Jefferson University</td>
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<th>Myra D. Piña, MD</th>
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Why do Hispanics have low rates of screening? Myra Piña: Many people in the community don’t know about colorectal cancer screening. Language can be a barrier. Even though some people in the Hispanic community speak English, many of them speak what I call functional English. They can function in their field of work. But when they go to the doctor’s office, the language barrier comes in.

There’s also a fear of being screened—a fear of getting a positive or abnormal test result and not really knowing what that means. And some people lack insurance and wonder, how am I going to pay for this?

Ronald Myers: Myra and her colleagues on the patient and stakeholder advisory committee also pointed out that people are working; they’re very busy. Trying to make time to do a screening test is a challenge.

How does the program you’re testing aim to increase screening rates? Ronald Myers: We use an intervention that we describe as “decision support and navigation.” We mailed Hispanic primary care patients who have never been screened, or are not up to date, with screening information—in both English and Spanish—about the different types of colon cancer screening tests that are recommended. Then, a trained patient navigator, who speaks both Spanish and English, called each person and talked them through the options.

Myra Piña: The navigators are able to reach out to the patients and make them feel that they weren’t under pressure. They explained in such a caring way that the person came to their own decision about following the screening plan. The navigator worked hard to create a helping relationship with the patient on the phone.

How have patients and other stakeholders influenced the study? Ronald Myers: They made the content of the print materials and navigation call process much more friendly and easy to understand. For example, our committee members corrected and simplified the terminology of the Spanish translation of our brochure describing the screening tests. The committee members also helped to develop a script for the navigator to use on the phone with patients.

Myra Piña: I found it exciting that, at the committee meetings, the more we met, the more the patient members began to participate. And they also took away knowledge. One of the members of our group brought the information we developed back to his family, and the family said, “Hey, Dad! It’s time!” And the father then went and got a colonoscopy done.

Research Done Differently.
**What were your study results?**
Ronald Myers: We’re very happy about the results. When we started the project, Hispanic patients in the Lehigh Valley Health Network practices had a screening rate of about 30 percent. The 400 people in our study came from the 70 percent that hadn’t been screened. It was a randomized trial, where half of the people just got the mailed materials, and the other half got that mailing plus the decision support and patient navigation. In the first group, the screening rate six months later was 39 percent. In the decision support and navigation intervention group, the rate was 71 percent. That’s a huge difference. When we looked at 12 months after the intervention, the group with just the mailing had a screening rate of 44 percent, and it was 78 percent in the intervention group.

We’re now turning our attention to how we move that intervention into routine care, so that it can make a difference for a lot more people, not just the people in the study.

*As of publication on pcori.org April 4, 2017

**Between Clinicians and Patients, Trained Community Members May Provide a Key Link**

An older woman with dangerously high blood pressure kept missing her medical appointments. She didn’t tell her doctor that her electricity had been cut off, forcing medical issues to take a back seat to getting the lights and heat restored. But she did tell one member of her medical team, Nadirah Rogers, who explained the problem to the woman’s doctor. Rogers also introduced the patient to programs that reduced her electric bill and helped her pay rent. Subsequently, the woman’s stress level—and blood pressure—dropped.

Rogers is a community health worker (CHW), a trained layperson who serves as a link between medical professionals and patients.

“Patients don’t see me just as someone working at the doctor’s office. They see me as just like them. We share experiences and struggles,” says Rogers.

**Rapidly Evolving Role**
Rogers participates in one of several dozen PCORI-funded projects that are evaluating whether using such trained laypeople can help improve outcomes. These projects typically compare outcomes between approaches to patient care that do and do not include CHWs.

CHWs—and laypeople in the related role of patient navigators—can take on a wide range of responsibilities, including health monitoring, care coordination, and educating patients about their diseases and the health system. CHWs and patient navigators may also connect patients with community resources to facilitate care or provide social support.

The role of trained community healthcare workers is rapidly evolving. Historical reports trace their origins to Russia and China in the early 17th century. In the United States, CHWs begin appearing in the medical literature in the mid-1960s. Recent years have seen increased incentives and opportunities for including CHWs in health care.

**Maximizing Benefits of CHW Services**
PCORI has funded more than 60 projects that look at CHWs, patient navigators, and others who perform similar functions.* Many of the projects are exploring whether lay members of a healthcare team can reduce disparities in health and care by lowering barriers to patients’ receiving timely care and following their treatment plans.

Sometimes patients’ families work with lay members of a medical team. One project examines the impact of peer navigators who assist parents of newborns receiving intensive care. Among the outcomes being measured are healthcare utilization, infant immunizations, and parents’ stress, anxiety, and depression.

A recently announced study will look at whether CHWs can magnify the effects of an educational campaign targeting physicians about the use of smoking cessation medications to help smokers with serious mental illness attempt to quit. This large-scale pragmatic clinical study focuses on people with illnesses such as schizophrenia, who have a much higher rate of smoking than the rest of the population. Even when smokers with serious mental illness want to quit, they often face difficulties getting the support they need. Researchers in Massachusetts are testing
whether CHWs can work with patients and prescribers to coordinate care, allowing more smokers with serious mental illness to quit and improving their quality of life. The study will follow 1,300 participants for two years.

We will closely evaluate the results of these and other studies to determine the impact of CHWs and patient navigators on easing access to care and improving health outcomes. These studies should help us fill the gaps in current knowledge about the effectiveness of these types of workers. We hope to ultimately provide information on how CHWs can best serve in a variety of healthcare settings.

The following are highlights of two PCORI-funded studies: One compares ways CHWs can support people with chronic medical conditions. Another measures the effects of an intervention provided by CHWs to people in Appalachia who have risk factors for cardiovascular disease.

HELPING LOW-INCOME PATIENTS WITH CHRONIC CONDITIONS

Low-income patients with more than one chronic condition face many barriers to health, and a PCORI-funded project wants to know if community health workers can help. “A lot of doctors just see patients for a brief moment, and they have no clue what’s going on in their life,” says Nadirah Rogers, a CHW at Spectrum Health Services in West Philadelphia.

Rogers is a CHW in a PCORI-funded study of a program called Individualized Management for Patient-Centered Targets (IMPaCT), developed by a team at the University of Pennsylvania. “Because patients set their own goals and agenda, the intervention is flexible and patient-centered,” says project co-principal investigator Shreya Kangovi, MD.

Currently, about 1,500 low-income patients living in West/Southwest Philadelphia are receiving IMPaCT in addition to their routine primary care. The program relies on CHWs who are carefully screened before hiring for their interpersonal skills and then trained in a month-long college-accredited course. The IMPaCT team wanted to test whether the program, previously shown useful for hospitalized patients, is effective in producing outcomes important to patients living in the community.

Setting and Meeting Goals

The PCORI-funded study recruited 592 patients who have two or more of the following chronic conditions: diabetes, high blood pressure, obesity, or tobacco dependence. Patients selected a chronic disease management goal with the guidance of their primary care provider. Half of the patients were then randomly selected to receive six months of tailored IMPaCT support from a CHW to help them reach their goals.

CHWs are now helping patients create action plans for addressing factors that patients believe have affected their health, including, for example, obtaining stable housing or child care. CHWs provide hands-on support, for example by exercising with patients, facilitating communication with a doctor, assisting with filling out housing forms, or helping place a family member in rehab. To prevent a “voltage drop” at the end of the six-month program, CHWs connect patients with long-term support, including a peer group that CHWs facilitate, says Judith A. Long, MD, the study’s principal investigator.

The investigators will see whether patients in the CHW-assisted group have better patient-centered outcomes: feeling better physically, achieving better chronic disease control, improving mental health, having better quality of care, feeling more in control of their own health, and requiring fewer hospitalizations.

Shaping the Program

IMPaCT shares PCORI’s emphases on patient-centeredness and community engagement, says Long. The program began in 2010, with hundreds of interviews with patients in low-income populations with high rates of chronic illness. The interviews’ goals were to determine what made it hard for patients to stay healthy and what they felt they needed to do to achieve their health goals.

Most of those interviews were conducted by IMPaCT lay co-investigator Tamala Carter, who comes from Southwest Philadelphia, as do many of the patients...
IMPaCT aims to serve. “I interview high-risk patients and get their voices on what makes it hard to stay healthy, not just medical but all life issues, and their ideas for improving their health,” says Carter. She has conducted hundreds of interviews, many of them on people’s front porches.

Kangovi says, “Tamala helped us channel the patient voice, often not engaged very concretely. We mapped the feedback to very granular details of the design of the intervention.” The team’s analysis of Carter’s interviews identified about 30 types of barriers that patients said prevented them from achieving their health goals.

For example, a CHW was having a hard time encouraging a 70-year-old woman to stop eating certain foods. When Carter interviewed her, the woman said that as a child she had been “dirt poor.” Carter recalls, “She told me that her goal in life had been to able to buy and eat whatever she wanted.”

Rogers has several family members with chronic medical conditions and hopes to raise awareness about the role of CHWs. “We work really hard to help people to reach their health goals, to get their health on track, and to see that it’s important for them to stay healthy.”

Long says that CHWs are chosen for being empathetic and caring. “Working with them is great. They really provide a very different perspective.”

**TACKLING HEART DISEASE RISK IN POVERTY-STRICKEN APPALACHIA**

Appalachian Kentucky has a far different feel than impoverished urban areas, but the people there suffer from similar—and sometimes worse—health problems. Appalachians tend to have low incomes and high levels of cardiovascular disease.

For those reasons, Appalachian Kentucky is the setting for a PCORI-funded study testing whether community health workers can improve health outcomes for people in underserved areas. In the study, trained community health workers are helping people take action to reduce their cardiovascular risks by teaching them self-management skills.

“Just telling people to seek care for cardiovascular risk factors is ineffective,” says principal investigator Debra Moser, PhD, of the University of Kentucky. “There aren’t enough healthcare providers, and there’s little focus on preventive health care. You have to teach people to manage their own care when it comes to making lifestyle changes.”

**Recruiting within the Community**

The study enrolled more than 350 individuals who did not have a primary care provider and had two or more modifiable risk factors for cardiovascular disease, such as high blood pressure, high cholesterol, diabetes, or smoking.

Similar to the IMPaCT study, the participants were randomly placed into one of two groups. Participants in one group received standard management of risk factors in consultation with a primary care provider assigned through the study, and in the other, the same primary care management plus a patient-centered self-care intervention called HeartHealth. In that program, CHWs trained by the University of Kentucky’s Kentucky Homeplace help participants overcome barriers to staying healthy.

“We didn’t realize how many people had good health insurance coverage but still wouldn’t go to the doctor because they couldn’t afford medicine or their co-pay.”

—Ashley Gross

“Athletic Gross, a CHW and one of Moser’s co-investigators, says it helped that she knows almost everyone in the county. “The investigators especially wanted the community health workers to be people from the community who could get out and talk to people easily, which worked out perfectly for me.”

Some of her conversations while recruiting patients were eye-opening. “We didn’t realize how many people had good health insurance coverage but still wouldn’t go to the doctor because they couldn’t afford medicine or their co-pay,” Gross says. “Some of these are people I’ve known my entire life.”

**A Whole-Health Approach**

The intervention takes a “whole-health” approach to enrolled individuals by promoting self-care to reduce multiple cardiovascular risk factors at once, rather than focusing on just one, Moser explains. With a patient-centered, culturally appropriate focus, the CHWs teach groups of participants about healthy...
eating, physical activity, stress reduction, stopping smoking, and other self-care activities.

Moser’s team collects data before the CHW sessions begin, after the 12-week intervention period, and after a year. They are recording such information as patients’ health risk factors, quality of life, and adherence to CVD risk-reduction practices.

The HeartHealth program has used not only CHWs but also patients to help design the intervention and to motivate fellow patients. For example, Moser says, one of these patient champions informed her team that learning in groups would be better than one-on-one coaching, noting that in rural areas, social support is essential.

Another patient-originated idea was to use healthy competition between group members to see who could walk the farthest, lose the most weight, or eat the most healthful diet. Patient champion Jonathan Butler, for example, continually engages other patients by suggesting that they take walks with him or compete using fitness trackers to see who takes the most steps.

The relationship is reciprocal, Butler says: “I try to ask them what they’re doing for their health. If they’ve got good ideas, I do what they do.”

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For Healthier Nights and Longer Lives

Patients are always at the center of PCORI-funded projects. But their perspective was fundamental to a University of Arizona sleep apnea study now under way. “The idea itself came from a patient,” says the study’s principal investigator Sairam Parthasarathy, MD.

In a clinical session, the patient said that his life had been turned around since he started using the continuous positive airway pressure (CPAP) machine at night. He added, Parthasarathy recalls, “If there’s any patient of yours who’s not using this machine, let me have a go at him. I’ll convince him that he needs to use it.”

The Problem, and the Problems with the Solution
Obstructive sleep apnea interrupts breathing during sleep, sometime hundreds of times a night.

It doubles a person’s risk of heart attack and triples risk of stroke. A more immediate consequence for patients, who may go years without truly restorative sleep, is severe daytime sleepiness that profoundly impairs their quality of life.

The condition can almost always be successfully treated with the machine that Parthasarathy’s patient swore by, which streams air through the nose to keep breathing passages open. Yet less than half of those prescribed CPAP use it regularly.

“It’s not like taking a pill,” Parthasarathy says. Patients must get used to a mask that blows air into their nose all night long—“not the most comfortable thing.” Proper fitting and adjustment are essential, and the apparatus requires regular cleaning. Users need guidance through any difficulties that may arise.

The complexity of the treatment, Parthasarathy adds, demands a team of healthcare providers working together. The reality, all too often, is fragmented care in which the patient’s needs may fall through the cracks.

“Most people have their sleep study, then they’re shepherded to a medical equipment company where someone with too little training gives them
the machine, and out the door they go,” says Adam Amdur, chief patient officer of the American Sleep Apnea Association, a patient advocacy group, and a member of the PCORI-funded project’s stakeholder committee.

“Using a CPAP machine takes time, acclimatization. Not everyone gets it right away, and there are sometimes issues with the mask, with the air pressure—if it’s too low, you feel you’re suffocating; too high, the same thing. Call your doctor and you’ll get, at best, five minutes,” he says.

“Someone needs to hold your hand to get you used to it—especially in the first 7, 14, 30 days.” Who better than a buddy who’s been there?

The Peer-Buddy Approach
Following his earlier patient’s lead and a successful pilot study, Parthasarathy and colleagues designed a program that pairs patients newly diagnosed with sleep apnea with mentors known as “peer-buddies,” experienced CPAP users who can share their success stories, enthusiasm, and practical tips.

These peer-buddies also convey the dire risks of untreated sleep apnea. “It’s one thing to hear it from me, it’s another for a peer to lay the cards on the table,” Parthasarathy says.

In the study, which is well under way, 257 sleep apnea patients from Tucson sleep centers are randomized to participate in a peer-buddy program or receive standard care. Fifty volunteers serve as peer-buddies.

“We cherry-pick them,” Parthasarathy says. “Mentors should be nice people, who can deliver the message consistently. They need an if-I-can-do-it-you-can-too mentality. Seeing someone they can aspire to be, who’s crossed over to the other side, gives new patients confidence.”

Mentors learn the ropes in two hour-long training sessions, and they receive a manual detailing how to educate others on risks of sleep apnea and benefits of treatment.

“I see my role as cheerleader, if the person is doing everything she should,” says Nancy Callicotte, who is mentoring two patients.

“If she’s having difficulties, I’m a resource.” One of her patients needed to try a different mask and get the pressure adjusted. “We worked through that,” Callicotte says. “It was rewarding to be able to encourage her, to see how well it worked for her.”

Callicotte directs patients to seek medical advice when necessary, she says. But she also provides help others can’t. “One of my people asked me how my husband felt about my using the CPAP machine—that’s a question she might not ask her doctor or respiratory therapist.”

Within the first three months of the study, patients receive two in-person visits from their peer-buddies for hands-on help in getting the CPAP machine to work and eight follow-up phone calls. In the next three months, another eight phone calls provide additional aid, comfort, and counseling as necessary.

“It’s one thing to hear it from me, it’s another for a peer to lay the cards on the table.”
—Sairam Parthasarathy, MD

And there’s more: the researchers added an interactive voice-response system to supplement peer-buddy support and coordinate care. If patients have questions, problems, or concerns, they can directly contact their peer-buddy, as well as members of their treatment team—doctors, respiratory therapists, nurse practitioners, and medical equipment representatives—via voice mail, text, or email. This automated communication process uses cell phones (for which participants are reimbursed) to eliminate the medical office bottlenecks that frequently block patients’ access to their healthcare providers, Parthasarathy says.

One of the mentor’s first tasks is to tutor the patient through the intricacies of the voice response system.

Continual Improvement
The project, as Parthasarathy describes it, is in “continual improvement” mode, constantly considering and often implementing input from patients, healthcare providers, and others. Eight patients are among the 60-plus members of a stakeholder committee that was assembled before the project started and convenes frequently in small groups.

“Patients have made a lot of suggestions that we’ve used,” Parthasarathy says. Among them: a planner to help patients track their mentor and care-provider appointments and a list of voice-response system options and codes to contact various team members that is laminated and attached to the CPAP machine.

After six months, Parthasarathy and his colleagues will determine whether their program has made an important difference in patient satisfaction and self-confidence, CPAP machine use, and parameters, like vigilance and quality of life, that would indicate better, more restorative sleep.

Amdur certainly experienced a dramatic improvement. Before he was diagnosed, he could scarcely hold a job, and he wrecked cars repeatedly. In the five years he’s
used CPAP, he says, he’s accomplished more than in the 20 years before: “My wife has a new husband; my daughter, a new father. I get up every morning enjoying my life.”

If the peer-buddy program proves successful, the researchers hope to make it broadly available. While improving sleep apnea care is the immediate goal, such a peer-mentoring/care coordination program might also help people deal with their treatments for other chronic diseases, such as diabetes, heart failure, and HIV, Parthasarathy says.

He adds, “We’re already asking patients for ideas about how our project can gain legs and run, about where we need to spread the message.”

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## Diabetes Results That Make a Difference

Diabetes runs in my family. Three of my four grandparents had type 2 diabetes, which is where your body doesn’t use insulin properly, and your blood sugar levels get too high. I also have an uncle with type 1, where your body doesn’t make insulin at all.

I knew I had multiple risk factors for type 2 diabetes. I had gestational diabetes when I was pregnant with both my boys. My body mass index is high; I’ve tried to lose weight but haven’t been as successful as I’d like. In my early 40s, I was diagnosed with type 2 diabetes.

I knew a lot about the condition I had developed because at that time, my work was around diabetes control and prevention in North Carolina. In the past few years, my role has expanded to include heart disease. I have served as a staff liaison to the statewide Diabetes Advisory Council, a coalition of diabetes stakeholders, for many years. A couple of years ago, a researcher from the University of North Carolina told the council about a study on finger sticks they were planning. I joined the PCORI-funded study as a stakeholder who had a personal interest in the topic and could talk about the results of the study with our council to share the results statewide.

### Avoiding Finger Sticks

The results are important. Our study found that the finger sticks people like me use to check our blood sugar levels don’t help much if we have type 2 diabetes and aren’t using insulin.

Why is this important? Testing supplies are expensive, and the process is painful—you’re sticking yourself and you’re bleeding! Now we know that people like me can manage just with monitoring our A1C, a measurement your doctor orders that shows your average blood sugar levels for the past three months. For people in the study whose blood sugar seems under control according to their A1C, it appears OK to skip finger sticks.

I remind people that this isn’t the case with people who have type 1 diabetes; for them, it’s never OK to skip your finger sticks, because your body doesn’t make insulin. If you’re on insulin, you need to watch your blood sugar closely.
Innovative Treatment Options for Underserved Populations

By Annette Crisanti, PhD
Associate Professor and Research Director, Division of Community Health, University of New Mexico School of Medicine

In December 2013, a participant in a study I was conducting arrived for what would be her 11th group therapy session for her substance abuse. She looked different this time: she was wearing lipstick, and she had braids and colorful barrettes in her hair.

The woman explained that earlier in the week, she’d gone out to buy beer. But on the way, something clicked. Thanks to what she’d learned in treatment, she reversed course and instead bought a small Christmas tree for the upcoming holiday—something she hadn’t done in a long while. She said she was happy, and she added that she hadn’t been able to say that in five years.

It was a small moment, but her success story is one of many from patients who participated in a PCORI-funded study that looked at the effectiveness of peer-delivered trauma treatment. Patients were randomized to either groups led by peer support workers—individuals who have gone through recovery themselves and have received training—or groups led by clinicians with master’s degrees.

Our goal was to see whether the peer-led groups were as successful as those led by clinicians at helping participants decrease substance abuse and PTSD symptoms while improving coping skills and mental and physical health. We found that they were, which presents an exciting possibility—that peer support workers might be able to fill critical gaps in areas where healthcare professionals are in short supply.

A Population in Crisis
One area where that is the case is New Mexico. The US Department of Health and Human Services has designated all but one of New Mexico’s counties as Health Professional Shortage Areas, meaning they don’t have enough healthcare professionals for their population size.

Compounding the problem, the state’s drug overdose death rate ranks among the nation’s worst, and it has tripled since 1990 to about 25 deaths per 100,000 people. The epidemic is staggering in Rio Arriba.
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