

Kaiser Permanente Research



Kaiser Permanente Research Bank

A tool for the future of health

A dozen men and women gathered in a bright conference room in downtown Los Angeles, poring over slides with colorful pie graphs and detailed demographic tables. The slides displayed results of recent efforts to recruit participants for the new Kaiser Permanente Research Bank.

The KP Research Bank is being built to serve as a long-term research resource that involves 7 Kaiser Permanente regions, including Southern California. It is designed to provide infrastructure to conduct studies that may help scientists better understand how people's health is affected by their genes, behavior, and the environment.

The audience that night was the KP Research Bank's Southern California Community Advisory Board. Board members peppered the research team with questions and suggestions. Had researchers tried text messaging to potential recruits? Had they considered returning genetic results to participants?

A resource for the long term

Researchers will use DNA and other health information provided voluntarily by Kaiser Permanente members to study how genetic and environmental factors affect health. Ultimately, they hope their studies will provide new clues as to how to diagnose, treat, and prevent certain diseases.

"This is really an investment in the future," said Deborah Rohm Young, PhD, MBA, the Southern California site principal investigator for the KP Research Bank. "The KP Research Bank will help push the envelope with the precision medicine initiatives going on across the country."

Recruitment for the KP Research Bank is a massive endeavor. Nationwide, researchers aim to recruit 500,000 Kaiser Permanente members. Southern California's share of that target is 102,000.

The KP Research Bank has a strong emphasis on working with diverse communities. Many racial and ethnic groups have historically been understudied by medical research, leaving questions about the applicability of findings across diverse populations.

"Other institutes may have similar initiatives, but the KP Research Bank is striving to include more members from diverse race and ethnic groups," said Research Scientist Reina Haque, PhD, MPH, who is affiliated with the KP Research Bank's Access Review Committee. "That is an important factor that distinguishes the KP Research Bank from others."



Melissa Preciado, Hector Gutierrez, Rica Ann Dela Cruz

Connections with diverse communities

Recruiting participants from a broad cross section of racial and ethnic groups can be challenging, even in a diverse region like Kaiser Permanente Southern California.

Community Advisory Board members provide essential insights into how to connect with diverse communities. Most of the board members in Southern California are grassroots community leaders. There is also a national board that brings together community members from all Kaiser Permanente regions.

Melissa Preciado, MPH, is the coordinator for the Southern California board, and helps coordinate the national board. She sees enormous value in the board members' feedback.

"As researchers, we can get disconnected with what the community has to say. Our board members give us a true perspective of the people we want to reach," she said. "Ultimately, we are doing this for the community. Therefore, we should do it with sensitivity to the needs, beliefs, and perceptions of the community."

Individual members have varied reasons for joining the board. But a common thread is their optimism that the difference the KP Research Bank, and health research more generally, will make in the future.

Community Advisory Board member Hector Gutierrez, a program officer with First 5 Los Angeles, believes in the potential of research to improve health for diverse communities.

"The goal is for all communities to be healthy, right? Your ZIP code shouldn't determine your health outcomes," he said. "My hope is that we take research and use it to catalyze community health, and improve the lives of communities throughout the region and nationally."

The challenge of specimen collection

Before recruitment could begin, the project team had to build the infrastructure to support it. Collecting a massive number of specimens required new strategies and tactics.

The KP Research Bank is not the first initiative in Southern California to gather large quantities of genetic specimens. The Research Project on Genes, Environment and Health (RPGEH), was active from 2012 to 2015. The project team gathered saliva samples from nearly 36,000 members, using kits that could be sent through the mail.

The KP Research Bank, however, required fresh blood samples. That added a level of complexity. Traditional tactics, such as sending a phlebotomist into the field or asking participants to visit a research office, would have required more time and resources than the team had.

Fortunately, the RPGEH team had foreseen the need for a more scalable approach. Miki Nguyen, MPH, then the RPGEH project manager, had worked to develop special research orders in Kaiser Permanente HealthConnect, the organization's electronic health record.

"By having these orders in KP HealthConnect, a member could go to a lab at any KPSC facility to get their blood drawn," said Nguyen. "Because it was for research, they wouldn't have a copay."

It took more than 2 years for that idea to become a reality. Nguyen worked closely with the KP HealthConnect team and the KPSC Revenue Cycle team, which helped work through the logistics of suppressing the co-pay on research orders.

Next, the team had to figure out how to get the samples to the national biobank in Berkeley, California.

"We had to make sure samples from the medical center labs could get to the Regional Reference Laboratory," said Nguyen. "From there, they needed to be processed, packed, and shipped to our storage site in Berkeley."

None of that would have been possible without the support of the regional lab leadership.

"Our SCPMG Regional Reference Laboratories are committed to providing meaningful answers to important clinical questions," said Darryl Palmer-Toy, MD, PhD, physician director of SCPMG's Regional Reference Core Laboratories. "Yet, few of the over 15 million samples that pass through our Regional Reference Laboratories each year have been used to their full potential to support SCPMG's vital research mission."

"By helping to identify, intercept, and process suitable samples for the KP Research Bank, we can both answer the pressing clinical questions for which today's tests are ordered, and solve clinical research questions and develop new tests to improve Kaiser Permanente care into the future," he added.



Miki Nguyen, Louie Farnacio, Dr. David Quam

Medical center by medical center

As the efforts to recruit participants got underway, the Southern California team decided to take it one medical center at a time.

"We felt it was important to engage the local medical center administration, and get their buy-in," said Nguyen, who is now scientific program manager for the Southern California KP Research Bank team. "Given the size of our team, we can only do that one medical center at a time."

First up was the Kaiser Permanente Panorama City Medical Center. Cynthia Cifuentes, MBA, the medical center's senior director of public affairs, quickly became an ardent champion.

"The KP Research Bank is really fundamental to what we stand for and who we are," she said. "I strongly believe this is something that could change health outcomes for the future. It will create a healthier tomorrow."

Cifuentes and her team partnered with the researchers to develop a robust communication plan. Local champions were identified to encourage their colleagues to learn about the program. Posters and pop-up banners were placed at key entry points of the medical center. Project team members set up in-person recruitment locations near urgent care and at the medical center's farmers market.

After an auspicious start, the KP Research Bank moved on to Kaiser Permanente medical centers in Antelope Valley, Woodland Hills, Anaheim, and Irvine. They aim to reach all KPSC medical centers by the end of 2017.



Mitra Vasseghi, Rica Ann Dela Cruz

“The KP Research Bank is tremendous,” said Nancy Gin, MD, medical director, Kaiser Permanente Orange County. “Research helps our group remain at the forefront of medicine. This project is just one of the many ways KP models medicine for today and in the future.”

Banking the future of cancer research

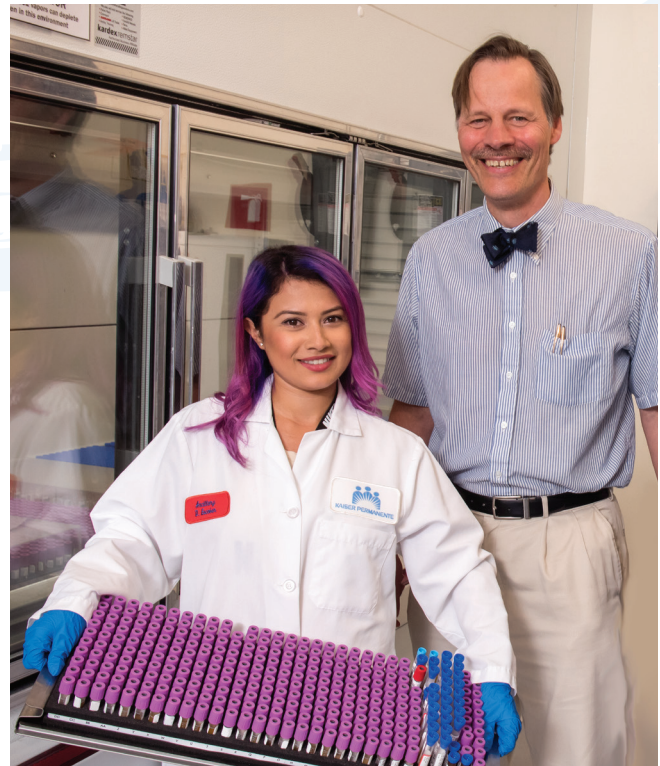
Cancer research is one of the most promising areas for the KP Research Bank. Genetic and biomarker research is critical to developing personalized medicine for cancer care.

Research Scientist Chun Chao, PhD, MS, a molecular epidemiologist, sees potential to identify genetic risk factors for short- and long-term health effects of different cancer treatments.

“Potentially, we could identify genetic markers that distinguish people who are at high risk for adverse effects of treatment, such as developing febrile neutropenia (fever and low white blood cell count),” said Dr. Chao. “We could also look at genetic predispositions for long-term effects, such as cardiomyopathy after radiation or anthracycline exposure.”

“We could also potentially help predict treatment response to different therapies,” she added. “For example, circulating tumor cells and cell-free DNA could possibly be used to predict treatment response.”

The KP Research Bank recently began recruiting people for a new cancer cohort, using rapid case ascertainment to recruit members shortly after diagnosis.



Debbie Escobar, Dr. Darryl Palmer-Toy

Research Scientist Kim Danforth, ScD, MPH, worked with the project team and natural language processing specialist Chengyi Zheng, PhD, MS, to refine an algorithm used to identify KPSC members recently diagnosed with cancer.

“They want to get it as close to the diagnosis as possible,” she said. “The goal is to identify and enroll them before treatment, so the blood samples are pre-treatment. Treatment may lead to changes in the blood, so it is important to identify markers before treatment begins.”

Community Advisory Board member Mónica Alvarado, MS, LCGC, is the manager of KPSC’s Clinical Genetics Department. She sees many gaps in knowledge about the role of genes, the environment, and behaviors in cancer and other common health conditions. The KP Research Bank has great potential to shed new light.

“I see it as planting seeds. Some will grow faster, and we’ll be able to make discoveries that we can start applying,” she said. “It’s really like planting a garden of knowledge that’s going to help us improve the health of people everywhere.”