



# UCSF Department of Medicine

## ZUCKERBERG SAN FRANCISCO GENERAL

### One Vision, Many Community Voices

*Patients and community are at the center of everything we do in the ZSFG Department of Medicine. This issue features two studies that incorporate community members who provide expert guidance to the work we do. They shape our research efforts to be more patient-centered and impactful, thereby transforming health care delivery, health and well being..*

#### ACCTiVATE Study: Health and Tech Coaching for Diabetes

Although diabetes is a chronic disease, many patients successfully manage their condition by eating a healthy diet, exercising regularly, monitoring their blood sugar level, and taking medication. Technology can also help optimize diabetes self-management, such as using continuous glucose monitors and communicating with their providers through patient portals like MyChart.

Many patients, especially those in safety net settings, could benefit from health coaching and training on how to use a continuous glucose monitor, send messages to their doctor, and refill medications online.

The Achieving Chronic Care equiTy by leVerAging the Telehealth Ecosystem (ACCTiVATE) study is a randomized controlled trial funded by the National Institutes of Health. Led by Delphine Tuot, MD, MAS, Professor of Medicine and Chief of the ZSFG Division of Nephrology, and Anjana Sharma, MD, MAS, Associate



Professor of Family and Community Medicine, this study is testing whether community health workers who provide both health coaching and digital training can help patients improve their hemoglobin A1C levels and their ability to use the patient portal.

To help guide development and implementation of the study intervention, ACCTiVATE has a community advisory board that meets regularly. Its members include representatives from the San Francisco Public Library, San Francisco Department of Public Health, San Francisco Tech Council, Mayor's Office, Information

Technology leaders at ZSFG and several patients from the San Francisco Health Network with diabetes or prediabetes.

Two of those patient representatives include Eddie Henderson and Patricia Hayashi. Both are graduates of Senior Vitality, a two-year technology training program run by the Curry



Patricia Hayashi



Senior Center, a Tenderloin nonprofit. The program provides virtual and in-person tech classes, health and nutritional coaching, and resources such as an iPad, Fitbit and digital scale. Ms.



Eddie Henderson

Hayashi developed her tech savvy through the program, now integrating these tools in her everyday life – like using Google Translate to tell her Chinese-speaking neighbor where to go for medical care. “In our senior population, there are so many people who think they can’t learn technology, or there’s a language barrier,” she said.

### Providing Expert Guidance

Both Ms. Hayashi and Mr. Henderson heard about ACCTiVATE’s community advisory board through Curry Senior Center staff members. Although they are not enrolled in the study, they shape every aspect of its design and implementation. “The advisory board helps me keep connected with the community, which is very important,” said Mr. Henderson. “Both Patricia and I have a great bird’s eye view of it from Curry Center, because we see it all through the many groups we’re involved with there.”

They provide feedback and expert guidance at advisory board meetings. For example, staff read them a draft phone script for recruiting study participants. Community representatives helped shorten the script, suggested language that was easier to understand, and recommended reordering the content to start by saying that the study had gotten permission from the patients’ doctors to contact them. They also encouraged the study team to also use text messages to recruit participants, an

approach that has proved quite fruitful. To help compensate them for their time and expertise, advisory board members receive gift cards for each meeting attended.

“The staff are so thoughtful,” said Ms. Hayashi. “They don’t look at us as just a statistic. They’re so eager and excited to get more patients. They always ask us, ‘What do you think we could do to help more people?’ It’s nice that the advisory board includes everyone from the people looking at the statistics, to the case managers who are actually working with the clients.” Some of her suggestions include enticing potential study recruits to introductory events with tasty (though healthy) snacks, allowing participants some scheduling flexibility to make enrolling in a long-term study less daunting, and brainstorming about how to publicize the study, such as tabling at health fairs.

“Having more things [like ACCTiVATE] is really important in the community, because everything’s getting cut – our rent is going up, and we’re getting our food stamps taken away from us,” said Ms. Hayashi. “People are so freaked out. We need to be more proactive about letting people know about resources for getting food, like food pantries or free meal programs.... Everyone’s time to control diabetes is different, but it’s important to show that there are successes, and it doesn’t require making your life miserable. You can make your life work with diabetes.... ACCTiVATE represents a vital shift from merely alleviating symptoms to proactively addressing root issues.”

Mr. Henderson appreciates not only sharing his perspective, but learning from other members of the community advisory board. For example, one of the Spanish-speaking community representatives said the most effective way to reach members in her community would be through family members. “Many of the people I know no longer have any connection with family, so the approach for getting people like us

involved in ACCTiVATE has to be different than in other groups, where often the entire family has to really get on board to get the most value out of it,” he said. “That was a totally different perspective that was very valuable for me to learn.”

He is grateful for the opportunity to serve on the community advisory board. “I’m thrilled to be living in the age of so many medical miracles,” said Mr. Henderson. “How can you introduce these to people in a way that will make people’s lives better and healthier? How do you get people to change, and teach old dogs new tricks? ... ACCTiVATE is meant to help people, and that’s what I love about San Francisco: we are the national leaders for helping people.”

“Members of the ACCTiVATE CAB have been key to the study’s success. Their input on study design and participant recruitment and retention, in particular, have been instrumental. We will continue to rely on their expertise as the study moves to its data interpretation and dissemination phases. I and the rest of the ACCTiVATE team are lucky to have them as co-investigators, continually learning from them and assuring that our work is grounded in reality and person-centered” said Dr. Tuot.

### California Statewide Study of People Experiencing Homelessness: Building True Partnerships

When Desiree (Dez) Martinez was 43, she spent five years on the street and in shelters, her car, and a Fresno encampment. “It was terrifying and traumatic,” she said. “Homelessness made me feel so invisible.”

After overcoming many obstacles, Ms. Martinez moved into stable housing and became a passionate advocate for improving conditions for those still unhoused. She fights for improved services, and helps others access housing. As founder and CEO of We Are Not Invisible, she leads



everything from food and clothing drives to successful advocacy efforts at City Hall to create low-barrier shelters and mobile showers.

In 2021, community members nominated her to serve on the Lived Expertise Advisory Board for the California Statewide Study of People Experiencing Homelessness (CASPEH).



Desiree Martinez

Led by Margot Kushel, MD, Professor of Medicine and Director of the UCSF Benioff Homelessness and Housing Initiative, it is the largest representative study of homelessness in the U.S. since the mid-1990s. The study team gathered thousands of survey responses and conducted hundreds of in-depth interviews with a representative sample of unhoused people from all over California.

From design to implementation, distillation, and dissemination, CASPEH was guided by members of the Lived Expertise Advisory Board. They represent a demographic and geographic diversity of perspectives, based on their personal experiences of homelessness. The advisory board met one to two times monthly throughout the study, providing expert feedback on everything from the wording of survey questions to methods for recruiting study participants and sharing results.

“What surprised me most was how deeply UCSF listened,” said Ms. Martinez. “They didn’t treat us like participants – they treated us like partners. They asked follow-up questions after hearing our perspectives. They respected the emotional weight of our lived experience.... Data without context can be harmful, but data informed by lived experience becomes very powerful. When

we pushed back on certain language that felt stigmatizing, the team didn’t just take notes. They rewrote the entire section, then asked us to review it again. Our input improved the quality of research and the willingness of people to participate.”

### Sharing Real-World Insights

One of her fellow board members was Jessica Giannola. She spent most of her childhood living with her family in vehicles, tents, and campgrounds all along the West Coast.

She eventually earned her bachelor’s degree in public health. Based on her work on the CASPEH Lived Expertise Advisory Board, Ms. Giannola applied for and was chosen to become a health coach at UCSF.



Jessica Giannola

In addition to her current job as a UCSF health coach, she has remained a vocal advocate for housing and human rights. Ms. Giannola has helped her own adult children and grandchildren gain stable housing. She also helped many members of her extended family get rehoused after they lost their homes in the 2018 Camp Fire, and worked as a disaster case manager with other families displaced by the devastating wildfire. She later ran for Chico City Council on an affordable housing platform.

When Ms. Giannola heard about the opportunity to serve on the Lived Expertise Advisory Board, she was immediately interested. “I was tired of just complaining and fighting – I wanted to make a difference,” she said. “Being part of this was exhilarating. I’ve always been willing to share my story. It helps to have participation from people like me. I have a foot in both worlds, with my own lived experience as

well as working as a professional in the field.”

The advisory board provided firsthand insights. For example, some unhoused people are labeled as refusing help if they decline to enter a shelter. “Some shelters have double- and triple-stacked bunk beds,” said Ms. Giannola. “If you have a 65-year-old who uses a walker, he can’t get up to the top bunk. Many people on the streets have disabilities after getting hurt at a job, and it snowballs until they lose their housing. When I explain that to people, they say, ‘Oh, I never thought about that.’”

Board members also helped the team develop a more trauma-informed approach to conducting research. “The survey had DV [domestic violence] questions, and I explained that many people are still with their abusive partners,” said Ms. Martinez. “For you to come to my tent and ask me in front of my abuser if I’ve been abused is not going to work. In an encampment, there’s no privacy.” Instead, she and other board members suggested writing sensitive questions on a small dry erase board, then holding it up so the respondent could respond nonverbally. Respondents were also given the option to choose an appropriate place to discuss such personal questions.

Advisory board members used their networks to connect UCSF researchers to people with lived experience in the



communities where the study took place. The LEAB worked with these local experts to help the study recruit survey participants. These local experts served as trusted messengers, helping to recruit survey participants and building trust. They explained that participating in research matters. As Ms. Martinez said, “Our street families would never talk to anybody, especially a group of people with tablets and clipboards” without having someone they trusted vouch for them.

### ‘I Am Somebody’

Members of the advisory board have also been central to interpreting and disseminating results. They present at conferences and webinars, and have co-authored publications such as a toolkit of best practices and lessons learned for building effective, respectful collaborations between organizations and people with lived experience. They have also started to see study findings become translated into practice; for example, some grants now require shelters to incorporate trauma-informed care into their programs.

Advisory board members were paid for each meeting they attended, as well as subsequent presentations and panels. “We’ve always done this work for free, because we’re so passionate,” said Ms. Giannola. “But to be told, ‘We’re going to pay you because your time and expertise is valuable, and what you have to say matters’ – that helped reshape how we looked at ourselves.” Ms. Martinez agreed. “Being respected, and being paid for our ideas and experience, made me realize what I’m worth,” she said.

The process of working together has built a lasting sense of community and catalyzed personal and professional growth. “The study was statewide, and Zoom brought together these strong advocates in one place,” said Ms. Giannola. “We saw that we weren’t alone, and the pushback we received from our local governments and

the social media attacks on unhoused folks all echoed each other. Seeing that we had so many similarities allowed us to realize that these are systemic issues, and to become a stronger force, together.”

“UCSF turned me into who I am today,” said Ms. Martinez. “The amount of compassion and empathy everybody there has is amazing. They taught me how to channel my passion – instead of going in with a bullhorn ‘I learned how to say, ‘Well, the data shows that...’ I’ve now worked on state legislation, and have been given honors from the city, county, and state. UCSF made me feel like I’m a human being, that I’m respected, that I am somebody. Everything I’ve done after them is because of them.”

“The LEAB members were the secret sauce for the success of CASPEH. They brought their brilliance and expertise to every part of the study—and continue to do so. I am so lucky to have them as collaborators, co-investigators, and now, friends” said Dr. Kushel.

-Elizabeth Chur

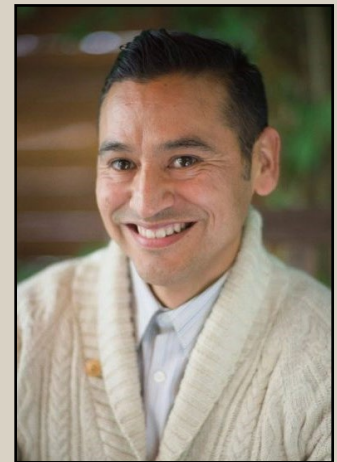
Editors: Neil Powe, Leonard Telesca, Ali Cunningham



## SPOTLIGHT

### Happy Holidays and Happy New Year

In Memoriam of our beloved colleague, Alberto Rangel, Social Worker, Ward 86



- Kevin Nolan of Pulmonary and Critical Care Medicine, was one of the recipients of the fall Spirit of DOM Staff Award
- Carolyn Hendrickson, MD, Pulmonary and Critical Care, has been appointed as the new Medical Director of Risk Management and Regulatory Affairs for ZSFG
- Marlene Martin, MD, Hospital Medicine, has been appointed as Physician Chief of Care Experience at ZSFG
- The IMPACT Scholars Program is accepting applications by January 29, 2026, for their program to help you share your findings with policymakers and influential organizations. You can apply at this link: [https://ucsf.co1.qualtrics.com/jfe/form/SV\\_3RiYB0vS3kPCvwa](https://ucsf.co1.qualtrics.com/jfe/form/SV_3RiYB0vS3kPCvwa)