



UCSF Department of Medicine ZUCKERBERG SAN FRANCISCO GENERAL

SHAPING NATIONAL POLICY

A core pillar of the ZSFG Department of Medicine's mission is to be a trusted authority in the public sphere, particularly to shape policy to promote health equity. Two of our faculty members recently led national efforts to improve the health and healthcare of patients with diabetes and kidney disease, producing landmark reports which will transform lives.

A Coordinated Response to Diabetes

Diabetes is a skyrocketing epidemic, affecting more than 34 million Americans. More than 40 percent of Americans will develop diabetes in their lifetimes, and the risk is significantly higher for people of color and those experiencing poverty.

Congress passed a bill in 2017 establishing the National Clinical Care Commission to recommend ways to prevent and reduce diabetes and its complications. It was the first federal commission to study the issue in almost 50 years, and its 23 members included government and private sector experts, including Dean Schillinger, MD, Professor of Medicine in the ZSFG Division of General Internal Medicine and co-director of the Center for Diabetes Research and Health Equity. In addition to caring for patients hit hardest by diabetes for 30 years and carrying out diabetes research, he brought expertise from leading the California Department of Public Health's Diabetes Prevention and Control Program and promoting regulation of sugar-sweetened beverages.

"My patients at San Francisco General deal with food insecurity, limited literacy, and not being able to get medications," said Dr. Schillinger. "The world of public health often doesn't get reflected in clinical care discussions, and it was a privilege to give voice to the disproportionate nature of my patients' experiences."

Dr. Schillinger made several strategic decisions. When asked to chair the commission, he declined, realizing he could advocate more effectively from the middle as a subcommittee co-chair. He also found an excellent ally in Ann Bullock, MD, director of the Indian Health Service Diabetes Program. "Since it is understood that diabetes is a social and environmental problem, not (solely) a medical problem, we teamed up on how we approached every meeting, discussion, and recommendation," he said.

He wanted to center the Commission's work around two foundational issues: health equity and federal agencies and departments which contribute to diabetes, which go far beyond biomedical factors. "Right now, health matters are adjudicated by healthcare departments like CMS [Centers for Medicare and Medicaid Services], but health is determined by transportation, education, labor and agriculture as much as the health care industry," said Dr. Schillinger. He offered to draft a framework for the Commission's deliberations which would include not only individual behavior and health care, but environmental, policy, and systemic factors.

He immediately encountered resistance. "On many occasions, people said, 'Oh no, that issue is well beyond the scope of our commission,'" said Dr. Schillinger. "But how crazy would it be to have a diabetes commission that can't talk about food?" He requested a legal consultation from the federal Office of Legislative Affairs to interpret the Commission's charter and determine whether the Commission could make recommendations to agencies beyond the CDC and CMS, such as the



Dean Schillinger MD, Division of General Internal Medicine

U.S. Department of Agriculture (USDA).

Ever the advocate, Dr. Schillinger didn't passively wait for the meeting outcome; he asked to attend the consultation. "I told (the attorney) patient stories that spoke to why agencies like the USDA and the Department of Transportation were important to our work, and I asked if the charter really intended to exclude, say, the Federal Trade Commission from regulating (sugary beverage) marketing to children," he recalled. "The lawyer said, 'It's not really clear that they're excluding those agencies, so I guess it's fine.'" He likened his participation in that meeting to being in "The Room Where It Happens," the song from the hit musical Hamilton. "You may not succeed, but if you're not in the room, you're guaranteed not to succeed," he said.

An 'All-of-Government' Approach

With the green light to pursue a comprehensive strategy, the Commission spent three years developing a report outlining an "all-of-government"



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approach to prevent and treat diabetes. The diverse panel came to consensus around 39 recommendations that crossed governmental silos and promoted coordinated interventions in areas including nutrition, housing, commerce, transportation, and the environment, in addition to healthcare. Different governmental areas can often work at cross purposes rather than rowing in the same direction.

The CDC's entire annual budget for preventing chronic diseases is \$600 million. Yet each year people spend nearly seven times that amount on sugar-sweetened beverages using Supplemental Nutrition Assistance Program (SNAP) benefits (formerly known as Food Stamps). "These are two agencies that are working in direct opposition to each other," said Dr. Schillinger. "That's screwed up! It would be better to say to (the Department of) Agriculture, 'Don't do anything about public health, but please don't make us sicker.'" The Commission's report addresses this issue.

Leveraging the ZSFG Network

Dr. Schillinger invited key informants to present the latest research on how social determinants of health intersect with diabetes. Many of these experts were UCSF faculty at ZSFG, and those who trained at UCSF. "It was extremely helpful to rely on my colleagues at the General," he said. "Being engaged in the larger network and bringing in other experts allowed me to say, 'It's not my idea. Here are three experts.' And not only did they know their material – they knew how to communicate it in meaningful ways."

Dr. Schillinger drew on his health communication expertise to make the science compelling. He presented studies conducted by Eleanor Bimla Schwarz, MD, MS, Chief of the ZSFG Division of General Internal Medicine, showing that women who breastfeed reduce their risk of developing diabetes later in life by 30 percent. "I suggested that we include a recommendation that the US Congress enact paid maternity leave legislation, because it would promote breastfeeding and prevent diabetes in women," he said.

Dr. Schillinger then described a patient with pregnancy-associated diabetes, which greatly increases the risk of developing diabetes after giving birth. "My patient was totally on board with breastfeeding to try to prevent diabetes," he told his

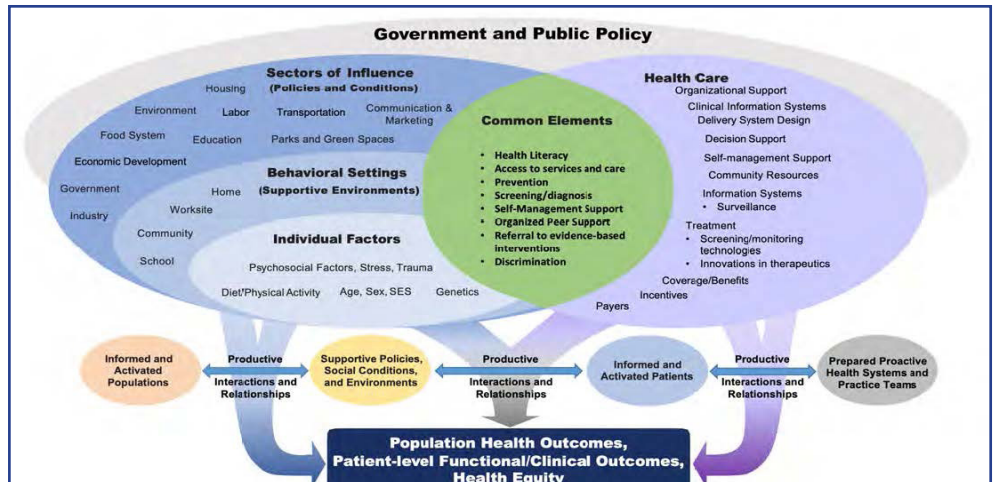


Figure from "Report to Congress on Leveraging Federal Program to Prevent and Control Diabetes and its Complications," US Department of Health and Human Services, January 2022

colleagues. "But she worked at a fast-food joint in the Mission and had to go back to work two weeks after delivery. Guess what? She stopped breastfeeding, and a few years later she developed diabetes."

After hearing that story, the other commissioners agreed to include the paid maternity leave recommendation. "These are scientists, but just sharing the science and the p-values didn't convince them," said Dr. Schillinger. "The combination of science plus storytelling swayed them."

He incorporated patient stories into the 200-page document. Government reports can be dry and abstract, and can go unread. To avoid this fate, Dr. Schillinger pushed the idea that stories and photos of people affected by diabetes be incorporated. Many were his own patients. "They were very willing to participate," he said. "They asked me, 'I could affect the government?' I said, 'Yes, you could.' I was intent on giving voice to people who don't usually have access to senators. Now they do."

Doctors are ideally positioned to change hearts and minds. "We have 100,000 patient encounters over the course of our careers, and those encounters are basically made up of stories," he said. "We ask patients, 'What's going on with you?' And they tell us their story. As public hospital doctors, we hold stories from the safety net that bring the science and patients' experiences to life in very meaningful ways. Because of that, we're in a sweet spot for changing how we all think about health

and policy."

Changing the National Conversation

After three years, the Commission's report was submitted to the Department of Health and Human Services, then to Congress, in January 2022. He also published a report summary in Health Affairs, a health policy journal.

"The only way this report will matter is if new legislation gets written by Congress and passed, or if agencies implement recommendations that they're already authorized to carry out," said Dr. Schillinger. "We're going on the road and offering to brief Senate committees. It's not just about one bill – we're trying to change the national conversation about diabetes."

When asked about what others might learn from his work, he replied: "It's a rare privilege to represent the experiences of our patients," he said. "We at the General have very important things to add to the conversation of health in America, and the skills and connections to be effective. So put your foot in the circle!"

SPOTLIGHT

February is **Black History Month**. For UCSF events and information: <https://mrc.ucsf.edu/events/black-history-month-events>.

SFGH Foundation hosted the annual the Hearts in SF virtually on February 10. **Sue Carlisle, MD, PhD**, Vice Dean of UCSF School of Medicine at ZSFG, was honored for her service to ZSFG. **Neil Powe, MD, Chief of ZSFG Department of Medicine**, was honored as a 2022 Hero.



Reconciling Race and Kidney Disease

In 2020, as the U.S. grappled with the horror of George Floyd’s murder and the racial reckoning that followed, those in health care also examined the legacy of structural racism.

One issue that sparked intense discussion was the use of race in clinical algorithms to diagnose and treat kidney disease. In July 2020, Neil R. Powe, MD, MPH, MBA, Chief of Medicine at ZSFG, and Constance B. Wofsy Distinguished Professor, was invited to co-chair the National Kidney Foundation-American Society of Nephrology Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Disease.

“Appropriately, there was a lot of activism around using race in kidney function equations,” said Dr. Powe. “In particular, young health professionals wanted to do something in response to structural racism. On the other hand, some advocacy promulgated fiction which prevented people from thinking objectively, leading to ‘solutions’ that created more problems than they fixed.” Some of those myths included that race was introduced into kidney function estimates in order to be racist, that the equations caused disparities in specialist referral and transplant waitlisting even though these disparities long preceded the equations, and that extrapolating clinical values from White patients to Black patients effectively addresses the issue.

Dr. Powe and his co-chair, Associate Professor of Medicine Cynthia Delgado, MD, a nephrologist at the San Francisco Veterans Affairs Medical Center, led the task force in a rigorous yearlong process to clarify the problem, evaluate options, and make recommendations. Their diverse membership included nephrologists, a laboratory medicine specialist, a pharmacist, patients, a scientist with experience in estimation of kidney function, and experts in health disparities, social issues, and clinical research.

“People had differing views on this issue,” said Dr. Powe. “Cynthia and I thought the best thing would be to establish a base of knowledge so everyone understood the history and progression of the science. We wanted the process to be patient-centered and evidence-based, and to discuss different perspectives. Making sure that everyone was heard

and respected helped us fashion a solution using a stepwise process.”

It’s Complex – and Important

One of the kidney’s most important functions is to filter waste products from the blood, which are disposed of through the urine. Physicians estimate kidney function to diagnose disease, decide whether to use or escalate doses of medications, trigger referral to specialists, and appraise whether a person can donate an organ or enroll in a clinical trial. Patients whose kidney dysfunction progresses to end-stage need dialysis three times a week to survive unless they receive a kidney transplant.

Although African Americans make up only 13 percent of the U.S. population, they are three times as likely to develop end-stage kidney failure as White adults – a problem which, on average, occurs five years earlier than in their White peers. African Americans are also less likely to receive a transplant or be referred to a nephrologist.

The “gold standard” for measuring how well the kidney filters the blood is labor-intensive for both patients and clinicians. To determine the measured glomerular filtration rate (GFR), medical staff inject a compound into patients who collect all their urine for up to 24 hours. This procedure is impractical for routine use in clinical practice. Almost 50 years ago, clinicians started using a simple blood test to estimate GFR by measuring the level of serum creatinine, a waste product produced by muscles. In 1999, in addition to serum creatinine, age and sex, race was included in an equation to estimate GFR (eGFR) because research demonstrated that a Black person with the same measured GFR, age and sex has a serum creatinine level greater than their White counterpart.

Some people believe that the inclusion of race was inherently or even intentionally racist and have sought to remove it. In recent years, many institutions, including Beth Israel Deaconess, Brigham and Women’s Hospital, University of Washington, UCSF Health and ZSFG removed race from laboratory reports of eGFR.



Neil R. Powe MD and Cynthia Delgado MD at ZSFG

The true story is more complex. Studies have consistently shown that African ancestry correlates with serum creatinine levels which are higher for reasons that are not yet understood. Although eGFR is an imperfect estimate of measured GFR, the introduction of race in these algorithms about 20 years ago actually sought to improve the accuracy for different patient groups by accounting for differences in creatinine.

Getting this right is important which is why, just before the Task Force started, Dr. Powe wrote an article for the Journal of the American Medical Association entitled “Black Kidney Function Matters.” Some ways of removing race run the risk of overdiagnosing kidney disease in Black persons. Overdiagnosing kidney disease can lead otherwise healthy people to believe they are sick. It also prevents patients from receiving full doses of medications that can prevent kidney disease progression such as ACE inhibitors, or other medications for pain management or cancer – or may rule out using these medications entirely. It may also prevent participation in research, exacerbating a longstanding problem for ethnic minorities. Conversely, underdiagnosis might interfere with accessing care such as nephrology care or kidney transplantation.

Evidence-Based Approach

To examine this multifaceted issue, the task force invited national experts to present on topics including the history of kidney function measure-

A Unifying Approach for GFR Estimation: Recommendations of the NKF-ASN Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Disease

Recommend immediate implementation of the *CKD-EPI creatinine equation refit without the race variable* in all laboratories in the U.S.
The equation refit excludes race in the calculation and reporting, includes diversity in its development, is immediately available to all labs in the U.S., and has acceptable performance characteristics and potential consequences that do not disproportionately affect any one group of individuals.

Recommend national efforts to facilitate increased, routine, and timely use of cystatin C, especially to confirm eGFR in clinical decision-making

Encourage and fund research on GFR estimation with new endogenous filtration markers and on interventions to eliminate racial and ethnic disparities

The Task Force gathered input from diverse stakeholders and carefully reviewed the evidence to create these recommendations

Cynthia Delgado, Mukta Baweja, Deldra C. Crews, et al. *A Unifying Approach for GFR Estimation: Recommendations of the NKF-ASN Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Disease.*
 AJKD DOI: 10.1053/j.ajkd.2021.08.003, JASN DOI: 10.1681/JASN.2021070988
 Visual Graphic by Edgar Lerma, MD, FASN



Courtesy: American Society of Nephrology

(from the equation) without understanding possible consequences”

“Really getting deep down to understand the bias, accuracy, and consequences of each approach was eye-opening,” said Dr. Delgado. “We couldn’t just focus on one aspect – it was a balancing act.”

A Thoughtful Solution

Through this meticulous process, the task force identified one approach that best addressed all the issues.

It involved adapting the current algorithm. But instead of generating a different estimate based on whether the patient was Black or not, the creators of the original equation adjusted or “refit” the equation to function for all patients, regardless of race. While prior approaches to remove race from the equation tried to sidestep the issue of race by extrapolating baseline creatinine measurements for the White population to African Americans, this new-and-improved equation was based on a participant cohort that was about 40 percent Black. This way, racial variability in serum creatinine levels was factored in on the front end of the process, rather than at the tail end.

“This was a ‘blended’ equation, which blends the data on creatinine for all racial groups,” said Dr. Powe. “It’s like making a banana-blueberry smoothie: what you put in up front matters. If you put in more blueberries, it will taste more like blueberries.” Because it’s impossible to craft an equation that perfectly estimates GFR for all populations, this blended version spreads out the imperfections across the entire population, rather than concentrating them all in the African American population.

This reflected a core value of the task force: promoting equity in kidney health. Rather than giving everyone equal resources, health equity focuses on giving each group what they need to achieve equal outcomes. By creating a “smoothie blend” in which Black patients are represented at a rate that matches their share of the national burden of kidney failure rather than their share of the general

population, it helps ensure the universal algorithm is best tailored for those who are most likely to develop kidney disease.

The task force also recommended increased use of a second biomarker called cystatin C which, in combination with creatinine, improves the accuracy of eGFR. Because it is more expensive than creatinine, it could be used selectively to confirm a low GFR in a patient with suspected kidney disease. The task force also encouraged funding of research into new eGFR biomarkers that do not vary by race, and on developing interventions to eliminate racial and ethnic disparities in kidney disease.

Dr. Powe has spent much of his career studying how social, behavioral and medical factors, including economic and food security, health behaviors and quality health care, affect kidney disease. “This new, refit equation will help reassure people that race isn’t being used in a way that is harmful to them,” he said. “I think it is unlikely to produce huge gains in some of the disparity areas because the real disparity drivers need to be addressed. But it can help build trust in the medical system.”

The biggest benefit is having a consistent national standard. “In recent years, patients might go to one hospital which used their own formula to determine that they had kidney disease, but when they went to a hospital three blocks away that used a different formula, they wouldn’t have kidney disease,” said Dr. Powe. “The danger of everybody changing their formula in their own way led to confusion and chaos. Now we have an approach that everyone can congeal around and implement.” Tremendous strides are being made to roll this out in clinical laboratories across the country, both at academic medical centers as well as at national labs like Quest and LabCorp.

“Being passionate and advocating for patients is marvelous,” said Dr. Powe. “But if we make changes without using science and evidence to guide our advocacy, it can actually harm patients. We were able to build public trust using science to ensure that measurement accuracy for Black persons was not compromised more than any other group by the abrupt changes that were being made.”

Elizabeth Chur

Editors: Neil Powe, Laurae Pearson, Brooks Bigart

ment; race, racism, genetic ancestry and creatinine; body composition and estimates of kidney function; laboratory issues with biomarkers and guidelines; and patient perspectives. The task force created statements of evidence and values summarizing their shared beliefs. “That process helped us understand our similar goals,” said Dr. Powe.

“It was really gratifying to see that whatever our area of expertise, we all felt it was important to get this right and not hurt any individuals or groups in the process,” said Dr. Delgado. “It was also important that we listen to all the voices in the room, not just the loudest ones, and stay open-minded. That’s why we made sure that every task force member organized a session, so no one member forced the thought process in a particular direction.”

The task force methodically developed a list of 26 possible approaches for calculating eGFR, rating each one against six different criteria. These included the diversity of the population used to develop each algorithm, its bias, precision, and accuracy, the feasibility and potential consequences of implementation, its level of patient-centeredness and on the consequences for general medical care or kidney disease care and enrollment in clinical research studies.

They compiled a Consumer Reports-style table with color-coded circles summarizing how each method stacked up against the criteria. “It was important to lay out every approach, whether ridiculous or feasible, and understand what the effects would be,” said Dr. Powe. “A lot of institutions hadn’t done that, and had just dropped race

