

# Increasing Access to Innovation

## ASN President Crews Outlines Path to Equity in Kidney Research

By Bridget M. Kuehn

To achieve equity in kidney care, the field of nephrology must help remove barriers to research participation and improve access to care innovations for those who are disproportionately affected by kidney diseases, said ASN President Deidra C. Crews, MD, ScM, MS, FASN, at the Kidney Innovation Conference in June.

The meeting, hosted by the Kidney Health Initiative, the Kidney Innovation Accelerator (KidneyX), and KidneyCure, brought together nephrologists, researchers, patients, industry representatives, and regulators to help advance innovation in kidney care. Crews, a professor of medicine at Johns Hopkins University School of Medicine in Baltimore, MD, and deputy director of the Johns Hopkins Center for Healthy Equity, shared her experience as a researcher focused on addressing the adverse social determinants of health that drive disparities in hypertension and kidney health.

Approximately 9 in 10 people with kidney diseases are unaware of their condition, and awareness tends to be lowest among some populations who have a high risk of poor outcomes, Crews explained during her talk. The groups that are impacted by health disparities, including kidney health disparities, are “individuals who systematically have experienced greater obstacles to their health based on things like their racial or ethnic group, their socioeconomic status, their gender identity, their physical ability status, their sexual orientation, or any other characteristic that has been historically linked to either discrimination or exclusion,” she said.

“These are the very same ones [who] tend to face barriers to accessing health-related innovations,” Crews continued. For example, they may miss out on the opportunity to participate in research or to benefit from the latest therapies due to a range of barriers.

### Breaking down barriers

Crews expressed that health disparities are both inhumane and costly. Health disparities in the United States are on track to cost the nation an estimated \$1.2 trillion annually by 2040 (1). Advanced kidney disease is a major contributor to those costs. “There is a great need for innovation, both for the health benefits [to individuals affected by health disparities] and because of cost considerations,” she explained.

She noted that the roots of those disparities often begin early in care. For example, Asian, Black, and Hispanic individuals are more likely to have delayed referrals to nephrologists. That denies individuals early identification and treatment of their condition. This behavior also cuts off these communities’ access to clinical trial participation and newer therapies, which may only be available through a nephrologist.

Groups disproportionately affected by kidney diseases may also have competing responsibilities like childcare or work schedules or physical challenges that make getting to a nephrology clinic or participating in study visits difficult, Crews noted.

Mistrust of researchers or health professionals is often cited as another barrier to research participation. However, Crews suggested reframing that discussion by recognizing that people’s experiences with health care and other institutions are a driving factor. “It is really fear of unfair treatment,” she said. “In many cases, [individuals from populations underrepresented in research] have had negative, unfair, and unjust experiences with various institutions. They may carry over that experience into research settings, which may inform their willingness even to accept an invitation to be a part of research.”

Another challenge that often stems from poor access to specialist care or to primary care for kidney diseases is a lack of access to information about research or care innovations. “These [groups that are socially marginalized] may have not received that sort of information,” she said. “It may not have been presented to them in a way [that] they can understand and interpret.”

Too often, researchers wait until late in the study development process to engage the patients who are most likely to benefit from the intervention, Crews reflected. “We should begin with [patients from populations that are socially marginalized] because they are going to be most likely to benefit because they are the ones most likely to have progression of their disease,” she said.

She described how investigators from groups that are socially marginalized are more likely to understand the concerns faced by people in their communities and be motivated and skilled in engaging those populations. However, the limited number of investigators from these groups is a real barrier. “Programs that work to support and expand the pool of these investigators are critically important,” she said.

### Early engagement is key

According to Crews, it is vital to engage people from groups that are marginalized in research early in the development of research protocols. Such engagement increases transparency in the research process. “It helps to build trust with those individuals when they’ve been invited to be part of the process,” she said. “It may lead them to feel [that] they can trust both the process and the findings of that work on the back end.” Crews took it a step further, emphasizing that it is essential to treat these individuals as true partners. “They have knowledge; they have experience that is going to help us shape the work we are doing,” she said.

It is important to engage study team members who share identities with the populations participating in the study. “That really does help to foster trust,” she said. Also key are good communication and meeting people where they are.

“It’s important to ensure we partner with various individuals to help us format the information that we are sharing in a way that people with low health literacy or limited English proficiency can actually understand,” she said. Helping patients overcome barriers to transportation, or providing flexible scheduling for study visits is also essential.

Additionally, untraditional recruitment venues such as community screenings or social media should be used to identify individuals who may not currently be receiving care for their conditions. Crews recommended providing diagnostic and educational information to prospective participants who discover through the study screening process that they have kidney diseases.

Crews also recommended outreach to community members and organizations to identify potential study participants and leveraging peer networks for recruitment. For example, Crews and her colleagues designed the Five, Plus Nuts and Beans for Kidneys trial to address real-world obstacles to healthy eating, such as poor neighborhood access to healthy food options, among Black people with early stages of chronic kidney disease (2). The researchers wanted to test whether nutritional advice on the Dietary Approaches to Stop Hypertension diet plus \$30 per week worth of potassium-rich foods would reduce albuminuria and improve participants’ blood pressure compared with a control group that received only a gift card for groceries.

Early in the trial development, Crews and her colleagues engaged with a local grocer and community-based groups for input on study design. They also established a community advisory board. In addition to working with the board while preparing the grant application and protocol development, the board recommended tactics to encourage participation such as the gift card for the control group. They also recruited participants from primary care clinics serving patients with limited incomes, provided participants with information on chronic kidney disease, and provided flexible scheduling and transportation to study visits. The study team sent frequent communications, holiday cards, and COVID-19 information with their community partners during the study, which overlapped with the pandemic.

“We had several Black or African American investigators as well as staff, which likely played a role in our ability to engender trust with our participants,” she said. As the study progressed, the researchers collected stories from participants and shared them with new study recruits, which Crews also found very helpful.

### Identifying opportunities

Crews also highlighted opportunities for developers creating innovative kidney treatments, study funders, and policymakers to help support equitable access to innovation and study participation. For instance, she suggested that developers of wearable kidneys include individuals who may work long days or juggle multiple jobs early in their development process so that the resulting devices would work under those conditions.

She also recommended that policymakers consider equity in policy design, implementation, and testing. For example, she suggested that the kidney health awareness campaigns developed under the Advancing American Kidney Health initiative ensure that they reach populations that are socially disadvantaged. Crews also proposed creating services to address social determinants of health into new payment models for kidney failure or transplant care. Finally, she urged study funders and policymakers to provide guidance on best practices for engaging groups that are socially marginalized in research and to support programs to train investigators from groups that are underrepresented in biomedical research. She noted that she benefited from participation in the Robert Wood Johnson Foundation’s Harold Amos Medical Faculty Development Program (3).

“Disparities in kidney health are profound, and examination of the root causes of disparities in kidney research participation point[s] us to different opportunities for enhancing inclusion of [groups that are socially marginalized] and integrating health equity considerations in all the aspects of research and innovation processes,” Crews encouraged. ■

### References

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