

World view



By Lisa Cooper

Rethink how we plan studies to shrink health disparities

Barber shops, churches, libraries – that’s where researchers must go to tackle inequity.

As many nations mark a year of deaths from COVID-19, all must reflect on a shaming fact: minority racial and ethnic communities have lost the most. In the United States, Black people, Pacific Islanders, Latino people and Native Americans have age-adjusted COVID-19 death rates more than twice those in white people. Black and South Asian groups have the highest death rates in the United Kingdom, as do Indigenous peoples in Brazil, and poor and Black communities in South Africa.

If researchers are to help fix disparities, they must think outside their comfortable laboratories, hospitals, clinics and offices. To make sure a project actually helps people, they must work with communities as closely as possible, as early as possible. This also builds trust with populations that have been harmed by past research.

I trained as a physician-researcher and now direct the Johns Hopkins Center for Health Equity in Baltimore, Maryland, which has just over 150 faculty and staff members and trainees. We have partnerships with 60 community groups and health centres. I co-chair the steering committee of the US National Institutes of Health (NIH) Community Engagement Alliance Against COVID-19 Health Disparities, which aims to enhance how academics and communities work together.

I see every day how insight from community engagement might have improved responses to the outbreak. I imagine testing sites set up at churches and schools at the outset, rather than as drive-throughs that require access to a car. Call centres for food assistance and other resources could have been staffed by people with appropriate language skills and cultural knowledge. People could sign up for vaccines at grocery stores and pharmacies, and wouldn't need Internet access or have to navigate complex websites.

At Mayo Clinic in Rochester, Minnesota, researchers turned to an existing partnership with African American churches to assess what parishioners needed as the pandemic ramped up, and tailored social-media and e-mail campaigns accordingly. Similar partnerships have produced webinars featuring scientists such as Kizzmekia Corbett, an African American immunologist at the NIH and one of the developers of the Moderna vaccine, with leading physicians of colour answering questions from the community.

I also see how disparities fuel distrust and misinformation. When a friend of mine got a haircut, his barber was advising people not to get the vaccine because he'd heard it was part of an experiment on how to alter DNA in Black people. Although this is false information, the barber is trusted and influential

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in that neighbourhood, so clients might believe him.

Community-engaged research means entering community spaces and describing the research process in plain language, including discussing new regulations that protect people. In Center for Health Equity community meetings, we talk about atrocities such as the Tuskegee syphilis study, which harmed African Americans from the 1930s to the 1970s by withholding effective treatment, and how this is now illegal. We ask what barriers community members experience before we consider what needs to be fixed.

One of our studies was on how Baltimore residents could eat more healthily and control high blood pressure (E. R. Miller III *et al. Am. J. Prev. Med.* 50, 87–95; 2016). We developed the programme with our community advisory board, a local grocery store, a health centre and the neighbourhood public library. In Baltimore, there is a 20-year gap in life expectancy between those who live in affluent neighbourhoods and those in poorer areas, such as areas surrounding Johns Hopkins Hospital. Heart disease is one of the largest contributors, and that is linked to diets high in salt and low in the micronutrients found in fresh food. The academics' initial idea was to compare how combinations of dietary counselling, an income supplement and a patient-education brochure affected blood pressure.

Conversations with the community revealed problems with that research plan. Just talking about the benefits of fruit and vegetables would do nothing. The shops people could reach without taking several buses sell only prepackaged foods. If only some participants received an income supplement, more would drop out. So, we worked with the grocery store to deliver food orders to the local library, and gave the supplement to all participants. We had little attrition and got promising results. Now we are working with a government programme to add support for counselling, online grocery ordering, and food delivery.

A common mistake is to approach a community with a fully planned study, leaving room only for agreement. Better study designs result when researchers engage with community members early, listen respectfully to input and share leadership. Another pitfall is failing to acknowledge past harm done by scientists and institutions, and explaining how you will avoid repeating those mistakes. Yet another is taking people's time, advice, data or other investments without giving anything back. Ask community members to support your work only if you will do the same for them.

I still have to explain over and over that what my team does is not only advocacy – it is science. Although engagement skills are underemphasized in our training, scientists and health researchers need them. Otherwise, we might do excellent work, but it won't help those who need it. It is our duty to meet the needs of communities, just as much as to report accurate data or prescribe the correct medication.

Lisa Cooper is a professor of medicine and health, behaviour and society at Johns Hopkins School of Medicine and Bloomberg School of Public Health in Baltimore, Maryland, and directs its Center for Health Equity. e-mail: lisa.cooper@jhmi.edu