

Podcast script: The Evolution of the Community Engagement Core

[Theme music]

Ashley Ahearn (AA): You're listening to Environmental Health Chat – a show from the National Institute of Environmental Health Sciences that explores the connections between our health and our world.

I'm Ashley Ahearn.

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In the early 90s Dr. Ken Olden - who was the director of NIEHS from 1991 to 2005- traveled to a part of Louisiana known as "Cancer Alley." For folks who don't know it, that phrase refers to the stretch of the Mississippi River that runs from Baton Rouge to New Orleans. It's a hot spot for industrial activity and it's also home to many communities of color.

When Dr. Olden visited the area, he spoke with community members who shared their concerns about the potential health risks they faced because of pollution from nearby industrial sites. He came to believe that government-funded science needed to be responsive to citizen concerns and that community engagement needed to be a more central part of environmental health research.

One way he did this was by making some changes within the Environmental Health Sciences Core Centers Program.

The NIEHS Core Centers program funds scientific infrastructure and equipment that are shared among researchers at a single institution. These communal resources facilitate scientific collaboration and innovation. When the program launched in the 1970s, community engagement was not a top priority. After his time in Cancer Alley though, Dr. Olden made it a requirement that all NIEHS Core Centers have a Community Engagement Core, or "C-E-C". These CECs were designed to foster partnerships between scientists and community members and make findings from environmental health research more accessible to the public, decision makers, educators, and beyond.

Now, the Community Engagement Cores have been part of the Core Center program for over 25 years! And it has no doubt inspired many scientists to do research that directly serves the public.

Dr. Kathleen Gray is one of those scientists. And like Dr. Olden, the path of her career changed when she spent time in Cancer Alley as a young scientist herself.

Kathleen Gray (KG): I was sent down there as an intern and spent a summer collecting soil and water samples to try to help communities answer their questions about exposure.

AA: In one small community five children in the same neighborhood had developed a rare brain cancer and people wanted to know if the nearby hazardous waste incinerator might be to blame. Dr. Gray had studied math and molecular biology in college, but after her time in Louisiana, she changed directions.

KG: Meeting people whose lives had been directly impacted by terrible health consequences, and who had reason to ask, 'how is the environment affecting our health and our children's health?' for me, that was just a whole new lens on the science that I had been studying in school. Really thinking about, how can this be applied, and how can we use all the tools and knowledge at our disposal to answer really meaningful, important questions for people?

AA: Dr. Gray is now an associate professor in the University of North Carolina at Chapel Hill Institute for the Environment, and she leads the Center for Public Engagement with Science.

Dr. Gray has been a part of the UNC Core Center for 22 years, where she now directs the CEC. And she's seen the way Community Engagement Cores have changed over the years. In the beginning...

KG: It was more one directional. It was actually called community outreach instead of community engagement, and it was very much sharing research results, getting information out. It was 'Let me tell you the work I'm doing.' As opposed to saying, 'Okay, here's the work we're doing. Does it answer questions? How is it responding to needs? How could we change it with your input?' Now, there are scholars who have developed – and I'm one of them, who've been supported by NIEHS over time – really developed their scholarship and contribute to national conversation to advance our unique disciplines in the space of environmental health sciences and community-engaged research.

AA: And Dr. Gray says that shift – from a one-way street to a two-way collaboration between scientists and the communities with whom they work – has made the research stronger.

In one study, Dr. Gray's colleague and director of the UNC Core Center, Dr. Melissa Troester, turned to breast cancer survivors to help guide her inquiry into how dietary factors might contribute to breast cancer. Dr. Troester and Dr. Gray were using mice for this research, and they shared their plan with the breast cancer survivors.

KG: And just by asking questions and saying, 'Well, why are you feeding [the mice] that? Why are you feeding that amount? And we want to better understand what you're doing.' The breast cancer survivors said, 'Well, what if you used a different amount?' We understand why you have this very high-fat diet and then you have a very low-fat diet, but what about something more in the middle?

AA: Traditionally, doses in lab settings can be on the extreme high or low side of the spectrum, but the community partners wanted Dr. Gray and Dr. Troester to create a research scenario where the fat in the mouse diet more closely mirrored what the average human consumes.

KG: And so some of our variables were changed as a result of that conversation. And some of our most interesting insights came out the new intervention or dosage that we implemented based on their input. So the participants, the community supporters, influenced research design, and my colleagues who were in the lab doing the research actually saw some really interesting results because of suggestions made by community partners.

AA: There are more than 20 NIEHS Core Centers around the country and – as you might imagine – each one focuses on different issues and serves different demographics, but the program was designed to encourage collaborations among centers. And that, Dr. Gray says, has been one of her favorite things about being a part of this national network.

She remembers when fracking for natural gas was first picking up in the eastern part of the U.S. A researcher from the CEC at the University of Rochester Core Center in New York reached out to Dr. Gray as well as other researchers from centers at the University of Pennsylvania and the University of Cincinnati – all of which are located in regions where fracking was on the rise.

KG: And we all work with different types of community-based organizations, but they were all concerned about the community impacts of fracking, so we did an interview project where we interviewed residents

of communities where this development was happening, and also community leaders. And because we were in different places and had different demographics in our communities, that meant we had a diverse cross-section of people who were talking about both the benefits they saw to their community of this development, and also the public health concerns they had that might accompany that development.

AA: By looking at communities across four states, Dr. Gray and the other CEC collaborators were able to identify common issues and take that information back to the broader research community and say, “here is what people on the ground are curious about and need answers to – let’s get to work”.

KG: And that project would have been interesting to do in one place, but by doing it in collaboration with three other centers, we got to a level of richness of detail, examples, depth of information, so that we really could come back and actually write a paper with researchers where we said, hey, this is a research agenda, an [environmental health research agenda](#), that is informed by input from the impacted communities.

AA: Community Engagement Cores have different areas of research that are informed and shaped by community organizations in their region. For example, Dr. Gray’s CEC in North Carolina has partnered with local public health departments and water quality nonprofits to test well water for contamination. They’ve collaborated with housing-focused nonprofits to bring an environmental health perspective to issues surrounding that work. They’ve partnered with schools to help incorporate cutting edge environmental science into lesson plans... the list goes on.

KG: All of that fits under Community Engagement Cores, and they can each be very different. It's not cookie cutter. And that is actually what I love about being part of a Community Engagement Core. We are required to respond to the issues in our state or in our community, and we are required to be relevant locally.

AA: Dr. Gray says another key part of being relevant and responsive to community collaborators is sharing results in a timely and easily accessible fashion.

KG: You cannot do research in a community and not share the results, and it can be complicated. I think this is one of the big challenges for me, and I hear it from colleagues, is the difference in expectations around timeliness of data. So, in academia, we collect the data, we analyze it, we do quality control and clean it up, and some people even hold on to it until they get that publication.

AA: Alas, the peer review process does not move at the speed of real life. Dr. Gray says when people share their personal data with you, as a scientist, it is your obligation to show them your results as soon as possible, even if the overarching conclusions are not black and white or may even be a bit scary.

KG: I think that's another place where NIEHS has really moved the needle, and we've seen great change, And so I feel like these days when people say to me, ‘Oh, that's too complicated, people aren't going to understand it. We're going to scare them.’ We actually have publications and studies where we can say, ‘Yes, we did think that was the case.’ But now we know, for instance, that even if it's a little scary, people would rather have their data than not have it. People would rather have you explain what we know and say there are limits to what we know, than get nothing.

AA: Dr. Gray hopes that community-engaged research only continues to grow in popularity, and she has some advice for scientists who want to embrace it.

KG: I think to work with communities, you have to be at a point where you can collaborate actively and allow space for other people's interests and priorities to shape the work, and if you're there, then you can build trust. And you build trust by being present, going to meetings, showing up, responding when people ask for information, providing it.

AA: Meet at a local diner, or [coffee house](#), show up at public meetings and gathering places. Make yourself available and known in the community, and be as flexible as you can, she says.

So many early career researchers aren't being trained in community-engaged research, but that doesn't mean there is not ample expertise around you at your institution – you just have to find them.

KG: There are always – even though it's a small group, it's a vibrant group – who's willing to mentor and connect you. So, look for those people in your schools of public health, in your schools of education, in your departments of public policy, and any number of other departments. They're there and you can ask them to help you develop a plan or create an on-ramp into community-engaged work.

AA: For Dr. Gray, her work still inspires her every day. She said she could be thinking about retirement after more than 20 years at UNC – but she's not.

KG: What I am thinking about, though, because I am farther along in my career, is – Have I done enough to create on-ramps for other people into this space? Am I doing enough with my current colleagues, or the people who report to me who are interested in this work, to create space for them and help them develop skills and opportunities? So that we can keep doing what we're doing, and so we can continue this process. And I give NIEHS a lot of credit for stimulating the development of community-engaged research. I want to see that continue whenever I get to the point where I am thinking about retirement, I want to walk away and look back and go, I'm so excited about those people who are coming behind me – and I do feel that way right now. And so that is a focus of mine, more so now than it was even five years ago. How am I helping cultivate the next generation?

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AA: I'm Ashley Ahearn. Thanks for listening to Environmental Health Chat.