

Mayo Clinic Q&A - Community engagement in research CAPTION F...

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SPEAKERS


Eula Dean, DeeDee Stiepan, Narrator, Dr. Chyke Doubeni

N Narrator 00:01
Coming up on Mayo Clinic Q&A,

D Dr. Chyke Doubeni 00:04
Community engagement is an ongoing process. And it's an evolving process of the multi directional partnership or collaborations amongst organizational entities and members of the community, and the sole purpose of this is to solve problems and address priorities that a community sees as being priorities for them.

N Narrator 00:23
Mayo Clinic is committed to being a proactive partner of diverse and underserved populations and engaging these communities in research is an important part of addressing health disparities.

E Eula Dean 00:34
Having the support of Mayo and our community has really helped us to see that there is something we all have in common. We want to do better, and I think that this partnership, for me it just started with the beginning of a learning process for our communities. And I was so appreciative of the experts who allowed themselves to just immerse themselves into the community.



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DeeDee Stiepan 00:59

Welcome, everyone to Mayo Clinic Q&A, I'm DeeDee Stiepan sitting in for Dr. Halena Gazelka. The work of raising up community voices and including community engagement and research is important to addressing healthcare disparities. One initiative from the National Institutes of Health has been the CEAL program, which stands for Community Engagement Alliance Against COVID-19 disparities. Joining us to discuss community engagement research are Dr. Chyke Doubeni and Eula Dean. Dr. Doubeni is the director of Mayo Clinic's Center for Health Equity and Community Engagement Research. And Miss Dean leads the Mayo Clinic Arizona CEAL Consortium. So, welcome both of you to the program. Thank you so much for joining us.

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Dr. Chyke Doubeni 01:00

Thank you for having us.

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DeeDee Stiepan 01:00

Of course. So, Dr. Doubeni, we'll start with you. Can you explain the concept of community engagement in research? What is health equity, and why is it so important?

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Dr. Chyke Doubeni 01:55

Really, thank you so much for having the two of us on this show, it's really important for us to speak about these issues. You know, so community engagement is an ongoing process. And it's an evolving process of multi directional partnership or collaborations amongst organizational entities and members of the community. And the sole purpose of this is to solve problems and address priorities that a community sees as being priorities for them. I want to go one step further. So, explain a little bit about community engagement, because it's based on principles that practitioners in the field have identified as important. So, the core of community engagement. And these are in no particular order. Understanding the community well before you engage, making sure that the community maintains ownership and control of the change that you intend to or try to make, and have a shared goal or vision. Because imagine going into a place and not having a shared vision for the community, they don't really need what you're trying to offer, and that doesn't go well. And making sure a partnership or partnerships are established with community or community members before you embark on any change or process, you're trying to make with the community, and mobilize community assets. You think about community as having means but many communities if not all of them have assets that should be drawn on to address the issues that the community identifies as being important. Another is being flexible and adaptable. And the second to last is committing to a long-term partnership because these issues that we seek to address oftentimes require a long-term partnership in working together. And then last and what we've introduced recently to this mix is being trustworthy. And this is for the perspective of the community. So, you also asked about health equity, and health equity is really central to this. And the National Academy of Medicine Perspectives wrote something that I want to read because it's important in their own words, "That is only with community engagement it is possible to achieve and accelerate progress towards the goal of health equity through transformed systems of health". I do so because it's important to see the link between community engagement and health equity, and that's really important. So, let me also then share with you what CDC and many people define health equity

in many different ways. And it's not, there's no single way to word it, but health equity is achieved when every person has the opportunity, right, to attain his or her highest or full health potential, and no one is left behind because of social disadvantage. And what is really central to this is this. It has the concept of fairness and justice built within it. And what we measure in research and in healthcare, is what we'll call health disparities, which has manifestations of health inequities. And these health disparities such as, you know, black people, in proportion to their population, size of the population have higher numbers of people dying from heart attack or cancer. And I say, you know as this country's experience, you know, a lot of bad racism also built into these health inequities and disparities.

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DeeDee Stiepan 05:24

Absolutely. Eula, tell us a little bit about your background and your role in community research with Mayo Clinic, and why health equity is important to you.

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Eula Dean 05:34

Well, let me begin by saying that I grew up in the rural south, in a very large family, on our plantation. Very few in my generation are still around that actually have this background. But I really saw this growing up in poverty and began to feel the sense of inequity in health care when one of my little nephews had a seizure, and my father rushed into the hospital. And even though we had a health card for him because his mother worked in New York and had a BlueCross BlueShield health card, he was denied health care because they didn't believe it was real. And only after my father was forced to pay almost all the money he had in his wallet did they take care of my nephew. So, that was really, and I was a very young girl at that time, the beginning of my really big feeling that something about it wasn't real. So, as I developed as an educator, I felt the need to share whatever I knew in my community. I felt the need to be out sharing a word of honesty and truth. So, I became a teacher for that reason. And so, my association with Mayo and with the CEAL group has really manifested in my desire to want to be a part of helping my community with awareness. And I think I was just really blessed when I received the call, I can tell you, I wish I had known to raise my hand and say, I want to be a part of that. But then I was asked to be a part of it because I have really been a force in the community by trying to make sure that our community has a level of awareness. And so, that's where I would say my place began. And that's where my place continues to manifest itself.

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DeeDee Stiepan 07:40

That's wonderful. Thanks so much for sharing that. For both of you, why has it been important for communities and researchers to work hand in hand during the COVID pandemic? And are there any specific examples that you could give?

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Dr. Chyke Doubeni 07:57

You want me to start? Okay.

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DeeDee Stiepan 07:59

Go for it.

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Dr. Chyke Doubeni 08:00

You know, from the first descriptions we provide it is clear that being in partnership is truly important. And that partnership has to be genuine, it needs to respect each other, and it allows us and a key part of this is that it allows you when you are working together to focus on the priorities that matter to the community. We often think we know what people need, right? I can tell you from my many, many years, if not decades of experience, we're often wrong. And community members are very knowledgeable. So, that partnership and co-creation and co-align, and I want to try to state this as clearly as I can, allows us to create things that are attentive and aligned to the cultural preferences and needs of the community, and are likely to be used by the community because it's from the community. So, that to me was really important, but I'd love to hear what Eula is thinking. Thanks. I think the thing that first comes to mind for me is part of our differences. You know, we look alike because we have similar skin color, depending on our neighborhood. But we're different. We wash up differently. We have different habits. We have different traditions. And I think one of the things that in the midst of this pandemic it has forced us to recognize what we want to be, ways we want to be alike, but it has forced us to recognize our differences in the manner in which we do things, and it's forced us to recognize our traditions, but at the same time there was one commonality. And working with the CEAL group and having the support of Mayo in our community has really helped us to see that there is something we all have in common. We want to do better. We want to learn, we may want to learn it at a different pace, we may want different techniques in the way it's offered to us, but we want to make our own choices. But none of us have denied ourselves actual opportunity to learn. And I think that this partnership has, for me, it just started with the beginning of a learning process for our communities. And I was so appreciative of the experts who allowed themselves to just immerse themselves into the community and teach at all of the various levels.

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DeeDee Stiepan 10:39

So, let's talk a little bit more about the NIH CEAL program. Can you kind of describe what it is and the work that each of you did as a part of CEAL?

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Dr. Chyke Doubeni 10:48

So, CEAL is, I can start that. CEAL was created as a direct response to gaps that the federal government saw as we were all responding to the pandemic. And it is created in part to try to help more people from backgrounds of color, African American people, Hispanic, Latino, Native American people who are seeing a disproportionate share of the pandemic's impact, to participate in the clinical trials and vaccines. And as one of those participants, you wouldn't know that from my voice. And so, it was created to make sure that we made these clinical studies accessible and open to them. And the other important thing that I talked about earlier that is under CEAL is trust. You know, during the pandemic there was a lot of issues around mistrust, misinformation, hesitancy is still around, it hasn't gone away. And so, NIH realized that it's important to create solutions locally. So, we were assembled as a statewide consortium

across Arizona to come together to create this solution. So, I'll give an example. Actually, Dr. Dean was the one who told me that one of the ways we can think about this, is you know, when we had polio, and they got polio vaccine, right? And they came back and celebrated it. And guess what, now Polio is eradicated. So, vaccines work, and we just have to be able to find people who people trust. So, we used the CEAL initiative to create trusted messages where we all say, okay, these are the challenges, how do we do it. And the partners around the table do that. And I can also tell you, as CEAL has been a leader nationally in being able to identify some other priorities, and we take those national, because 21 states including Puerto Rico and D.C., Washington, D.C., that are part of the CEAL Consortium. So, it's basically a community alliance that creates trusted messages, deliver those messages using trusted members of their community. It usually means that a community identified has been effective, and work with the community as vehicles of those transmissions, and making sure that what we're doing and seeing made sense to the community, because it will tell us that without any workforce issues that build a big issue for us, mental health we just did a webinar on it. Dr. Dean, I'd love to hear your thoughts about it.

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DeeDee Stiepan 11:08

Yes, absolutely.

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Eula Dean 11:36

Well, I think that one of the things that helped was we started to identify individuals in the community who had the respect, who already worked in community, whether they were located in our churches, whether they have positions of power in terms of their work, in terms of the workforce, but I thought that was very helpful. And it opened some doors for us to really be able to walk into our community and say, look you know me, you've heard from me before. And almost all of us have experienced some form of rejection in healthcare in terms of not having been treated or some form of disrespect. So, we had to honor and listen to those concerns, and then say, but here's who we are. Here's the healthcare system. Here's what we offer. And, you know, I go back to the very first webinar that we did, and we really placed ourselves in a very humble position of saying, we want you to know what's happening with COVID-19. And so, we're bringing this information to you. And we allowed them to ask their questions. And I think it made a difference. We wish that every step of the way could have been 100% perfect. And we understand that we still have struggles. But I believe that the manner in which we started with a humble heart to say, this is what I've learned, here's my expertise. I love my family. I want my family to be healthy. I think those were the things that made a difference for us to be able to offer this information.

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DeeDee Stiepan 15:46

Absolutely. For each of you, what do you hope to achieve through the work that you're doing in community engaged research?

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Eula Dean 15:56

I'm going to start with that because I think that one of the areas that we've had our greatest

I'm going to start with that, because I think that one of the areas that we've had our greatest fear is being willing to step up and say, okay, I will sign my name on the paper. And I'm willing for my body to be used. And I'm willing to participate in this study. That's been very difficult for many of our communities because of history. And so, what was important, and what I think is happening is Mayo didn't force it on us. Mayo and the health care system in our community, because of years of partnership of health care systems, has taken it slowly, and is gingerly inviting us to the table. And I think that that has been very helpful. So, I see progress. And I see even in my own, whether I'm knowledgeable or not has nothing to do with it. If you look back at your history and you say, but I know how you treated me, I know what my family has experienced. But I think that many of us have overcome, because we had a consistent return on our investment, meaning that you are listening to us. And so, that's what we hear, and now we're more open to allowing ourselves to be participants.

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Dr. Chyke Doubeni 17:22

And to build on that, just a lot of that, and keep it brief is at the core of it. And as Dr. Dean stated, what we want to do as researchers is to be able to build trust, lasting trust, and be trustworthy so that people can believe in science and can believe in and trust health care that they need to get. And also get an opportunity to get that health care in a way that aligns with your needs. But there's also an important thing that we've learned through our communities during this process. And that through community engagement and partnerships we are better positioned to work together to address the kinds of mundane things, the unexpected pandemics, and other things that life will throw at us as a people. And through those partnerships we can work together as a group to address them. So, community engagement and engaged research can allow us to be stronger for when the next crisis may come along. So, for me that's one of the most important things that are taken away from this. And I can tell you, I've learned a lot from Dr. Dean. She has only missed one meeting, you said, and that was because she could not afford it. She has been to all of our meetings. She's been very honest with us and sharing with us and telling us we needed to hear her. Trying to right us when she thought we were going the wrong direction. That's what we need from our communities. We don't need communities to agree with us, but to guide us. And we've been very fortunate to be working with lots of really great people in the community who really believed in this partnership. And I think that puts us in a better place for the next crisis if it comes.

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DeeDee Stiepan 19:13

Well said. Well, thank you both for the amazing work that you've done. Our thanks to Dr. Chyke Doubeni and Eula Dean for being here today to discuss community engagement in research and its role in addressing health disparities. Thank you both.

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Narrator 19:27

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