

# Improving Representation of Diversity in Clinical Trials Through Academia and Community Collaboration

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While the FDA, industry sponsors, academia, and others have taken important steps to address the challenges of clinical trial diversity, progress has been limited. Overcoming barriers to recruiting, enrolling, and retaining underrepresented groups in clinical research requires deliberate, concerted, and sustained actions. Patient and community engagement, partnerships, and collaborations can play crucial roles in overcoming barriers to clinical trials. The goal of this session is to create a safe space for courageous conversations where academic researchers can share their experience building meaningful community collaborations to deepen relationships, build trust, gain an understanding of community priorities, and make research programs more responsive to the needs, values, and perspectives of the affected populations.

## Featured Speakers



Moderator

**Edith Mitchell,**  
MD, MACP, F CPP, FRCS

Sidney Kimmel Cancer Center at  
Thomas Jefferson University



**Ruben Mesa, MD**

Executive Director, Mays Cancer  
Center, UT Health San Antonio MD  
Anderson Cancer Center



**Carolyn Fang, PhD**

Professor, Cancer Prevention &  
Control, AD, Population Science,  
Fox Chase Cancer Center



**Matthew Kulke, MD**

Co-Director of the Boston University  
- Boston Medical Center Cancer  
Center

## Key Themes in Experiences

### Education, initiatives, and challenges

- "[Patients] rolled into the emergency department with GI bleeding or breast mass...but they had a lack of access they couldn't get off of work or they were afraid if they came in they get reported to immigration." – Dr. Ruben Mesa
- "You could translate something word by word and then end up with a document on the other end that is nonsensical."  
Translate it in a way that people can understand what we're really trying to get across." – Dr. Ruben Mesa
- "We have learned many important lessons as it relates to culture in our area. It's very family-based there... it is critical that [the family] be included in decisions around treatment as well as most certainly any clinical trial." – Dr. Ruben Mesa
- "The first time [patients] hear about a clinical trial should not be when they're in the clinic...The Community Ambassador Program...is trying to take that first step by training members of the community. They undergo a seven-week training program in which they learn about clinical trial information: what the process is, what all the steps are, what are the key elements and components involved in clinical trials. Then they go out with this information and reach others in their own communities to explain clinical trials to describe clinical trials. It's all directed towards demystifying the process so that people understand what it is that is involved in a clinical trial." – Dr. Carolyn Fang
- "Boston Medical Center has a wealth of experience in dealing with underrepresented groups. There are huge resources, translators, patient navigators, social workers, food support, and strong connections with community health centers. Our biggest intervention over the past few years has been trying to change that mindset to really make clear that clinical trials, especially in the cancer realm, are not only part of regular clinical care but are many cases, the best clinical care for the patient." – Dr. Matthew Kulke

**"Over the last two years, certainly, Covid-19 has made a great change in how we practice medicine, and for many patients with Covid-19 also having cancer. And we recognize from the news media and others that more underrepresented minority patients have disproportionately suffered from both Covid as well as cancer."**

– Dr. Edith Mitchell

## Covid and cancer

- "Minority patients or those with challenges in terms of economic resources or social determinants of health would not be able to participate in telemedicine because of a lack of access to devices or other pieces. Now we've tried to overcome that, with bilingual individuals being able to provide tech support." – Dr. Ruben Mesa
- "Sometimes we're really trying to engage older patients, their children. I think many of us would relate that we've seen that the [technology] issues have sometimes been as much related to issues of age and comfort level than others. I do think the ability to do some of this by phone has expanded greatly. We clearly see access to high-quality Wi-Fi or internet signal is a factor in this equation. Access to cameras and laptops and such a clear barrier, the phone has helped." – Dr. Ruben Mesa
- "Covid, in many ways, has been a huge wake-up call. And over time, those clinical trials have become more available universally, they become more accessible. The programs [at Boston Medical Center] that are going out to the communities establishing those relationships are making clinical trials available. So we are in a much better position now. And I think we're starting to see that some of those lessons we learned from covid will now translate into the cancer sphere. Cancer is also a fatal disease and desperately needs clinical trials." – Dr. Matthew Kulke
- "Prior to covid, we had large events where we could gather 100-200 people together in a room to do our educational interventions and do navigation but obviously, that had to stop during covid...so I do feel that there will be significant consequences. We are still out there doing our community screening events but it's on a much smaller scale so it's much more laborious to reach a large number of people. We're doing one-on-one versus 100 people at a time. And I think that that will have a negative impact in the long run." – Dr. Carolyn Fang

## On inclusion and exclusion criteria that some sometimes inadvertently eliminates those patients that need to participate in clinical trials

- "Over the past several years, one of the most exciting things to witness scientifically is the amazing responses and impact on patients [from treatments that have been developed because of clinical trials]. Those clinical trials were not always easily available to everyone who lives in this country. It's exciting to see the focus on this. And I think I would just urge everyone, it doesn't have to be perfect, to take some small steps. In our experience, just some of those small steps results in doubling of clinical trial enrollment." – Dr. Matthew Kulke
- "It is critical science that our trials represent the population of individuals that may be receiving the therapy. You know, we've evolved from the old days when we gave a drug to everyone with lung cancer...there's a group that was highly likely to respond, and there was a majority that we're not likely to respond at all. So it's not easy, but it is important, and the benefits, really can help all of society, because the lessons we learn from subgroups of people will lead us to further discoveries that impact others." – Dr. Ruben Mesa
- "I want the people in the community to feel empowered to be a part of this dialogue; that they are a part of the clinical trial conversation, they can have a voice in how clinical trials are shaped and developed. We are eager to hear everybody's opinions. We want everybody to have input. We don't want to be the one saying this is how it should be done, but we want to hear how people want these things to be done and how can we best overcome some of these challenges. We should work together, and it should be a partnership with equal voices and equal input and equal ownership and I think that that's really where we're going to go." – Dr. Carolyn Fang

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