Francesca Montalto: Welcome to Sabin Vaccine Institute’s Community Conversations on Vaccines, presented by immunization advocates.

Vince Blaser: In this podcast, we speak with professionals closest to vaccine delivery and decision-making in low and middle-income countries to hear the latest in immunization challenges and explore programs and tools to build and maintain community trust and vaccine equity.

Francesca: We’re your hosts. I’m Francesca Montalto.

Vince: I’m Vince Blaser.

Francesca: Welcome to the second episode of our fourth season of the podcast. Like the first episode, we are here in New York City recording on the sidelines of the United Nations General Assembly, and we’re really excited again to be recording in person. We have two wonderful guests with us here today.

Vince: Yes, thanks, Francesca. It’s great, as we said in our last episode, to be able to be in person with a lot of the people that we have worked with in our Vaccine Acceptance and Demand program at Sabin and dive into the issue of vaccine acceptance and demand research. We heard a lot about elements of that during the sessions this week. We’re thrilled to have Dr. Anant Bhan with us today Dr. Anant Bhan. He is a principal investigator, researcher, mentor for Sangath based in Bhopal, India. Anant, welcome to the show.

Dr. Anant Bhan: Thank you. Pleasure to be here.

Vince: With us, our own Dr. Kate Hopkins, director of research for Sabin’s Vaccine Acceptance and Demand program. Kate, welcome.

Dr. Kate Hopkins: Thanks so much.

Francesca: One of the things we did in our last episode is we asked Esther and Rashid to really reflect on the week. We’ve been in many, many meetings throughout the week. There’s been a lot of information to take in, a lot of insight. We’d love to know your top two or three impressions and takeaways, especially as it relates to working in advancing research on vaccine acceptance and demand in low and middle-income countries.

Dr. Kate: Sure. It’s definitely been an exciting week thus far. I would say my top three themes that I’ve heard repeatedly this week is an emphasis on multi-sectoral and multi-disciplinary collaboration. You can't save the world alone and it needs to be
very much a collaborative effort. The second one being, and I’ve heard this multiple times, whether in sessions about primary healthcare systems or vaccine manufacturing, that co-design or community involvement or locally-led approaches, however you want to say it, are key to sustainable solutions.

Then I think the third point would be, there’s plenty of evidence showing that vaccine confidence is a key driver of vaccine acceptance, and we’ve heard that there’s no vaccine confidence without vaccine equity.

**Francesca:** Yes, I’ve heard that this week and it’s just so impactful and it’s so important to remember that. Anant, I’m sure you can agree with these takeaways. Do you have anything to add?

**Dr. Anant:** Yes. It’s my first time at the UN General Assembly and it’s certainly been a very interesting experience. One of the things which I’ve observed is that it’s great to see that lived experience has been given a lot of focus, the fact that we had so many community health workers, frontline professionals, medical doctors, nurses, midwives actively involved and showcased as a part of a lot of these events. They have really been major contributors to our response to the pandemic, and they actually have the insights from the ground, which are important for all policymakers, and especially discussions at global fora like the UNGA to listen into.

It’s also key that as policymakers think about primary healthcare, they think about what can be changed, what needs to be changed, and how that change can happen. I think that’s where, again, these conversations become crucial. It’s really nice to see a lot of ministers and policymakers from Africa, because without them, of course, any change cannot happen. I would’ve wished that there was more representation from Latin America, from the Pacific, from South Asia.

The ministers, very interestingly, seem to have a good nuance to understanding of the topics, but what will be good to see is how we take that in terms of the talk, then being translated to action and implementation on the ground, and perhaps giving them the right takeaways from meetings like this so that they can implement, that would be really crucial.

It’s an interesting time in global health. There’s a lot of talk around decolonization, specifically, and I think in discussions like this, we really need to then demonstrate how decolonization can happen, by making sure that we have adequate representation in the rooms wherever we talk about reform, and hopefully, that is a process that will continue to happen.

**Vince:** Anant, you mentioned decolonization there, but also the lived experience. I know that that is central to the type of research that you and your team work on, and especially in the areas of vaccine acceptance and demand. Maybe just tell us a little bit about why you and your team decided to get involved in this type of research in the first place and what’s some of the top findings?
Dr. Anant: Sure. For those of our listeners who might not know Sangath, Sangath is a 26-year-old organization. We started in a state called Goa in Western India, but now we are present nationally in multiple sites in India. I am based out of the Bhopal hub, which is in Central India, and we've been working with the health system locally for the past 10, 11 years. One of our key areas of work certainly has been community health workers and working with them and trying to respond to needs. There's been a lot of work we've done on mental health and well-being, but we've also realized that we need to look at the larger picture from a health system's perspective.

Over the last couple of years, we've been very interested in looking at this whole issue on marginalization, health equity, and access, and this actually draws from the lived experiences, again, and work of colleagues and collaborators on our team. For example, we have Dr. Aqsa Shaikh, who's a trans woman, but also a public health specialist. We have Dr. Satendra Singh, who is a physiologist by training, but is also a disability rights activist in India. We have done past research, which has been led by people like Dr. Harikeerthan on the team as well as my own involvement and the involvement of some other members of the team on health equity.

As we were reflecting on the early experiences in the pandemic, one of the areas we thought was important to catalog was how marginalized populations were experiencing the pandemic, what were the intersections of them trying to access health services, and the need to actually ensure that we capture all of that. That's how we got started on the initiative, which is located at Sangath Bhopal. It's called the Initiative for Health Equity Advocacy and Research.

We started first with the project which looked at the experiences of transgender persons broadly during the pandemic, but then we thought, as vaccines started coming in, that's another area which we need to capture. Fortunately, we were made aware of the seven funding opportunities at that point of time, we put in an application and were selected as one of the cohorts.

What we've done here is tried to set up, first of all, a team which has members of the community. We see that as being extremely important at co-production, which Kate was earlier talking about, has to be also exemplified in the work that we do. We've consciously tried to ensure that members of our team also are drawn from the communities that we want to work with.

We broadly, in this project, are working with two communities, transgender community members as well as persons with disability. We have tried to work with these community members through an a iterative process of doing a lot of workshopping, even in our design of the kind of questions we ask, it's largely a qualitative study, but we've also put in innovative elements around photo voice, around video storytelling to try to capture various facets of what we are trying to learn.
What we’ve done is we’ve tried to ask individuals what health needs have been like during the pandemic, what have been their intersections when they have tried to access COVID vaccination. What we’ve learned so far is that communities have been largely very positive around vaccination, they’ve been very welcoming of it, and I think they realize that vaccination is a crucial response also because many of them are vulnerable, including, of course, to the virus and its implications, but also, in terms of the possible consequences of not getting vaccinated.

That having been said, their own intersections with the health system earlier do sometimes make them concerned, reluctant, and fearful about what would happen if they were to reach out to facilities. These are facilities sometimes where they are not given inclusive care, they might not be welcomed, they might be discriminated, they might be stigmatized, and so that also, of course, then influences their own perception around facility-based vaccination, which is largely how vaccination was being rolled out, at least initially.

The actual rollout of vaccination in our own research, as we have found out, has also had gaps. For example, persons with disability might find it difficult to access vaccination while they go into facilities because facilities might not have accessibility built into their design. They might not be able to, for example, go to a fifth floor of a building where vaccination centers might be located because there might not be any elevators or lifts. Or if they’re trying to register an appointment and they are blind, then unless the website is accessible, of course, again, they cannot set up an appointment unless they have help or assistance available.

Similarly, for transgender persons, often there is a requirement in India for the website that you need to have an ID card for you to be able to register to get a vaccination appointment. That is often not something that transgender persons might have, especially if they’re transitioning and they don’t want to go back to their earlier identity, which they consider as a dead identity. In the absence of having any other way than you’re stuck in limbo.

In some cases, I think governments have been more proactive locally, they have done outreach vaccination efforts. Concerned officials might be available who might listen in and make exceptions. What we don’t have is a systemic design which allows for marginalized communities to be able to access vaccination. These are the things we’ve been trying to find out and also figure out what we need to do differently.

It’s clear that community engagement, and mobilization, focused campaigns is a requirement, and especially when you’re talking with marginalized communities and their needs. That is something that we should do more of. We need to be cognizant around structural inequities. That is something that we try to explore because those do shape experiences around any access, including COVID-19 vaccination access. As I was saying earlier, this has also linked back to historical mistrust around how the health system has engaged with them.
The influencers in this paradigm often are family members, but also community members, trusted circles. If we can also work with those, that could actually help decisions around vaccination. The source of information, the importance of context, and trust building hence becomes extremely important. These are some of our early findings. We are still processing our findings, and hopefully, we'll be able to- [crosstalk]

Francesca: Many early findings. I can't wait to see what else comes out of this research. Now, Kate, Sabin have a social and behavioral research grants program. Anant is one of 18 research teams that has been doing research. The third cycle, I believe, ends in December. You’ve recently put out a call for proposals for the fourth cycle.

Dr. Kate: Yes, it's very exciting.

Francesca: Very exciting. Applications for that go through October 31st. If you're listening before then and you want to apply, you better fill out the application now.

Dr. Kate: Please do.

Vince: vaccineacceptance.org.

Francesca: There you go, yes. We'll put all this on our website, immunizationadvocates.org as well. All the information for Kate’s program and for Anant's research will be on there. I'm curious, in addition to Anant’s findings, what have the other research teams been finding for vaccine access, equity acceptance?

Dr. Kate: Absolutely great question. I think before I get there, I want to pause and just say, this grants program, what we're trying to create through this program is much more than a grantor-grantee relationship. I said earlier that the key to solutions is creating multidisciplinary, multi-sectoral collaborations. Really, what we’re doing is building this research coalition. We recently convened in Dubai, and all of our grant partner teams to date, we invited two representatives per team to Dubai to hold a three-day workshop.

It was an excellent way to meet face-to-face people all over the world, convening all these experts to talk about early findings such as what Anant described, what's going on in your country, what's going on in regions, what are we seeing that are comparable or dissimilar across regions? Then how to take that evidence base into action. Really excited to get a fourth cycle in and add to this coalition, make it bigger.

Stemming from conversations like we had in Dubai, a lot of the key themes, adding on to what Anant has shared, because those definitely were some key themes, and maybe dig a little bit deeper for specific examples, is that surrounding community-based participatory approaches, they’re key to gaining the trust of the community that you’re working within and working with. We don’t want research on
communities, we want to find solutions with communities and to enable these sustainable solutions.

We’ve heard a lot of needing to train and empower community influencers, both your traditional influencers within the health sector, but also outside of the health sector. Anant had mentioned community influencers within the communities that are part of these marginalized communities. Importantly, they can also be traditional healers. I heard a really interesting statistic yesterday in a session, that in Africa, people will see a traditional healer five times before they want to see a professional health worker. We cannot ignore these community influencers. We need to work with them to move the field forward.

The reason why these coalitions and networks and convenings are really important across regions is that communities are very diverse. There’s not a one-size-fits-all approach to fix a problem. That’s where social and behavioral science fits in. We understand exactly what’s happening in the communities, what are community-led solutions to fix the problem. The goal of these coalitions are to help shape an interdisciplinary research agenda to create evidenced, informed policies and practice.

**Vince:** We heard a lot in some of these events this week about the need for cross-collaboration, community building to better understand and apply learnings from each other. That is a general platitude that is far easier said than done. Kate, I know that at Sabin we’ve been working on this Vaccination Acceptance Research Network. You mentioned the grant partner meeting in Dubai. Take us inside those discussions that you all have with each other. Why is it so important that researchers, like what Anant’s doing in India, that they talk to folks in West Africa, they talk to folks in Latin America who are doing maybe somewhat similar but somewhat different types of research in this area?

**Dr. Kate:** I think the majority of funding comes from higher levels, a lot from the West, and it’s so far away from what’s happening on the ground. It’s critical for researchers, academics, civil society, collaborative approaches on the ground to truly know what’s happening in the community. I think this takes a very long time, but it is a critical process that we must go through to reverse this decline in immunization. It can take years. Anant, what is your experience being close to the community and the amount of effort and time and patience that your organization has had to have in connecting with these marginalized populations and gaining their trust?

**Dr. Anant:** That’s a good question also because it’s been a learning process for us. I think the first thing we’ve tried to institute in our own teams and our approach is humility. When you are working with communities, you need to recognize that they will have valid concerns, they might have misconceptions, and it’s important to engage and hear communities out.
Again, when we say communities, it sometimes gives the impression that these are homogenous entities. There’s so much diversity and complexity in communities that you need to really figure that one out and take the time to do trust building and also figure out who are the right, in a way, influencers, but key change agents within the communities through whom you can access those sections of marginalized populations who are traditionally not heard.

The second thing is there is a lot of stigma, which also influences access to health, which includes also, of course, vaccination. We’ve seen that a lot in our work in mental health which we’ve been doing. What we’ve tried to do is also take an approach which tries to destigmatize mental health, for example. For that, we go out to schools, we will go out to local government institutions, right down to the village level, we will go to Anganwadi institutions, which are institutions at the village level where nutrition supplementation is given to kids and pregnant women and we will have whole meetings.

Sometimes this involves gamifying information on the health issue that you have in mind. Sometimes it’s open conversations, sometimes it’s just laying out a poster and having a collective discuss what does this means for us in our communities. That helps, I think, in some ways because then open conversations can happen because these conversations are led by community members or individuals who are drawn from those communities and not by some expert coming in from outside who claims to bring in all of the knowledge and then, as you said, we are just here to give a didactic lecture.

We really need those open conversations. Sometimes, of course, there are misconceptions, but sometimes you also learn around what are the communities thinking about, what do they think their priorities are, and why they might not be engaging with the program. That could be vaccination or that could be any other program for that matter. We’ve tried to do more of that and we’ve taken a similar approach in the research that we are doing.

We do a lot of open engagements and ask communities what their thoughts are, are we asking the right questions? Would they like us to reframe it in some way? Then take back our early findings to them, tell them that, "This is what we are finding. What are your thoughts on this? Are we missing out on any key aspects? Who else should we be talking to?" Then try to ensure that that gives us more comprehensive understanding of what needs to be done.

Dr. Kate: I think what Anant just shared really highlights solutions for the people by the people. I think what we’re trying to do in our program, and Sangath is doing it beautifully, is really elevating the voices of those on the ground to the decision-makers. There’s community-informed solutions and decisions being made.

Francesca: That’s something we even touched on last episode. Rashid, he emphasized people on the ground, in his case, health workers, they need the
platform, they need their voices elevated so they can tell leaders, ‘This is what's needed.’

**Vince:** Listening to both of you, I’m curious to get your thoughts on the balance between urgency and the time that it does take to develop those relationships, both in the community research, but also researchers with each other? Obviously, during COVID vaccine outreach, we were trying to get as many COVID vaccines out to every community in the world as possible given the devastation of the pandemic. Currently, we have the largest sustained decline in childhood immunization in 30 years and, of course, those millions of children that don’t get their scheduled vaccinations. That can mean and does mean deaths.

There is, on the one hand, that constant urgency that is there, but on the other hand, knowing the nuances that you all have just articulated very well, it does take time. Curious, especially in the research field, how you try to balance that urgency and that long-term need to develop trust.

**Dr. Kate:** That’s a great point. I think as far as getting the evidence base out there, research, especially during the pandemic, has moved from being such a scientific manuscript publication focus to beyond that, other strategic communications, opportunities, and not waiting for a published paper to come out before you share your findings. I think that's what we're trying to do through our research coalition, that's what we’re trying to do through our Vaccination Acceptance Research Network, to give these researchers the opportunity in real time to share what their findings are on the ground.

**Dr. Anant:** Yes. What we’ve tried to also do besides our community sounding boards is have an advisory board which draws from the community, but also has vaccine program managers, senior funders who work closely with governments at various levels. We keep going back to them and we keep telling them what we are finding. Of course, sometimes they have interesting feedback to give, but I think what is also important is that they take some of this learning into their own discussions which might be happening in ministries of health or which might be happening, for example, when they’re meeting with other key partners in the immunization landscape.

What we also tell them is that there is a lot which might be specific to COVID, but there is a whole lot which is non-specific to COVID as well, because it’s about the larger intersection of communities and health access. If tomorrow you want to design programs which are more inclusive for vaccination, if you want to introduce new vaccines, if you want more adult vaccines to be there in the fold, then all of these learnings are important for that as well. At the end of the day, if a program is not sensitive to community needs, whichever vaccine it might be, it is going to have problems in terms of coverage.
There is a lot to learn from COVID. Of course, there was a need for an urgency, pandemic being the cause for that, but now I think we certainly need to find that balance, as you rightly said, because we’ve had so many drawbacks for a whole lot of other programs, especially routine immunization. The time for catch up is there, but the time for also reflective learning from the pandemic is crucial.

**Dr. Kate:** I think Anant brought up an important point of this feedback loop from the community to also-- it’s the community as well as the health system. There has been many conversations this week in New York about how 70% of the health response is at the public healthcare level, and so there needs to be investment made at the public healthcare level too, and most importantly, in the health workforce.

Part of our social and behavioral science research is to understand what do health workers need, how can we support them? There’s monetary investments, but then there’s other resources that they need too, and they also need information. Misinformation is, obviously, a huge issue at the moment. We are in what they call an infodemic era, an overabundance of information, some misinformation and disinformation, and health workers are relied on to-- they’re at the forefront of immunization, but they’re also recipients of misinformation, so how do we help them sift through all that too so they’re communicating the correct messaging?

**Vince:** That term info infodemiology and infodemic has been something that has come along with the COVID pandemic. I think sometimes maybe there’s a thought of, ‘Oh, you have to be an infodemiologist, you have to come from some specific background or you have to know.’ I think we’re all struggling and challenged with how communications and the way that has shifted, and especially the impact that has on vaccines. I think it’s especially interesting the backgrounds that both of you come from.

I know, Kate, you worked on vaccine trials and whatnot before. Anant, you had talked about that you came from working on many different areas of social research, you worked on mental health, and so I think that points to understand that infodemic, you have to have a lot of different disciplines involved. Maybe you can just say how you all have felt that that has been important in the discussions that you all have been having with each other and other researchers.

**Francesca:** How you’ve incorporated your past experiences to better the research or the projects you’re working on.

**Dr. Kate:** This goes back to the absolute need for multi-sectoral or interdisciplinary partnerships. That’s critical. I think we all have experienced lessons learned, what has succeeded in certain settings, what has not, especially in fighting this issue of misinformation. It’s really important to share those wins and losses because we can learn from failures as well. Getting these experts together from different sectors with different disciplines, sharing case studies, it can help move the field forward.
**Dr. Anant:** Yes. One of the areas I’ve been working with colleagues is community engagement now for many, many years. One of the things with community engagement is everyone thinks that they’re doing community engagement, including us. It’s the policy, because if you look at how community engagement has to be approached, one, it requires, again, a science to be there.

You have to recognize that this is not just taking a framework which has been written up in a paper, in some fancy journal and applying that, but actually seeing what works, what does not work, how do you have an empirical approach to also understanding what are the kind of things which are working. Then, again, build up, just in the same way you would build up any program, to seeing what is working in a particular context.

Similarly with infodemic or usage of terms like vaccine hesitancy, sometimes what one sees is a lot of reductionism and vilification, and it’s like the communities are the problem, "Why don't they get it? We are doing everything for them." While not recognizing that segment of the population which is probably opposed to any a vaccine is there certainly, but it’s probably a small segment. What you’re really dealing with is a lot of individuals who are confused, who’ve not been reached with the right information segments and needs to be listened to so that they’re valid concerns are responded to.

They could actually very quickly become champions on your side and help with work on getting our vaccine acceptance and demand up, but that requires, again, for us to be listening into them, engaging with them, building trust, and then acting on what feedback we are receiving. I think for the field, this is extremely important and that’s where I think the work which Sabin is doing in building the partnerships with key organizations in LMICs becomes crucial because that pathways are crucial, again, for the approach that we’re taking.

**Dr. Kate:** I think to add to that, one thing we’ve learned from talking to our different partners is that for communication to fight against misinformation, there needs to be investment in contextualized communication strategies to provide the desired information with the correct appeal by the most trusted and influential messenger in the community using the best method. That can be either online communications or offline communications. It’s very nuanced depending upon the community, but those are some strategies that can be used.

**Francesca:** Now, as UNGA is wrapping up, we’re all getting ready to head home. Do you have messages that you want to share with listeners, with public health leaders, vaccine decision-makers around the world?

**Dr. Kate:** Absolutely. I think the only way we can reverse the alarming trend of immunization decline is if global health policy and financing really begins to center around the people and the systems needed to make immunization programs work. The pandemic has definitely highlighted deep vaccine inequities, and there needs to
be enabled access to vaccination through both increased local or regional vaccine manufacturing capacity and delivery, but also investments in the primary healthcare system and health workers themselves and the local community needs to be involved from day one.

Francesca: Such great points and we actually touched on those also in the last episode. It's really interesting that, obviously, these are important, they keep coming up and really needs to get done

Vince: The momentum seems to be there, then it's now getting to the political-

Francesca: It's actually taking action, we need to take action.

Vince: -down to that budget advocacy. Anant, your takeaways?

Dr. Anant: Sure. I think Kate has summarized it very well, but also, I want to add on and say that let's call on policymakers to see vaccination as a crucial public health investment, but as part of a larger approach to true universal health and healthcare, this requires, of course, us to focus on the availability of services, the availability of trained and supported health professionals who are taken care of, especially frontline community health workers. We also need governance mechanisms which acknowledge the role of social determinants in health and health access.

Vaccination programs should focus certainly on the infrastructure and outreach and coverage, but equally importantly, focus on building connections and trust, ensuring that we respond to valid community concerns. I think it’s also extremely important that we have transparency and openness about acknowledging, for example, that there might be minor risks with some vaccines, there might be adverse events.

What’s often done in many countries is you don’t really talk about it. Those small, rare adverse events can become controversial. They are spread through WhatsApp with other individuals that, “There are problems with this vaccine, it’s causing these kinds of issues.” We have to be honest and say, “Of course, with any large public health intervention, there’s going to be occasional possibilities of adverse events, but if that were to ever happen to anyone, we will take care of them, and we will also be open and transparent on what we are learning.”

Communities appreciate that there are policymakers as well as program managers who are being open about what they know and what is being done, so let’s not hide information. If we do that, then I think we will be able to probably build on the trust that we are hoping to have with communities. Finally, please listen to your communities and community health workers, the solutions to complex global health problems sometimes will lie in their grounded wisdom.

Vince: I think the safety point, I just want to say before we close, is an element we hear over and over again. It’s very crucial, like you say, to be transparent and
completely out there because that’s key to that trust. You noted universal health coverage. When this assembly reconvenes again next year at the same time, there will be a high-level summit on the progress or maybe in hook, cases like thereof, towards universal health coverage.

I think universal health coverage can seem this all-encompassing term that doesn’t mean that much, but what it really means is, like you say, that everybody have not just paper access, but real access to the essential health services. That means things like vaccinations that can save their life. While it is a very macro term, it’s extremely crucial, and so we look forward to continuing conversations with you both, with all of our partners that we work with across Sabin to continue to learn from each other and then connect that to push for action among policymakers. Thank you all for joining us today.

**Francesca:** Thank you so much. It was so great to see you in person.

**Dr. Kate:** Agreed.

**Dr. Anant:** Yes, I know.

**Vince:** Thank you. We need to do it again sometime.

**Francesca:** *Community Conversations on Vaccines* is brought to you by the Sabin Vaccine Institute and presented by immunization advocates. To find out more about the Sabin Vaccine Institute and how our programs are working toward a world free from vaccine-preventable diseases, visit sabin.org. Find Community Conversations on Vaccines at immunizationadvocates.org/podcasts or wherever you get your podcasts. Be sure to click subscribe to be the first to hear future episodes. On behalf of the team here at the Sabin Vaccine institute, thanks for listening.