**Transcript: Talk In Equality reflections episode**

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Gary Hickey
Hello and welcome to the final reflections episode of our podcast series Talk In Equality.
I'm Gary Hickey from the Agora Digital Centre at the University of Southampton, and I'm joined today by Lillian, Anusree, and Patrick. Now for those new to the podcast series,
could you please just tell us about you and your community organization and briefly what you do and I'll start with Lillian.

Lillian (Guest)
Hi everyone.
My name is Lillian Ndawula and I work as a development worker with ethnic minorities in Canterbury and we bring together ethnic minority groups and individuals to give them a voice and to raise awareness around health inequalities, raise awareness around health issues that affect us as ethnic minorities and also to bring together our young ones to teach them around cultural issues and to pass that on to them.

Gary Hickey
Brilliant, thank you, Lillian, and welcome and Patrick to you.

Patrick Nyikavaranda
Hello everyone.
My name is Patrick Nyikavaranda and I'm one of the directors of Diversity Resource International.
This is a community LED organization that is based in East Sussex but works across well,
the whole of the UK and internationally, and one of the primary focus is that we have is on empowering and reaching and also making sure that people from minoritised ethnic minorities feel like they belong in their communities, feel like they can contribute, feel that they have the skills and the resources to actually do something for themselves and their communities as well.
And we mainly take a community development based approach on everything we do.
We involve the communities to ask the questions to solve the questions and also to provide any answers that may be beneficial to individuals, families, communities and hopefully all countries really.
So that is diversity resource international.

Gary Hickey
Brilliant.
Thank you, Patrick, and welcome, and finally Anusree.

Anusree Biswas
Hi, Gary.

Gary Hickey
Hello.

Anusree Biswas
Thanks for inviting me, yes, although my name's Anusree Biswas Sasidharan.
And I'm one of the directors of Bridging Change, along with Nora Mazzawi.
And we're relatively new organization, although we've been around a while and a lot of our work and interest is around supporting minoritised ethnic people within Brighton and Hove, but also within Sussex and also like Patrick nationally and internationally and most recently in Brazil looking at health inequalities.
Looking also about food justice and about representation for communities, our work does involve some research, but it also, like Patrick and Lillian, also looks at community development and know that this is also things that they also do as well. We also look at working in partnership with Black Asian minoritised organizations, but also other organisations, more infrastructure-based organizations or councils and local authority, same sort of thing.
But you know what I mean?
And health.
So working sort of on projects as well with academic organizations and looking at how we can bring the voice and sort of representation to the fore, we sometimes think is missing.

Gary Hickey
Brilliant.
Thank you Anusree.

Now for the benefit of the listeners and I guess orientate ourselves let's recap and we've got some in this podcast series because in the very first episode I spoke to all three of you and you shared your experiences and your perceptions of inequalities in health and health research and what role you thought that the research could play in addressing this or your hopes for what research could do.
Lillian Anusree you then went off to speak across four different episodes to Jeremy Taylor at National Institute for health and care research.
Matt Westmore at Health Research authority.
Simon Denegri at the Academy of Medical Sciences and Doctor Ibi Fakoya at King's College, University of London, and for listeners, please do check out those podcasts because they are brilliant.
But I want to ask you Anusree and Lillian.
What for you were the key issues to emerge from those interviews that you'd like to expand upon.

Lillian (Guest)
For me I've I enjoyed the podcast.
It was my first time to interview people on the podcast, so that was quite an experience for me.
But on the issues around inequalities, I felt some of the issues that we need to highlight around the need to be more proactive as researchers, but also for the people who are within the research and maybe funding the research to be more proactive in actually looking out that this health inequalities are being addressed, also the willingness, there was willingness and opportunity to do research with ethnic minorities.
But maybe they don't have, didn't have the knowledge about these groups and how to access them..
Also, I thought that there's need for more culture sensitization for the researchers and the people who are involved in research.
At the moment there was definitely that they wanted to do things, but probably sometimes it was because they didn't have that culture sensitization to put that at the top of their thinking, the other thing I thought about was the need for a sense (5:30).
We did talk about it around the need for a center of excellence or ethnic, racially minoritized ethnic groups around research, maybe around Kent, Sussex and Surrey.
And I don't know if Anusree can add on to that.

Anusree Biswas
Yeah no, it definitely enthusiastically agree with everything you said Lillian.

I think you really captured a lot of the conversations and I think what was wonderful was that our guests were quite honest about where they were and some of the barriers that they faced trying to break into those areas and the newness of it as well.
I think some had got further ahead on the issues around working with minoritised ethnic communities and you know, I guess we are asking more of them about the level of sophistication about developing those with community development organisations and working more collaboratively and in new ways and actually funny enough, you know, Gary, you and I went to a meeting earlier, which was talking about exactly this from the NIHR, which is really exciting and exactly in the terms that we would be quite excited about.
So that was quite exciting.
I know that's probably something we might talk about later, but that was really exciting.
And I mean, I particularly loved speaking to Iby because she was like a perfect of the interviews in that sense that she really captures some of the difficulties and some of the issues that were emerging now and what needed to be addressed.
And almost she was providing some of the solutions that discussion that Lillian and I had with her, that she had a lot of interesting commentary on how these things could be addressed.
So it was really interesting and all of our guests were really generous with their thoughts and ideas and it would be interesting to take those little further I'd like to unpack those maybe after I've had some time to think about it.

Gary Hickey
Yes, I agree.
Just for the benefit of the list though, Anusree and I run a call about the national institute for health and care research program.
The development grants, which is about fortune engaging with and close relationships between underserved communities and indeed, researchers, and I think you're right Anusree it, felt to me like the there was some understanding there from the organizations about some of these issues, and there's a willingness, but some of these organizations are big, they're huge and they have admired in it in a certain way or historically in a way of working.
And it can be very difficult to change that, but it does feel like the will is there.
And if doctor Ibi is listening, I will definitely be in contact because I found that podcast really, really fascinating

If I may I'm going to take you all right back, and you probably forgotten this, but the very first episode where we explored some of the changes that in an ideal world you would like to see that would enable community development organizations to have a greater influence in health and social care research.
And I know during a podcast series it was something that you touched on with the podcast guest time and time again about how can community organizations get more involved in this various types of research.
And I'd like to reflect on some of the things you said and get a sense from you whether or not you were heartened by what you heard from our guests or whether what they've said has changed your mind in any kind of way.
So I'm just gonna read out a list of things that you said and please feel free to respond.
And Patrick, please feel free to just to jump in if you want to expand on anything here.
So some things you raised with ACE (9:07) where you talked about community organisations and the research they do, being taken more seriously, you spoke about the lack of long term funding for community organisations.
You spoke about the importance of getting community organizations involved in the beginning of a research project rather than once researchers have actually received funding.
And crucially, and I think this is a big thing that you mentioned,
Lillian Simon again was about funders, and researchers need to recognize the importance of building trust with communities and also recognize that the time this takes is inevitably gonna go beyond the funding cycle of a single research project.
And something else you raised in one of the, and this may have been doctor Ibi also touched on this was that there needs to be a more holistic approach to research.
Recognizing that social and health issues impact on one another because we tend to focus on, don't we single things?
Because that's the way funders work.
So we're gonna have a, we might have a funding cycle or a funding scheme for dementia, which is very worthy, of course, and very important.
But I think your view, particularly Lillian, was this idea that actually there's lots of things that can impact and they join together and perhaps we're looking at it through slightly the wrong lens, albeit well intentioned.
And finally a need for a shift in power relationships between community organizations and researchers.
I'm very aware I've just read out a very long list of things there, but if I'm just throw it over to you, but any comment on those things to expand on those

Anusree Biswas
So yeah, I mean, I think your first and last point about community organizations and researchers being, you know, community organisations being taken seriously and power relationships shift.
I think that is quite an important area because I think particularly, I think this is in regards to Black, Asian minoritised groups and organisations, they're often end up not being taken seriously is a bit frustrating.

Lillian (Guest)
I do agree with Anusree that there is still need to have some changes there where community organizations are taken seriously by the research world and also I felt that there was no maybe call it a pathway for long term funding for this, you could feel that the people we talked to where aware and wanted to do a lot more, but they didn't give us any kind of pathway or thinking of how they were going to maybe find some funding or what to change that funding process so that there is more long term funding.
I felt that they recognized the importance of building trust. But probably there's need to more investment in that process of building trust, because it's not a one off thing.

Gary Hickey
Sure.

Lillian (Guest)
It's something that people need to commit to and be engaging with those communities so that that trust can be built. It won't be built in a one off a project that will be funded here and then the next year nothing happens. So there is need for that.
I felt that they did recognize that they said the importance of it, but we still need that investment into that work, and also they the importance of involving the community groups from the beginning and I think Doctor Ibi Fakoya did say that. And so yes there's still a lot of work to be done but I feel it's both our work and their work it's not just them but both of us need to work towards that and is finding those opportunities for us to work together that we need to now look for.

Gary Hickey
And in terms of building trust Lillian or indeed anyone, because it's something we talk about a lot, as a group, but beyond the podcast, what the types of things that a researcher or a research funder could do to actually help build that trust?
Because it's very easy for me particularly to sit here and say we need and I often write about it, we need to build trust.
It's really important, but then the next step will OK, you say that if I gave you Gary £1,000,000, if anyone out there listening wants to give me £1,000,000, please do. What should I do with that million pound?

Anusree Biswas
I think it's something about, you know, investment in a long term, something sustainable because often what happens to all of us and I'm sure Patrick will be great to fill in on this is a short termism.
So sometimes we get a project that might last a couple of months, might get one a year, a year and a half, and then after that it goes and there's nothing that continues.

And I think that's sustainability is really, really important.
So I mean, it's not just about money, it's about maintaining that relationship.
So even if the money isn't there that they continue speaking to us and find and create ways to involve us, because I think some of the bigger organization charities and you know, they have long term funding, it's already built in and there's something about systems and systemic thinking and system thinking.
You know, we're not often a part of that and I think it's not just one fund, it's about the whole system thinking how do we meaningfully involve these organizations that bring added value can actually save money in the long term if we engage them throughout, keep that contact and relationship.
I don't know if Patrick wanted to add because I know we have talked about this before.

Patrick Nyikavaranda
I think you I wanted to continue on your point earlier on, I think when obviously you all mentioned around a shift in power relationships between community organisations and researchers. I, based on obviously the series of podcasts that have gone on, this is something that for me sounds like it's been about conversations.
So it's been a two way discussion rather than one way and that's first of all is I think how especially for our communities we think about, OK we're getting to know you as a researcher, we're getting to know you as a funder, we're getting to know you as a partner and then we are also saying well these are some of our challenges.
These are some of our almost like misgivings when it comes to research or how you fund our community projects.
So for us as community organizations, led organizations, really the engagement process involves a lot of discussions and just to give you 2 very good examples, which I think Anusree has touched on.
The first one has been researchers or funders that come to community led organizations and say, listen, we've got this great research idea. Let's work together, and then it's all about the processes, the processes around, how do we get the funding or what do you do with the money?
And then if for some reason, that funding opportunity doesn't succeed, it's almost like, well, goodbye. See you until next time. And then we are left feeling used, but then ongoing discussions conversations for us are equally as important even when there is no money involved for a lot of us, it's not about money, it's around what we can do through any kind of change, even if it's around information sharing.
So just this series of podcasts have really helped, I guess, for some of us to see what funders see in terms of any challenges or any opportunities, but also to hear from researchers as well around their perceptions as well.

Gary Hickey
Lillian.

Lillian (Guest)
To add on to what Anusree and Patrick have said, and of course the sustainability would help, but also something that we've talked about the thing between ourselves around having a group or that centre of excellence where even at a strategic level because the community groups can do the work on the ground.
But at the strategic level, whereby it becomes like a sounding board or somewhere where the researchers or funders would come to, to say, what are the things or what are the issues that are affecting minoritised communities that we need to research on?
What kind of research should we be doing?
So there's that group that they can maybe they format they fund it , So it's a running group that can be consulted on before this research is commissioned so that the research that is commissioned is relevant to the communities and then the communities can be also involved to implement that. I think that would also help in that continuous engagement that Patrick was talking about.

Gary Hickey
That's really important. And thank you. Anusree.
Yeah, sure.

Anusree Biswas
Can I can I add one thing to Lillian?
Yeah, because it just prompted me to think that cause often you know our expertise is seen as of adding to the public, I’ve forgotten what it called participation, and I would argue that actually we offer more as community development organizations.
We provide an expertise, a professional expertise, that should be valued in that way, you know, and I do think that sometimes it gets missed off. It is an expertise that’s often just seen as though it's just community, that's fine. And I, I don't think that's a fair representation of what we do.

Gary Hickey
And if I can ask, it goes a little bit to the point that’s raised in the very first podcast about you're feeling that community organisations aren't taken as seriously as they could or should be.
So why do you think that is?

Anusree Biswas
I think it's because we don't, well I don't know thinking about it now it’s because I think it's we don't have a strong enough infrastructure if we don't keep getting projects, we either do it for nothing, which some of us do anyway or we fail. And it doesn't take much for it to fail. It, you know, it's quite boring stuff, but it's true. It's that infrastructure, not having that to maintain us and I think that's really, really difficult.

Lillian (Guest)
Would they also be as an issue around stereotyping?

Gary Hickey
Go on, Lillian. Do you want to expand a bit on that?

Lillian (Guest)
Yeah. Whereby because I've been seen many people from the communities doing their research, so there's stereotyped as non-researchers, they’re not a research, you know they don’t know much about research. So nothing goes that way. So they don't think about involving minoritised communities because of that.

Gary Hickey
So that program development grant that Anusree and I were talking about earlier from the National Health care research, might go some way to bridging that might in it because that's quite explicit, isn't it about working with community organisations?

Anusree Biswas
Definitely I did like that emphasis and I thought it was really, really good. And they did also talk about the systemic issues that they have which is really interesting acknowledgement, that you still need an NHS partner. And that's fine because I think that applies to whomever they are referring to with community development.
But it leads me onto a slightly separate point and not about the NIHR at all. It’s just that we're not always trusted as a group to be trusted with the money, you know. And I think it would be nice to be a little bit more trusted.

Gary Hickey
Thank you.
I've got one final question. It's kind of like end on a positive. And could you tell me something positive you've got from the podcast series? Now that might be positive in terms of something that you've gained from doing this series or you've heard. Or just a positive about something that some of the, or one of the guests might have said that gives you hope for the future. So take that idea about positive as broad or narrow as you'd like.

Anusree Biswas
Well, I thought what I did really like about all the guests that they were really honest. And I do think that's important. They weren't trying to paint over the cracks, so the difficulties and I do appreciate that. And I think that is part of the acknowledgement is really important about where they are and where they would like to see themselves. And I think they all did acknowledge that they were not where they'd like to be. So I was really heartened by that. So I thought that was really positive for me.
Yeah, I'll just leave it at that.

Gary Hickey
Thank you Anusree. Lillian.

Lillian (Guest)
I agree with Anusree that all the people we interviewed were very honest in the way that they saw the need for addressing inequalities in research. But also knowing about some of the things that they were doing that maybe we would not have known had we not talked to them. And I'm hoping that because they were quite high up in the positions that they were that hopefully with these interviews that they would be able to maybe try and implement some of these things. Or we can then continue to work with them. And they seem to be willing and very enthusiastic about seeing what else can we do after this podcast so that we can work with them to take this further.
So that was a positive for me.

Gary Hickey
I think Anusree wants to come back in and then over to Patrick.

Anusree Biswas
Yeah, I was going to say Lillian has prompted me and reminded me that actually one of the issues that were brought about, some of the things that had been done about gender inequality and some of the initiatives that they had already brought in, and we'd asked the question if it could be extended to minoritised ethnic people, so it would be really exciting to see if they could just bring some of those ideas that they already have and just adapt it to minoritised ethnic people. That would be really exciting.

Gary Hickey
Thank you.
And Patrick?

Patrick Nyikavaranda
Just wanted to say that as small organizations, we often have problems in terms of us getting our names out there. In terms of us advertising what we do as organizations. So I think this has been a wonderful opportunity for us to be known by researchers, for us to be known by commissioners and for us to be known by other groups.
But another positive that I will raise right now is the fact that behind the scenes a lot of work has gone to producing these podcasts and we've worked well together as I would say a team. And these are different organizations set up at different times and in different regional parts of the country.
But we've worked really, really well together and I think for me it's a positive that this kind of working relationship is actually building upon something else that we've built before and we keep stepping up rather than stepping down or breaking down our own steps.
So I think for me that's really been a positive thus far and I'm looking forward to seeing what the future brings with our partnership, because it's works really well.

Gary Hickey
Brilliant. What a great, I don't think any of us can top that as an ending note. So thank you, so, and thank you all for allowing me to be involved in this podcast series. It's been an absolute pleasure working with you all.
This is our final podcast in this series, but let's never say never. You never know. Someone might come up with some funding for a series too, so you never know do you. I’d like to thank of course, all of our wonderful guests for being available for these podcasts series that they were really great to lesson soon.
And of course, a big thank you to those of you who are listening to this podcast.
If you’ve listened to this one and you haven’t to listen to the others please go back and listen to those as well.
So thank you all and have a good rest of your day. Evening. Morning, whenever time listen this podcast goodbye.

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