0:0:0.0 --> 0:0:4.830
Gary Hickey
Welcome everybody to this first episode in the series Talk In Equality.

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Gary Hickey
My name is Gary Hickey and I work with the Agora digital centre, the online centre for connecting People with research and I'm delighted to be the guest host in this first episode of this podcast series.

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Gary Hickey
And then this episode, I'm gonna be talking to the founders and the owners of this podcast series. And there are three representatives from three different community organizations, and I'm going to be exploring their motivations for doing this series and their experiences of health and social care research in terms of engagement, involvement and indeed, participation. So let's introduce our three guests today, Lillian, Anusree and Patrick.

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Gary Hickey

So if you'd like to introduce yourself and I'll begin with Lillian first, could you just say something, Lillian, about who you are and the organization that you represent.

0:1:0.100 --> 0:1:19.770
Lillian Ndawula
Thank you, Gary. My name is Lillian Ndawula, and I work for an organization called Ethnic Minorities in Canterbury, which was formerly known as Ethnic Minority Independent Council. I work on a voluntary basis and I am a development worker.

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Lillian Ndawula
EMIC, as it's commonly known, works in Canterbury mainly, but also we've worked with groups in Thanet and in and in Dover. We worked to promote culture diversity. We support initiatives at reducing inequalities both in health and social care.

0:1:43.360 --> 0:1:49.50
Lillian Ndawula
And we will also work to improve and empower individuals in the communities.

0:1:49.630 --> 0:2:9.750
Lillian Ndawula
We raise awareness of the issues and challenges that are faced by minority ethnic communities in those areas to those providing services and we work as a voice or as a conduit between the main service providers and the communities.

0:2:11.960 --> 0:2:17.430
Lillian Ndawula
Most of our work is done with other.

0:2:18.210 --> 0:2:25.260
Lillian Ndawula
Grassroot community groups and we work mainly with the.

0:2:28.250 --> 0:2:54.910
Lillian Ndawula
Chinese community we work with Romanian Community Polish community. We have been also joined by the Ukrainian community of late and we also have the African communities and the police communities that are best in here. Our work is challenging as of late we've had many other new communities joining us and we've tried to help them to settle in into the area.

0:2:55.810 --> 0:3:11.770
Lillian Ndawula
Most of the times we do promote harmony between our own communities, but also between communities and the local groups, social inclusion and health and well-being are the other things that mainly we talk about.

0:3:12.560 --> 0:3:19.30
Gary Hickey
Brilliant. Thank you, Lillian. Anusree, could you introduce yourself and your community organization.

0:3:19.560 --> 0:3:49.280
Anusree Biswas
Hi Gary, I'm Anusree Biswas Sasidharan and I'm co-founder and co-director of Bridging Change along with Nora Mazzawi and Bridging Change is an independent organization with its intention to build up strong sort of dynamic and successful Black Asian minorities ethnic groups and communities and organizations. We’re really keen on seeing people build up their infrastructure but also really challenge inequalities.

0:3:49.480 --> 0:3:55.470
Anusree Biswas
Particularly health inequalities, but also around food access and representation, more widely.

0:3:55.850 --> 0:4:18.440
Anusree Biswas
And I mean, it really started around at trying to address some of the disparities around organizations trying to find their way. But we also do a lot of research and engagement work with communities within Brighton and Hove, but we do expand into Sussex as well. So that's sort of a quick sort of overview of what we do.

0:4:18.570 --> 0:4:27.300
Gary Hickey
Lovely. Thank you Anusree and we pick up on some of those issues as we go through the podcast. Patrick please introduce yourself and indeed your community organization.

0:4:28.440 --> 0:4:59.290
Patrick Nyikavaranda
Hello, my name is Patrick Nyikavaranda and I am the director of research and leadership at Diversity Resource International and just a little bit about diversity resource international. It is a nonprofit social enterprise that supports ethnically diverse and migrant communities and we have 4 core activities which are committed development, community research, leadership and enterprise and training towards equity and inclusion. And one of the things that we believe in.

0:4:59.390 --> 0:5:24.250
Patrick Nyikavaranda
That these activities aim to reduce inequality and promote a fair and inclusive society. And just lastly, really we work widely with the public and voluntary and community organizations to bridge the linguistic and cultural communication gaps and to raise awareness of the impact of structural discrimination and to bring about what you may call a greater social justice.

0:5:25.230 --> 0:5:40.190
Gary Hickey
Brilliant. Thank you, Patrick, and lovely to see you all today. So I'll start with you, Patrick. Cannot questions proper if you like what has motivated you to do this podcast series on inequalities in health?

0:5:42.510 --> 0:6:12.890
Patrick Nyikavaranda
I think, basically from a personal and professional capacity and one thing that in my role at DRI, I have encountered is, that there is almost this lack of understanding around the needs of the Community based on what they express. And so one thing that I think this podcast should help to raise our communities needs.

0:6:13.0 --> 0:6:39.730
Patrick Nyikavaranda
From us, the way we see it, rather than the way someone is reporting it, and also something around engaging widely with other, I guess organizations and also researchers in addressing some of these needs because we live in a society where we are interconnected and these stories that we share will actually help not only us, but then everyone else in the in our communities.

0:6:40.660 --> 0:6:47.770
Gary Hickey
Thank you, Patrick, and Lillian, turning to you, is that similar to your motivations or would you like to add something to that?

0:6:50.760 --> 0:6:51.530
Gary Hickey
Hope you're mute.

0:6:55.560 --> 0:7:14.250
Lillian Ndawula
Yes, I'm very similar to Patrick on a personal level part of the ethnic minority communities and we've realized and we live really the inequalities in health we have that first hand.

0:7:16.330 --> 0:7:43.880
Lillian Ndawula
Experience of that but also working with community groups for over 30 years. I think now I've been working within the communities and one of my roles when I started working with the communities was managing a national program for African communities on HIV and in that.

0:7:43.990 --> 0:8:12.360
Lillian Ndawula
Project we soon realized the need for research and being best in everything that we were doing on research to help with developing the services that we were we were doing and living in Kent and walking in Kent. I soon realized that there was little or no research that we could use to develop services that are specific for the ethnic minority groups. So that really.

0:8:13.750 --> 0:8:14.900
Lillian Ndawula
Increased my.

0:8:16.860 --> 0:8:45.270
Lillian Ndawula
Because the need for us to look into research and also my interest in finding out more about research and how we can use research as a development worker to develop services that are targeted to the communities that we were looking for. So through my engagement with the National Institute of Health Research, I realized that working with that group.

0:8:45.370 --> 0:9:2.860
Lillian Ndawula
We would be able to do work or some of the research that was needed with the help of the National Institute of Health Research and hence yeah, my motivation and being here today is through those connections and networking.

0:9:3.480 --> 0:9:10.270
Gary Hickey
Brilliant, thank you, Lillian, and Anusree Have you got anything to add to that in terms of your motivations are they similar different?

0:9:11.0 --> 0:9:41.830
Anusree Biswas
A very much similar I mean I think because I've been involved in health inequality in examining health inequities and in social care is certainly been in the forefront of my mind. But it felt like there wasn't much of a space for it to be heard. I mean, I think COVID-19 was really a catalyst. But, you know, like coming together of really looking at it more nationally and more broadly, I think people were more open to listening to health inequalities as it affected. Pardon me.

0:9:41.950 --> 0:10:13.580
Anusree Biswas
black Asian minoritized people. And really, I think it gave us an opportunity to do some more investigation in the area, which is really nice and so really have an opportunity to understand where people and communities, how they were experiencing those health inequalities and get a bit more precise information. So I think this felt like a very timely podcast, really just to have an opportunity to see what colleagues are saying and also really, you know, verbalize some of the things that we've been talking about for years.

0:10:14.650 --> 0:10:33.920
Gary Hickey
Brilliant. Thank you. And of course, it was during COVID-19, wasn't it that that we all got to know. Ohh. Or rather I got to know you. because we sort of started meeting up during that time when I say meeting up we weren't breaking the curfew rules at all. It was all online just want to be clear about that and

0:10:35.700 --> 0:10:37.350
Gary Hickey
Anusree I’m going to ask you this question.

0:10:38.200 --> 0:10:42.690
Gary Hickey
And it's a very big question, but as a representative of a community organization.

0:10:43.560 --> 0:10:52.200
Gary Hickey
What are some of the challenges that you have faced in doing research and I know that's a very broad question, so please interpret that as you will.

0:10:53.100 --> 0:11:24.530
Anusree Biswas
I think often it is about not having opportunities to do the work and very not to be funded. So a lot of the work was often, sort of doing work. It was extra work for us. So we might be doing a piece of work that was unconnected to health inequalities. So we were really keen to draw some of those linkages together. So that was some of the frustration that there wasn't enough momentum behind it. So I think that has changed somewhat. They're feels to be a see change and I hope.

0:11:24.660 --> 0:11:54.890
Anusree Biswas
That it goes beyond flavour of the month and that it becomes something more consistent since thats some of the challenges we're facing, and also a major one, is that often black LED organizations like ourselves were not given the opportunity to do the work so often. Others who are not black LED organizations who were not, I would say agile or flexible enough to do the work as the way I feel we do the work. Knowing those communities really well. It was a real barrier too I think.

0:11:54.970 --> 0:12:26.500
Anusree Biswas
I research in that area more generally and I feel there's a real disconnect from academia to community development organizations. I felt that was a real problem, which I think also I hope is a changing as well. So those are kind of something barriers, I think we face and it's a frustration, but I do feel things are changing. I can see that our local ICS for instance they're putting some investment into looking at health inequalities.

0:12:26.680 --> 0:12:31.70
Anusree Biswas
As our councils, but I'd like to see more because I think we're a long way behind.

0:12:32.340 --> 0:12:43.10
Gary Hickey
I was gonna probably further that Anusree because you, you know, you said on quite a positive note there that you felt there was some change and I was just gonna ask you to explore a little bit about some of those changes.

0:12:43.800 --> 0:13:15.250
Anusree Biswas
Well, including this project that we're working on now, Reaching Out, I think is a perfect example of a recognition of this area. So NIHR, You know I think that they've reflected on some of this. I think they're at the start of their journey, but it's been great. You know, working with you, Gary and Lillian and Patrick, just to have a space to have these discussions, but likewise, as I said I think they're just awakening and I think.

0:13:15.430 --> 0:13:37.540
Anusree Biswas
There's something about, you know, it was George Floyd COVID I mean, I know there's been lots of discussions about them, but there's something about that time that really made us focus on it in a way that we've not had an opportunity. And I think if those two huge events worldwide events had not happened, I'm not sure we would be having these discussions.

0:13:38.390 --> 0:14:7.960
Gary Hickey
I suspect you might be right there Anusree and just for the benefits of the listener when Anusree mentioned Reaching Out that was a funding scheme from the Center of Engagement dissemination at the National Institute for Health and Care Research. The NHL. And we originally got some funding from them to develop, if you like. This working group, we've done many things together including various presentations and indeed this podcast series

0:14:8.260 --> 0:14:17.960
Gary Hickey
 Patrick over to you about challenges you faced in doing research.

0:14:18.960 --> 0:14:49.450
Patrick Nyikavaranda
Yeah, sure. As a community organization, I think Anusree touched on this and something around funding because we are aware that it costs money for data collection and data analysis and also dissemination of findings. And so that has been a major challenge I must say. And one of the initial challenges we faced, but something that I will say due to the resilience.

0:14:49.690 --> 0:15:20.600
Patrick Nyikavaranda
And resourcefulness of our communities and our organization really was an initial lack of expertise. But like I said, due to our resilience and resourcefulness we actually set up a group of our Community researchers and a Community research team to actually manage some of the research areas that were a challenge for community LED organizations. So although it was a barrier initially, it's not turned to.

0:15:20.690 --> 0:15:26.760
Patrick Nyikavaranda
A strength, because we've since built upon that as well and I guess.

0:15:28.330 --> 0:15:58.850
Patrick Nyikavaranda
Another challenge has been the wider lack of support for small community LED organizations. And when I say lack of support, it's lack of investment in some of our projects or lack of professionals or academics working with us initially, so that had been a challenge and I guess on the other I think something to add on to that is like a lack of.

0:15:58.950 --> 0:16:31.450
Patrick Nyikavaranda
Being taken seriously and into in terms of the research that we've done and that has been a challenge to to us and to our communities because our communities have said this is the research that we want done and these are the findings that we are actually wanting to be put across on the table for action to be taken. But then you've had this question saying, well, you're community LED organization, what do you know about research? What do you know about these things?

0:16:31.610 --> 0:16:44.180
Patrick Nyikavaranda
So yeah, it's been a real big challenge. But like I said, our communities are resilient, our communities are resourceful. So we are breaking down those barriers slowly.

0:16:45.100 --> 0:16:46.270
Gary Hickey
What do you say that, that that the needs of the cookie wasn't taken seriously? Are there forums? Do you think that you you can go to to present your case? To present what you would like research undertaken or are you saying there's an absence of those forums or is it that they're there and you're just not being taken seriously.

0:17:9.450 --> 0:17:14.800
Patrick Nyikavaranda
I would say yes to all those 3 answers out to all those three questions I mean.

0:17:34.670 --> 0:17:34.990
Gary Hickey
Hmm.

0:17:16.470 --> 0:17:46.600
Patrick Nyikavaranda
They're not really fit for purpose, for starters. And even though we are sometimes invited to some of these forums, it almost feels like it's just a tick box exercise to say yes, we've got a community leader organization. Yes, we've done our job. But also I think I have to say on a positive note, again, just acquiring Anusree, in the sense that the regional project has been a positive experience for us, it's.

0:17:46.680 --> 0:18:16.730
Patrick Nyikavaranda
Helped us talk about the needs of the community, or rather, you know, just be the representative of our communities on this project and it has also helped us almost like gain confidence and reach out to where the audience. So that has been positive and it's something that we as an organization and I think I'm speaking on behalf of my colleagues here today, that we can continue engaging.

0:18:16.830 --> 0:18:34.640
Patrick Nyikavaranda
And because it's a perfect example of how you know best to work with each other, and we've built strong bonds as organizations as well as a result of this. And so we are having a collective voice when it comes to addressing the needs of our communities.

0:18:35.540 --> 0:18:47.950
Gary Hickey
Thank you, Patrick. And just for clarity for the listeners when you talk about community researchers, you mean members of the community, don't you who actually undertake in the research and that presumably and trained up as researchers?

0:18:49.120 --> 0:19:3.310
Patrick Nyikavaranda
Indeed smelled of the Community that have been trained in research methods and undertaking and analyzing, and also disseminating the information and feeling back, especially through their communities.

0:19:3.970 --> 0:19:7.620
Gary Hickey
Fantastic. Thank you, Patrick. And Lillian, challenges for you.

0:19:9.600 --> 0:19:39.130
Lillian Ndawula
I come to this question. I think from a community side and not as a research organization, so more a community that needs the research or needs to be researched for that matter and for us it's been the lack of awareness.

0:19:39.450 --> 0:19:49.430
Lillian Ndawula
That there is even any research that's being done we I think through knowing the NIHR, we've known that there is the arc.

0:19:51.160 --> 0:19:56.630
Lillian Ndawula
We didn't know about that before, but we understand there’s.

0:19:56.780 --> 0:20:0.500
Lillian Ndawula
An arm in Canterbury.

0:20:1.680 --> 0:20:31.130
Lillian Ndawula
So is that lack of any knowledge of what is going on? We don't know what kind of research has been done. We know there's no little or no research that has been done within our communities because we would have known about it. So that lack of any research has meant that when we're developing our own services, we have little or nothing to base on.

0:20:31.290 --> 0:20:48.850
Lillian Ndawula
Which makes them a bit weaker and hence funding becomes more difficult to get because we don't have that strong evidence on which to base any of our proposals. We use very much anecdotal evidence.

0:20:49.400 --> 0:21:19.740
Lillian Ndawula
we have people who are interested in doing research. We have a few people who have done some research, but I think the acknowledgement and giving it the credibility that it deserves. I remember during COVID there was research that was done with the Zimbabwean community but it was something that.

0:21:19.870 --> 0:21:50.330
Lillian Ndawula
was initiated by a few people from the community and I remember them trying to get it recognized as you know, a credible research. So what Patrick talked about being taken seriously when we do that research, is been a challenge and of course the lack of the genuine involvement of the Community members in doing and research is a challenge and we know.

0:21:50.670 --> 0:22:12.710
Lillian Ndawula
It makes the research a bit more expensive, but I think because it makes it more appropriate and more effective, it's worth giving out more of that money to do the research. So yes, the other thing is that the few people who have come to us to find out anything have expected us to do it for nothing.

0:22:13.410 --> 0:22:25.360
Lillian Ndawula
Without any investment in the organization, without a thought about the time that we take to engage with the communities. So those are some of the challenges that we have had.

0:22:26.280 --> 0:22:44.510
Gary Hickey
Thank you, Lilia. And anyway, you started touching on my next question and it's another big question. And I was gonna ask about your experiences, positive or negative, in terms of engagement, involvement and participation in research. And I'll stay with Lillian because you started getting onto those things.

0:22:45.890 --> 0:23:7.70
Lillian Ndawula
Yes, thank you. Definitely lack of the genuine involvement by the communities that are being researched has been an experience where with the literacy research that has happened, people do come and get that information. But we also don't get much feedback.

0:23:7.840 --> 0:23:33.160
Lillian Ndawula
And that has been a big issue in that people are left thinking of what happened to the information is it worth actually getting involved the next time that we asked. So it gets harder and harder for those who want to do the research within the communities. If nobody comes back to give them the feedback and also.

0:23:34.400 --> 0:23:36.90
Lillian Ndawula
There being no action.

0:23:36.870 --> 0:23:59.650
Lillian Ndawula
That is followed up to say that this service was actually developed because of the results of this research. So there isn't that connection

0:23:59.730 --> 0:24:5.920
Lillian Ndawula
I think ignoring the skills of.

0:24:7.120 --> 0:24:7.920
Lillian Ndawula
The community.

0:24:8.860 --> 0:24:30.990
Lillian Ndawula
A lot of the people in the community have skills, have the skills that can help with the research, and I think those have been ignored in that everybody who comes in to do the research comes in with their researchers, with their people and they're the ones who can do research. But I think as we discussed during some of our sessions in the Reaching Out.

0:24:31.70 --> 0:25:1.820
Lillian Ndawula
Group that using those people within the Community as Community researchers, training them as community researchers and living that skill within the community, helps the research to reach further, because the effects of that research to reach further, because I believe that when research is done, there should be something that's left within the Community that they learn or they can act on or you know something that's left for the community.

0:25:16.40 --> 0:25:24.380
Gary Hickey
lots of.

0:25:25.230 --> 0:25:28.760
Gary Hickey
Interesting things you were saying there that I wanted to pick up on?

0:25:29.990 --> 0:25:32.420
Gary Hickey
On one of them and and it was about.

0:25:33.600 --> 0:25:39.470
Gary Hickey
I think from what you were saying, is there something here and I don't want to put words in people’s mouth about.

0:25:40.180 --> 0:25:59.370
Gary Hickey
Ownership of the research. So you and Patrick in particular have spoken about community researchers and the skills they have. And then the action that follows. Is there something about ownership of the research that you would like that is perhaps absence at the moment

0:26:0.30 --> 0:26:23.500
Lillian Ndawula
that's very true. There is absence of that and by involving the Community, the Community feels that it owns, you know, that research is a collaborative work with the researcher or the principal researcher who's coming to do that research. And, yeah, it also helps on.

0:26:25.60 --> 0:26:33.690
Lillian Ndawula
Fatigue of being researched, you know, they're getting involved in it, they don't feel like they're things that are being used.

0:26:34.410 --> 0:26:45.750
Lillian Ndawula
So, yeah, definitely there a need for the communities to own that research and it also helps for it to be more meaningful to them.

0:26:46.720 --> 0:27:11.660
Gary Hickey
Lovely. Thank you, Lillian. Anusree I'm gonna come to you because I know One of the things you've spoken a lot about in the past. It is about engagement. And perhaps how the research community, indeed funders aren't always very good or appropriate in their engagement. But please again answer the question as you see fit. But I know that's something that I'm sure you want to talk about.

0:27:12.220 --> 0:27:43.90
Anusree Biswas
 Yeah. No, it is. And also I'm reflecting on my own research experience as well because I've not got it right either. And I think when you're a part of a system, if you're a part of a project, you just go in and you go out, specially if it's an area unfamiliar with. So it's quite interesting and it feels very you're helicoptering in, do your piece of research and engagement make really good relationships because, you know, I really actually do really like people. And I think they get on with me. I think I'm not too offensive.

0:27:43.210 --> 0:28:14.310
Anusree Biswas
And what happens? I take advantage of that and then I'll leave because I wanna do my research. And actually what I didn't do and reflecting in those particular projects was, you know, do a lot of, you know feedback which is what you're supposed to do. And you know very much how you know it's my learning but it was not a part of the process then and when it was successful I mean I had done it before because I did community development, which is perhaps one of my favorite jobs ever, where I went out into the community and you talk to people and you create relationships and actually, it's not just about coming and doing some research because I have already made those relationships and funnily enough, it didn't even require a great deal of money to do it outside of that because it was already there and it was quite lovely really it felt very natural, felt very good.

0:28:45.460 --> 0:29:17.10
Anusree Biswas
and it felt very comfortable. There was no pressure to do a project and then that's it. I'm not having a relationship with you because those relationships would be quite genuine and we were taking people through their own pathways, you know, through education. It was a lovely piece of work and advocacy and research were just other parts to it. So that was really good. So that's a reflecting on my sort of practice, which has been problematic. I have to admit that and be honest. So I have some sympathy with researchers.

0:29:17.110 --> 0:29:48.450
Anusree Biswas
However, my sympathy is, let's say, with the funders, because I think they need to be a little bit more generous and a little bit more, you know, horizon seeking, you know, they need to look a little bit broader and have some sort of a vision as to where this is going, because I think there's a bit of irresponsibility doing these and jumping in and out because for community development organizations, we are struggling and a lot of the time, you know, we work for nothing as well. So if we don't have a project, we just carry on particularly to us, the Bridging Change we will just carry on. I'm sure our colleagues will too, because we know what that's like.

0:29:57.850 --> 0:30:30.190
Anusree Biswas
But we are trying to make moves so, but we've had really lovely relationship. I just wanna also say things like IDS which is the Institute of Development Studies, is really interesting as a new piece of work. They're not used to working in this country, but we're working with them and they're using some of their development sort of tools and approaches that they use elsewhere, where there is a sense of recognizing privilege. And it's really quite interesting. And so we have become almost like not the research, but they understand where we are positioned in the research.

0:30:32.220 --> 0:31:2.430
Anusree Biswas
There is real prioritizing of community development groups so they will sort of push us forward and say actually we push you forward to experience say like going to Brazil, which we will be going to or going to Toronto. I don't want to show off but it was really nice because they put us forward. They didn't think that we just do the work here and then they go off and do the fancy stuff. So it's been wonderful to be a part of that because we feel really valued

0:31:1.380 --> 0:31:21.120
Gary Hickey
 I was gonna jump in Anusree because I think some of the things you mentioned there it seems for that that importance of building those relationships and again I'm just putting this out there as a statement I guess rather the question and it feels to me perhaps the system, the culture, the environment in which we work.

0:31:21.920 --> 0:31:45.200
Gary Hickey
Doesn't put sufficient value on that. And yeah, I don't know if we got any sort of comment on that, if that is how you feel or indeed any of you feel. But from what Anusree’s saying that's a key thing that I picked out there and it's when you feel valued I think everybody gets more out of that of the enterprise.

0:31:45.820 --> 0:32:17.140
Anusree Biswas
Definitely. I think it's, you also want to give more when you feel better you. I mean I think we all do when we're valued, we will more likely to give more to the project and get best value as well. And I think you know I mentioned it before you know when people say they come in, take your ideas or something which does happen and we've had ideas completely ripped off and that is really frustrating. I am less likely to wanna work with that person and I think I said you know there's some.

0:32:17.240 --> 0:32:49.870
Anusree Biswas
Really fabulous chefs out there who write these great books cause they go out to these amazing places and go write. That beautiful curry that you've made here. Let's take some of this ideas from you while steal your generations of information. Put it in my book, monetize it, sell it. I'm sorry. I think that time has passed and I think we're a bit wiser to it as well. We're not innocence anymore. We want to be valued as well. And I think we have a right to ask for that. I think it's.

0:32:50.310 --> 0:32:51.860
Anusree Biswas
The least that we are.

0:32:52.930 --> 0:32:54.860
Anusree Biswas
Able to expect in that relationship.

0:32:55.300 --> 0:32:59.940
Gary Hickey
Thanks Anusree. Um Patrick, I just to remind you the question again, it feels like a long while ago.

0:33:0.60 --> 0:33:7.710
Gary Hickey
So what has been your experience of research in terms of engagement, involvement and participation?

0:33:9.720 --> 0:33:40.90
Patrick Nyikavaranda
Well, I think I will say I totally totally agree with what my colleagues have just saying in terms of the experiences, they seem to be the same that we have experienced. And I think I will have to say that I am actually a researcher in terms of my main job and academic research. And so again, Anusree has touched on that in terms of the hard experiences are similar to mine as well. There are things that I've done right.

0:33:40.170 --> 0:34:10.700
Patrick Nyikavaranda
And that there are things that I've done wrong and I do sympathize with some of the researchers coming into the communities to conduct research. However, in terms of, I guess, involvement, engagement, participation, it is expected that our communities are approached when it comes to the subject matters around health inequalities especially, and so some of those.

0:34:10.800 --> 0:34:40.810
Patrick Nyikavaranda
Involvement and engagement opportunities have really been horrible, I must say, terrible even. And I always talk about the good, the bad and the ugly, and that's how it's really been that some of them have been good. Yeah. Some of them have been bad, but some of them have really been outright ugly because it's just people interested in collecting information and just leaving communities or participants and not even a courtesy of providing.

0:34:40.910 --> 0:35:11.830
Patrick Nyikavaranda
Support information, especially when it comes to sensitive subjects but they have been really, really good working relationships with some individual researchers as well as institutions, and these are some things I think that I would say we value a lot. I think there's been talk about being valued, feeling valued and yes, indeed we do give a whole lot more to these relationships that are built.

0:35:11.940 --> 0:35:42.750
Patrick Nyikavaranda
As a result of people being genuine people caring enough, and it's not just a piece of research, but this is talk about people's lives, people's futures, so that we do appreciate and through that, I guess in terms of engagement, we have built these relationships and this reputation that we are an organization that is locally connected but also nationally.

0:35:42.830 --> 0:36:13.650
Patrick Nyikavaranda
Involved now and internationally involved, so our networks and our core projects and I think well just our ethics really around ensuring quality for everyone has been something that's attractive to researchers and research into institutions. So we are increasingly working alongside institutions on finding applications and this is the kind of engagement.

0:36:13.750 --> 0:36:44.220
Patrick Nyikavaranda
That we were looking when we started research to say, listen, we want to research these issues with you alongside you. We want to be equal partners in means in you know in this research. So I would say that's that's really really been positive and encouraging, not only for us and as an organization, but also encouraging for the participants that we then go into the communities to talk to about the research because they're saying to us.

0:36:44.340 --> 0:37:17.120
Patrick Nyikavaranda
That OK, you are actually conducting this research alongside the academic researchers, and that is all they ever wanted for us and for them that their are people in the community are actually undertaking this research. So I will say I end up on a positive note on the process of engagement that I think the relationships that we've built personal and I guess professional as well have really been inspirational in terms of us continuing the engagement.

0:37:17.310 --> 0:37:18.110
Patrick Nyikavaranda
Work as well.

0:37:18.840 --> 0:37:25.690
Gary Hickey
Great. Thank you. I'm gonna stick you, Patrick. I've got one final question. So what would you change?

0:37:26.410 --> 0:37:34.540
Gary Hickey
If indeed anything, and I'm sure you would, to ensure that community development organizations have a greater influence in health and care research.

0:37:36.380 --> 0:37:47.690
Patrick Nyikavaranda
I think I will start off by saying that they are taken seriously for starters and for me, I think.

0:37:48.930 --> 0:38:20.40
Patrick Nyikavaranda
just knowing very well that we've worked really, really hard to produce a piece of research and we are presenting it. It is not our voice, but the voice of our communities. So do take that research seriously and I will say again, it's been said so many times around, you know, the lack of funding for community development organizations. And there is actually a need to fund.

0:38:20.520 --> 0:38:48.590
Patrick Nyikavaranda
Directly whole activities around health research within our our organizations. So we're not talking about one month two month of investment we're talking about long term investment for our organizations and I think I'll stop there because my colleagues are the more wiser ones when it comes to making recommendations.

0:38:49.480 --> 0:38:52.660
Gary Hickey
Thank you, Patrick. Lillian you. What do you think?

0:38:54.920 --> 0:39:1.350
Lillian Ndawula
I agree with Patrick about the support that community organizations.

0:39:1.430 --> 0:39:10.630
Lillian Ndawula
need and also the involvement of the Community members.

0:39:11.710 --> 0:39:29.680
Lillian Ndawula
So that they are involved right from the beginning of thinking that to do that research to the end in writing the report and that kind of collaboration I would like.

0:39:31.440 --> 0:39:33.110
Lillian Ndawula
To see.

0:39:33.920 --> 0:40:3.790
Lillian Ndawula
researchers and the community. I think like Anusree was talking about that kind of engagement and building those relationships. And for probably the research is underfunded is to realize that that takes time. A lot of the time they come with this time limited research. but they have not factored in the amount of time that.

0:40:3.930 --> 0:40:20.180
Lillian Ndawula
it will take to engage with the communities. Some communities will be easier to engage with. It takes a shorter time, but other communities are much harder to engage with.

0:40:21.560 --> 0:40:50.330
Lillian Ndawula
 I would also like in terms I think it did ask about health and care, for research to be done with both the social care and the healthcare, because the social issues that affect a lot of the minor ethnic groups affect their health and I would like to see both those types of research being carried out and seeing the connection between the two,

0:40:58.150 --> 0:41:27.420
Lillian Ndawula
Action research, if I understand it, where there is some actually, I think Patrick alluded to that way, at least you give some information about the issues that you're researching for you leave some information so that people learn about it more. But I would like to see the long term that Patrick was talking about whereby it is some research and action going on within that so that there's that continuation between the research and the results of the research and the action that's being taken as a result of that research.

0:41:28.220 --> 0:41:32.320
Gary Hickey
Brilliant. Thank you, Lily. And Anusree have you got anything to add to that.

0:41:34.710 --> 0:41:35.280
Gary Hickey
Of course.

0:41:33.210 --> 0:42:5.160
Anusree Biswas
of course. Always something to add. Yes, and I don't know if you recall that we did a report in December 2021 that really did explore some of these issues. And I mean, I think both my colleagues, Lillian and Patrick have really hit the nail on the head, you know. There is something about investing in community organizations and also things around being Co applicants where you're really taking part really involved and really part of the.

0:42:5.260 --> 0:42:35.750
Anusree Biswas
Structure of that and not just at the point of, you know, handing that proposal even beforehand, you know, so you have those discussions and really ask those questions when you have the chance and perhaps build things into the research itself. I mean, I do think I have to be crass and say it is about investment and money. We do need that because we just can't run otherwise and also there needs to be a shift in the power relations, you know, and that's where things like Co applicants is really helpful and just having I think.

0:42:35.820 --> 0:43:6.960
Anusree Biswas
I'm seeing a little bit more of that, but I'd like to see much more and much more embedded, you know, and that should be one of the questions that people are asking when they're thinking of doing a you know, a piece of research. Who could we bring into this to make our research more appropriate, more meaningful to the communities that we're looking at, you know, and not just, you know, treating people like subjects. Actually, I don't think that. I don't think you're able to do that anymore. And having experts by experience, for instance, I could carry on, but I will stop there.

0:43:8.270 --> 0:43:38.500
Gary Hickey
Brilliant. Thank you. Well, it's always great talking and working with you all. So thank you, Lillian Anusree and Patrick, and thank you to the listeners for listening to the first in this series of podcasts and talk in equality in future podcasts Patrick, Anusree and Lillian will be hosting the podcast, and we'll be talking to funders of research and indeed researchers. And then we're going to ask for we can get back together again.

0:43:38.790 --> 0:43:51.580
Gary Hickey
And then the series just reflect on the podcast series and the responses we got from funders and researchers and see where we are. But thank you again for listening and goodbye.