**Podcast with Dr Ibi Fakoya-20230626\_103410-Meeting Recording**

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 **Anusree Biswas** started transcription

 **Lillian Ndawula (Guest)** 0:10
Welcome to our podcast series, Talk In Equalities, where we'll be looking at how we can try and address inequalities in health and social care research, with a specific focus on minoritised ethnic groups in the UK.

 **Anusree Biswas** 0:42
I am Anusree Biswas Sasidharan.

 **Lillian Ndawula (Guest)** 0:45
And I am Lilian Ndawula. We are speaking to community organisations, leaders within research and some researchers.
Health inequalities experienced by minoritsed ethnic groups have been well documented. In this series we will explore with funders, researchers and community organisations the role that can be played by health and social care research to help address these inequalities, and perhaps looking to increase representation. In this episode, we will discuss the importance of engagement and what researchers can do to address the lack of representation from minoritised ethnic communities in research.

In today, Anusree and I will be speaking to Doctor Ibidun Fakoya.
Doctor Ibidun Fakoya joined King's College London in 2019, having previously held research positions at the University of Bristol and University College London. She joined the KHP Women and Children's Health team in 2021, where she called it the Ask the Institute programme and leads the Resilience Health Systems Project. She holds a PhD in Social Epidemiology and public health from University College London.
And an MSc in environmental epidemiology from the London School of Tropical Hygiene and Medicine, EB is experienced at leading qualitative and multidisciplinary research teams to carry out a wide range of studies, including programme evaluations, systematic reviews and evidence synthesis. She has extensive experience designing and leading health related research projects in different scenarios and countries, including studies that aim to assess the effectiveness of health interventions. EB has provided expert technical advice too, and developed links with community-based organisations across Europe, the US and sub-Saharan Africa, and has worked with the World Health Organisation and the European Centre for Disease Prevention and Control welcome Ibi Fakoya.

 **Anusree Biswas** 3:09
Ohh.

 **Ibidun Fakoya** 3:10
Thank you. 

 **Anusree Biswas** 3:21
thank you so much for bringing yourself your experience and your presence. We really appreciate you coming today. I just had a question really about you, you know, wanted to know a little bit more about your research interests and your passions and what drew you to the specific areas that you chose to work in.

 **Ibidun Fakoya** 3:23
Yeah, it's a really interesting question and thanks for asking me that. I recently contributed to a book about HIV & HIV research, which I was involved in for many, many years, and I had the opportunity to reflect back then on how I got involved in health inequalities research and research with minoritised communities. And it all started after I left university. So I did my first degree in Biological Sciences and realised that nobody cared about plants.
And so I decided I was going to do environmental epidemiology cause I had this idea that although I've very passionate about the environment and I had this idea that although people don't care about plants, they care about people. So if I do environmental epidemiology, then that will be a really good use of my time and away and get people to care about the environment. But actually people don't care about people either. And so there was very little funding for environmental epidemiology. And I got involved in HIV research.
The HIV epidemic has it affects Black Africans in the UK, and so that's how I started with this. And that's what drew me to my interest in understanding how community engagement can really improve research. If you do it correctly.

 **Anusree Biswas** 5:04
Ohh, that's brilliant. Thank you so much for that overview.

 **Lillian Ndawula (Guest)** 5:08
Thank you, Ibi. So what have you done in your work to improve engagement with people from ethnic minority groups as well as increasing the representation in the participation and involvement in research?

 **Ibidun Fakoya** 5:24
OK, so as I said before I started out, at University College London, getting involved in that HIV research and I used to run this programme called African Communities HIV project or actually it was called the African Communities HIV Research Programme, which Lilian was one of the first people to employ me in involved in all of this many, many years ago. And this was in 2003. And I first got involved in that project, which was about bringing together African communities to ensure that their voices were represented in research because at that time most of the HIV research in the United Kingdom was focused on men who have sex with men and mainly white men who have sex with men. Very little research involving Africans, particularly African women, who were one of the main groups being affected by HIV at that time, and much of the research that was being done with African women, didn't involve African women themselves.
And so the whole point of that project was to collate information about the research that was being done and then bring together people living with HIV and communities and get them engaged in research from the beginning. So that's how I started with that.
And I did that for a few years. And then also that's how I got involved in evaluation. So I was evaluating what was the National African HIV prevention programme in this country at that time, which was a really interesting programme because again, the Department of Health, as it was then, had charged African communities to look after their own health and gave community partner organisations funding so that they could fund interventions to raise the profile of HIV among African communities increase the uptake of HIV testing and therefore reduce late diagnosis, which was a really big problem among African communities back in the early 2000s. And so I was heavily involved in the evaluation of those programmes, which had a big community element to them.
And yeah, So what else have I done? So after that I did that for several years and then became involved in something called (6:24) AMAZE, which was advancing migrant access to health services in Europe, which was a very big cohort study that was funded by the European Union to look at the barriers for accessing HPV testing, treatment and care.
For migrants, all migrant groups across Europe, and I was heavily involved in that. It formed part of my PhD and what was really good for me about that was that I was able to take all of the learning that I had from the previous work that I've done and ensure that it was incorporated into this study, which was mainly run by clinicians and people that kind of understood community engagement but didn't really. And so I was able to ram home my beliefs of actually, if you want to do research with African communities or any migrant or minority community, you have to involve them from the very beginning. So I set up a community group and got them involved in driving the study.
Yeah, I mean, I could keep going. 

 **Anusree Biswas** 9:06
ohh I had quick question. I was gonna interject. I was gonna ask if, it's so interesting that you've involved community partner organisations because many researchers often don't. And I wondered, you know, did you notice that in parallel projects that there was a real absence in that?

 **Ibidun Fakoya** 9:29
When you say parallel projects.

 **Anusree Biswas** 9:31
The other projects say similar projects who might have been doing similar things to you or trying to do similar things to you where they also involving particularly sort of say African women for instance the voices where they heard elsewhere.

 **Ibidun Fakoya** 9:48
I think at the time.
People were trying and I think one of the things that's interesting about my work now is that it's much harder for me to get community involvement and engagement, partly because I'm a health system's evaluator. And So what you're doing is driven by the way people implement their interventions, but also outside of HIV. Community involvement is really difficult. And I think HIV is a very activated community, partly because of the history around HIV and getting medication and the need for treatment across Africa and in the UK and the US you know that whole history of gay men being involved and activism around HIV is so absent from other health conditions. And so a lot of what they call PPIE, Patient and public involvement and engagement is just lip service. It's not very good.

 **Lillian Ndawula (Guest)** 11:03
I think you touched a good point there. The difference between what the HIV field has done and what is happening in other fields and what I always wonder is why people learning from what has been done within the HIV field and try and use that. The learning from that into other areas, for example diabetes.
Where? You know it's it is affecting minority groups, but there isn't that learning from the HIV looks like they're starting from scratch, yet they are examples, there and I just wanted to ask just to focus a bit more on what do you think worked well and what didn't work well in ways of trying to help others who are trying to do similar things to focus on that, but what do you think as you were working there, what really worked well and what you think should have been done better.

 **Ibidun Fakoya** 12:09
Yeah, I think like we said, one of the great things about working in HIV research is that you've got a really activated community of people. And so that makes it easy in some ways. But I think it's also really important for people to recognise that could community involvement is really just quite difficult and it can be, I mean, it can be really easy, can also be really quite difficult. So it's at its best when you go to communities and you ask them what it is that they want to know about.
And from the very beginning involve communities from the concept of your research through to design data collection, data analysis, data interpretation, and then dissemination, right. So if they're involved for the whole research pathway, then people are more likely to be participate and engage. So when we ran Maisha 2016, which was a sexual attitudes and lifestyle survey.
Where? I mean if I explain it to you, you might. It might sound insane that we were trying this, but it worked. We went to commercial venues across London, we mapped them. We went to them, we asked the community leaders in those at venues and the people involved in those venues if we could come send field workers, who we would recruit is so Africa field workers who we recruited went to those venues and they gave out a questionnaire asking people about their sexual lives and their sexual attitudes.
And they gave an anonymous HIV test, so they gave saliva samples, which we then tested and then linked back to their questionnaires. That would have been impossible if we had not involved communities from the start. And if we had not involved them all along. So I think that's one of the things that you have to do.
But all the intentions in the world can fail if you come across gatekeepers who simply uninterested in robust research. And so one of the more difficult things that you can come across is people who have a predetermined and preset idea of what they want the findings to be and who are less interested in robust scientific research and so then as a epidemiologist or as a scientist yourself, you're conflicted because you need that robust research to happen and you don't want to dismiss what people want to do, but at the same time, you've got your pressure from the university, pressure from peer review. You wanna publish this paper? And so I'm thinking of a different community based survey that we were doing where you know, we had this Community advisory group and they wanted to import questions and they wanted to ask questions. But something's are not. You can't answer them using a survey. They're best answer to qualitatively.
And so you find yourself having to give a crash course in research methods to people and explain how analysis works. And, you know, compromise. Some of the things that you want to do. I remember on, in fact, it was that same survey we ended up having a gender question. We had six response items. So people wanted that representation there. It was more important to them that there was the representation, and it didn't matter how many times I said, well, you can have six categories. What?
The majority of those answers are going in the bin. We're not gonna analyse it because there's not gonna be enough data. But it was more important for that representation to go in. So what am I saying? I'm saying you've gotta compromise if you want community involvement in research and you've got to listen to people from the very beginning.

 **Lillian Ndawula (Guest)** 15:57
Thank you very much.

 **Anusree Biswas** 16:00
Yeah, that's really great cause you've sort of gone into the next question which is brilliant and talked about some of the challenges, were there any other additional challenges apart from gatekeepers.
Although you did, didn't you talk quite widely where there any other challenges? Was that your main challenge?

 **Ibidun Fakoya** 16:19
To be honest, the main challenges are within the Academy themselves. Self within academia, particularly from people who are used to thinking about research in terms of clinical trials and very hard quantitative data, and don't understand mixed methods research.

 **Anusree Biswas** 16:25
Hmm.

 **Ibidun Fakoya** 16:37
these are often people who can't see how their own biases influence everything they do in research. They just don't get it. They lack the capacity to reflect on how their assumptions influenced even the questions they are prepared to ask from the very beginning. Even the nature of the research they want to do, and particularly their assumptions about ethnic minority communities, I remember fighting very hard with a group of researchers to explain to them that yes, Africans can use mobile phones.
I mean it sounds dumb now, but you know we can have a survey that's online because African people can use mobile phones. If you know anything, you will know that most of the innovations around financial technology have come from Africa. This is where it came from. Why do you assume that, you know, Africans can't use mobile phones? And so other assumptions that they have around the way people live I remember and arguing about including a hunger scale in a survey because they assumed that hunger only affects people living in Africa. But when we did the cognitive testing on the survey and deploy it on the survey, 20% of participants had experienced hunger at a level that was equivalent to some of the most hungry people in the world. Just because you're a migrant, living in Europe doesn't mean that you aren't going to face those challenges. So getting those people to understand that you need to involve communities and it's really important that you do so that they can challenge their biases has been one of the most challenging things that I would I would say and they just don't understand like I say, how their assumptions have an impact from the initial concept to the way they collect the data, who they involved to collect the data, how they analyse it, how they interpret it, how they disseminate it, you stick it in a journal, nobody reads it, nobody does anything with that. 

And these are the kind of people who say things like the numbers speak for themselves, which is ridiculous. So they don't understand mixed methods, research at all. And we know it's not true that numbers speak for themselves. Statistician once told me that if you torture numbers long enough, they will tell you whatever you want to know and I think.

 **Anusree Biswas** 19:16
Yeah.

 **Lillian Ndawula (Guest)** 19:16
True.

 **Ibidun Fakoya** 19:19
That's quite clear. So yeah, I think they think about community involvement in research as a purely lip service thing. PPIE is something that's now on every form. So we do it and it doesn't matter who we do it from. And so I think one of the other big challenges I will say is getting researchers to understand that you need to go to a variety of different people. It's no use just talking to support groups.
Support groups have a great and they often represent some of the most vulnerable people. But you need to think outside the box and who you approach. Approach dance groups, cultural groups, sporting groups, faith groups and different wide variety of people that are not involved in health to get information about what needs to be done because generally speaking, a lot of those support groups speak to the same people over and over again. So you see this quite often in the work that I evaluate whole interventions designed on the views of 20 people from the support group, the same support group that designed the previous intervention,

I sound quite money. I'm sorry.

 **Anusree Biswas** 20:31
Ohh this is brilliant and it really resonates with I think with us but with other community development organisations who work with researchers and I think it's really powerful what you say and very welcome what you say. Certainly from our point of view because it feels that it's very there's an honesty like a, you know it feels a lot closer to what the actual truth of our lived experiences are and would be really, you know if more researchers took that approach we'd be delighted.
To see that cause it just feels like a really great approach from our point. Well, my point of view certainly, so you kind of started given your advice to researchers which is really, really helpful about not being so sort of a focused on one group and that will skew understandings of the group more widely. So do you have any other advice that you could give researchers to increase representation of people from minoritised ethnic groups in their research?

 **Lillian Ndawula (Guest)** 21:08
Yeah.
And.

 **Anusree Biswas** 21:31
Both in terms of participation and involvement.

 **Ibidun Fakoya** 21:35
Yeah. So like I said, involve people involve groups, variety of groups from the very beginning, when you're writing your grant application start then.
So the question is relevant and if the question is relevant, people participate. That's one of the ground rules for me and pay people for their time. Don't assume because somebody volunteers at a food bank that they're gonna volunteer for your study, so many people seem to think that it's OK to take up hours and hours of people's time without compensating them for it when they themselves would not be compensated.
Your work for free in that way.
Yeah, like I said, try and keep away from the usual suspects.
I think particularly in NHS organisations, because there's time pressure and there's funding pressure, it is easy to go to the same people over and over again but get what wide range of views.
Yeah, like I said, increase participation by ensuring community involvement by the outset. And I think one of the things that I learned when I was doing my Aisha (18:51) 2016 that sexual attitudes and lifestyles survey was that when you involve researchers from the community in the research, you can do a lot of really good work and people need to consider thinking about that. Not just people like me, just because I'm Black doesn't mean I'm representative of the community or yeah, I've got all of my scientific biases in there. I've been trained in a particular way to think that always has an impact on the way I want to design something.
So yeah, get communities involved in the data collection and the data analyst, and also ensure that you have mixed methods research. I'm just gonna be one of these boring mixed methods advocates where it's not just a case of numbers. You need numbers and stories cause stories really influence people, and so the more stories we tell, the more people hear them, the more likely they are to want to get involved in research.

 **Anusree Biswas** 24:04
That's brilliant. Thank you.

 **Lillian Ndawula (Guest)** 24:06
Thank you, Ibi. I think I resonate with some of the things that you attached on there, especially where people go to the same groups or they talk to one person from that community and the thing that they have, reached those communities or they expect you to reach those communities for them, but you can only reach a certain a certain number. But also I think the fact that I think we've talked about this in our discussions with the reaching out group around building the trust, trust with the communities. I think it's that time that the researchers put in, and sometimes maybe the researchers don't have that much time when they're thinking about their research and forget that they need to build those networks, those relationships first with different communities, because you're not just coming to us as a community group and we don't know anything about you. You have not sat with us to talk about what you want to do. So in doing that, you also get more genuine I think responses because sometimes us as communities would give their response that we think the researcher wants to hear.
But when you build those relationships, then you find that you can get more genuine.
Answers is that has that been your experience in?

 **Ibidun Fakoya** 25:36
Yeah, I think it takes a lot of time and a lot of work to build those relationships with different communities, and I think when I was working in the African Communities HIV research programme and, you know, evaluating NAHIP (21:23), there were a lot of things that I did that at the time I didn't realise I was doing. I didn't realise that I was building those relationships and I was putting all of that work.
I look back now and I realise actually I spent six years building those relationships so that I could, when it came to delivering on different surveys in the university I could just reach out to different people and say, hey, listen, do you wanna join my community advisory group? And people always like, yeah, sure, we know that's coming.
I think a lot of people now just think I can tell some terrible stories, which I won't do cause I know this is going out in public, but people who think that they can just rock up to a bunch of hairdressers and say, yeah, sure and think they will implement their intervention and participate in the study in a way that will be useful without recognising that they don't have a relationship and they wonder why they're intervention fails. Well, you've just paid people to do something they're not really involved. The trust, isn't there? So I agree, Lillian. We do need to spend that time building up trust and building up relationships. But nobody wants to fund it. And that's the big challenges that actually, if funders really thought about what they wanted to do, they would be funding universities or researchers’ organisations just to have that relationship ongoing throughout time, regardless of what's studies going on, because it’s always attached to an individual study, there's no sort of like an overall programme which is.
Where it becomes problematic.

 **Lillian Ndawula (Guest)** 27:43
So would you think it's worth for the universities themselves, because they're the ones who bring in the researchers or for other funders themselves, maybe the universities do have that as an outreach programme into their local communities, or if it's a hospital, that research the research arm (23:13), I don't know how, how the hospitals do it. Any research has been done within the hospitals to be able to build those trust themselves so that when they bring in the researchers.
They already have that ongoing working relationship with the groups.

 **Ibidun Fakoya** 28:17
Perhaps I think universities and hospitals are all funded in such a way that it's quite precarious for that kind of thing to take place. So having that ongoing long relationship with.

 **Lillian Ndawula (Guest)** 28:26
Ohh.

 **Ibidun Fakoya** 28:30
Organisations is quite difficult, especially since.
Austerity and various things that happened that so many organisations were defunded and disappeared, and there was all of that. You know that bonfire of charity organisations that occurred first in sort of 2008.
2010 that kind of area era, and then again after the pandemic, so many organisations completely felt. So it leaves this core of organisations that are more corporate and less embedded in the Community than they like to admit.
Being quite controversial by saying that.

 **Lillian Ndawula (Guest)** 29:18
Thank you Ibi. So if the goal is to reduce health inequalities, what is the thing that you would change?
In the world of research to help us reach that goal.

 **Ibidun Fakoya** 29:33
I thought long and hard about this question actually because I think the changes in research when it comes to health inequalities, but actually if we think about researchers and what researchers need to do, I think they need to incorporate our understanding of why the determinants of health, the wider determinants of health into our research a lot better.
I don't, you know, really have the answers, but I'm a big fan of Nancy Krieger, who is an American epidemiologist, and she has this thing called eco social Theory where she advocates that we underpin our epidemiological research with theory, and we need to examine how different historical, societal, and ecological constructs have an impact on the health of different groups.
So I think one of the problems that we have in research is that when we're looking at health inequalities, we focus on individual risk factors, BMI, hypertension, cholesterol. That's how we deal with it. We don't focus on the whole person, let alone the whole system. We don't think about the causes of causes. I think in the Guardian at this weekend, some Marco Marmot was writing about how austerity has had an impact on the height of children. Have you seen that? And.
It is things like that that we need to start thinking about so.
Yeah. While people are happy to fund interventions into like I say, paying people, paying hairdressers to measure blood pressure to we can detect blood pressure amongst Black, African or Black Caribbean communities. So yeah, let's fund this intervention where we pay Black hairdressers and Black barbers to take blood pressure so we can increase the detection and management of hypertension. Everybody wants the fund that cause that sounds really sexy and interesting, but nobody wants to fund
an intervention into the causes of causes like, for example, how about we fund an intervention looking at noise abatement on estates and how noise abatement might improve people's blood for pressure cause we know that noise is linked to high blood pressure, things like that. And if you live on an estate, you know how noisy it is to live in on a state and how you can be kept awake for weeks nights after nights because some local person blares their music. I know this security guard one time when I worked at normal market, he had like a heart condition and you know eventually got signed off. But he used to complain to me about somewhere where he lives. Some guy where he lived in Walthamstow who everyone called the area man because he would blast music for a sort of like six hours a day across the area and keep everybody awake and disturbed. And I always thought, yeah, of course you are stressed out and tired all day. You work alone or low waged job. You live in a place where you don't get any peace.
Those are the things that have an impact on people's health and sure, yeah, detecting at an individual level and treating it individual level is useful. But actually let's think about some of the wider determinant of health when we do our research.

 **Anusree Biswas** 33:00
I'm so excited by what you're saying, Ibi. I want you to come here and stay on and lead lots of stuff right here. I'm really excited and I think it says something about, you know, sort of Black and minoritised ethnic leadership, seeing them in, you know, roles of leadership, to have that insight and have that way of engaging with communities and having that sort of vision of what good research could look like, where there is so a narrative and taking more of a.

social anthropology view, and doing that ethnography, which is so exciting but coming from a social anthropology background myself. So I welcome that approach.

 **Ibidun Fakoya** 33:40
Exactly. And I think, yeah. Social anthropology. Social sciences, mixed methods research has a huge place in wider determinants of health and the health inequalities research but is sidelined. And right now there's a huge focus on something called population health management, which is all about data-driven metrics and dashboards and primary care and nothing about the causes of causes, which is what Nancy Krieger and others talk about when they mean yes, we understand the web of causation, we know the high blood pressure leads to higher pretension, which leads to a cardiovascular disease. But what's causing the high blood pressure?

 **Lillian Ndawula (Guest)** 34:27
Yep.

 **Ibidun Fakoya** 34:27
Why are we focused on that?

 **Anusree Biswas** 34:30
Absolutely. Because we spoke earlier to a sort of research funder around preventative.

research and it's certainly something that we would be keen to see much more of. And where do you think that could come? Do you think there's a way to encourage that kind of, I mean, I know you're struggling as well to encourage that with amongst wonders and academia. Is there anything that we could do to support that or help build it, that movement towards that?

 **Ibidun Fakoya** 34:59
I think.
When we talk about Community involvement, we do it properly and communities are able to advocate for the then funders have to listen. If we, if we can go back to funders and say, actually communities are interested in a more holistic approach and more interested in tackling the wider determinants instead of being focused on smaller little bits of the puzzle, then maybe funders are interested in that, but without going into sort of a wider critique of neoliberalism and the whole way in which society works, I'm not entirely sure how we could do it, because we're very much focused on the individual and rather than and that's the real conflict that we have particularly, I probably as community based organisations that you have, is that people are focused on what individuals can do and what you can do for yourself and personalised.
Whereas for many Black, African and Black Caribbean communities and probably Asian communities as well. There's a collective identity and there's a collective way of working and pushing things forward and that we failed to utilise and we fail to understand or tap into.
I I'm not sure how we convince funders or convince medicine at all health services research in this country there actually let's tackle things at a slightly higher level.
Wider level, not higher.

 **Anusree Biswas** 36:34
Because I was quite interesting cause I cause I I'm quite interested in personalised care, but I really do take your point there. But there's a whole because make it. Maybe it's so personalised, there's no, so I don't know that nuance in a way. Ironically, even though it's personalization, it's not looking at issues that might be affecting a whole swathes of people.

 **Ibidun Fakoya** 36:53
I think yeah. And I think there's a difference in understanding of terminology and language. So when a lot of people talk about personalised care and the talk about personalised care that's going on in integrated care systems. They're talking about precision medicine. They're talking about genomics, they're talking about sending you off and testing you for different things and then tailing your medication for that. Whereas where when individuals are talking about personalised care or groups, and they're talking about holistic care, they're talking about actually thinking about me as a whole person and my whole body and my whole life.
When you when you prescribe something for me, so not just.
Be a blockers or calcium channel blockers.
Do some social prescribing, some gardening works and other things that reduce loneliness. We really recently evaluated a really interesting programme called the Winners Women's Health Network, which are a social prescriber in Lambeth, PCN decided to bring in because they're social prescribers, were being overwhelmed by mainly women who had been referred to them by GPs with social problems and they're being overwhelmed because there's no other organisations to cater for them. So actually the majority of women, majority of these people, they were being they were being referred to them. What was their main problem? Loneliness and isolation. And so they created these weekly will actually where they biweekly workshops, networks where they taught these women out to live.
How to look after their own health and they
put them together and offer peer support. It sounds so simple and straight forward and lessons that we learned 20 years ago, but somehow, we have forgotten them. This is again innovative.

 **Lillian Ndawula (Guest)** 38:53
Okay.

 **Anusree Biswas** 38:55
I just want to finally say thank you so much Ibi, really enjoyed having you it’s been fantastic hearing your reflections and your thoughts and your passion it’s been really wonderful thanks so much for taking part in our podcast.



**Lillian Ndawula (Guest)**
thank you so much for having me it’s been really great.

 **Anusree Biswas** stopped transcription

Outro to be added