**Podcast with Simon-20230612\_153451-Meeting Recording**

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45m 22s

 **Lillian (Guest)** 0:33
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** 0:50
I am Anusree Biswas Sasidharan.

 **Lillian (Guest)** 0:53
And I am Lilian Ndawula. We are speaking to community organisations, leaders within research and some researchers. Health inequalities experienced by minoritised ethnic groups have been well documented, in this series will be 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 participation and involvement, we will discuss the importance of engagement and what funders are doing to address the lack of representation for minoritised ethnic communities in research and in participation and involvement.

In today's episode Anusree and I will be speaking to Simon Denegri, and I'm going to say a little bit about you, Simon.
Simon Denegri is an executive director of the Academy of Medical Sciences.
Prior to taking up this role in October 2019, Simon was the national director for patients, carers and public at the National Institute of Health Research, NIHR and Chair of Involve the National Advisory Group for the Promotion of Public Involvement in research funded by NIHR. He was chief executive at the Association of Medical Research Charities from 2006 until 2011 and prior to this Director of Corporate Communications at the Royal College of Physicians from 2003. He also worked in corporate communications for Procter and Gamble in the United States from 1997 to 2000. Before this, he led successful campaigns for the Alzheimer's Society between 1992 until 1997. He was awarded the OBE for services in NIHR, Public Health, Social care research in the Queen's Birthday honours of 2018, Simon, you're very welcome today.

 **Simon Denegri** 3:06
Thank you. It's lovely being here. Thank you for that very kind introduction, Lillian.

 **Anusree Biswas** 3:12
And gonna go straight into questions with you, Simon. Could you tell us a little bit about the Academy of Medical Sciences and what it does really?

 **Simon Denegri** 3:22
Yes, very happy to do that. So the Academy of Medical Sciences is a fairly young organisation. This year was celebrating our 25th anniversary. We were established in 1998.
We bring together over 1400, what we call fellows into a fellowship. we elect a number each year. Our fellows are the most influential scientists across the whole of medical science in the UK, from statisticians to lab-based scientists. They are very much the heart of the organisation.
We also have a wider community of several thousand early career researchers or emerging research leaders, as we sometimes call them that have been supported by our grant funding and career support, who are very much part of the organisation.
So we do three things really in broad terms. Number one, we aim to influence policy and the environment around us that the so that science is able to thrive in the UK but also internationally we have a very vibrant global programme of work.
The second is we provide as I've sort of preferred to you earlier, career support and innovative grant funding for researchers as they climb the career ladder and we have some very innovative schemes to do that to help produce inequalities in the research workforce. And thirdly, we do a lot of work and increasing amounts around public involvement, public engagement, public dialogue, often alongside.
Some of our other work, whether it be to do with COVID or climate change and health issues.
So those are the three main things to do and I head up the organisation. I have a president and a Council on offices and I head up the staff Group, which is there to take forward all of those activities.

 **Lillian (Guest)** 5:36
Thank you very much. Simon. What do you think funders like your organisation or NIHR could do about reducing health inequalities within minoritised ethnic groups? I know you touched a bit about that. If you could just give us a bit more on that.

 **Simon Denegri** 5:55
Uh, yes, very happy to. Well, I believe that research funders are in a very powerful and influential position because very little can happen across the sector. In fact, in any sector when it comes to inequalities, without resource on funding to support it. And I'm sure as you're aware that this is an area that often doesn't get support and resource enough.
But they are very important and I think powerful and helpful to this agenda. If they do a few things and I think number 1 is they can make health inequalities a priority a focus of their calls and their work and the way that they want their partners to operate with them. So really make sure it's at the top of the agenda.
They can ensure that they are funding good work in this area that's going to be important and Influential.
They can ensure a supply of really robust and good evidence to support a reduction in inequalities or in equities.
And they can ensure that evidence is in the public domain and is open and transparent for all to use and to, you know, scrutinise, to think about how it might be implemented by them. And I think fundamentally at the core of it though, is they can all involve people from as diverse backgrounds as possible in the way that they make decisions. And of course, my primary interest as a patient advocate, historically, it's to see patients and public and citizens involved in the decisions that research funders take, whether it be what they prioritise in research or where that money goes, or how they do things. Because my fundamental belief is that the more diverse population, they have involved in that, the better their decisions will be and the more effective and valuable the money that they will spend.

 **Anusree Biswas** 8:08
Thank you. I just wanted to ask you about engagement with people from ethnic minority groups. I mean, you did touch on this as well as the increasing the representation in participant and involvement in research.
How is it working in your organisation? Cause you talk about early careerist?
Could you tell us a little bit about what you're doing and what you what plans you have?

 **Simon Denegri** 8:33
Yes. So I think that's probably four or five levels on which we're trying to make some headway here.
The first is and I probably should have mentioned it earlier, is that we have a new vision and strategy and the vision statement is good health for all, supported by the best research and evidence, so it's very much a statement that our ambition is to see health improve for all people and all communities, and that to do that, health must be based on the best research and evidence, and that has to be also drawn from the widest possible evidence based and people doing it. So it starts with our vision
number one. And then of course our values. So we have 5 values including inclusivity, which is fundamental to the way that we work and the way that we want to increasingly work over the next 10 years, which is the time frame of the strategic framework produced. But then of course, you need things lower down to begin to direct the work that you actually do. So last December our Council, which is our main decision-making board, our board of trustees for want of another term. Passed our EDI strategy, our equity diversity and inclusion strategy. And then that was launched and published on our website in March. And the goal number 2 in that is about to support a biomedical and health research culture that promotes and values equality, diversity, inclusion, and for that, it means having a dedicated budget.
For collaborations with grassroots networks that represent ethnic minority, biomedical and health researchers, we've done a bit of collaborating with the Black women in Science Network last October, which is very successful as part of their celebrate new event.
We've done this for a good few years. We've always believed that it's really important to have a robust data gathering exercise and reporting that publicly so we collect diversity data across all our work streams so that there's live data about the Academy and the stakeholders we are engaging and we'll continue to do that. And we'll occasionally as we did two years ago, ask that to be independently examined and verified because we think that's very important that people, it has the credibility.
But I think we'll also just continue to look at ways of innovating. So if I take another example from, you know, another area of inequalities but relevant to this and obviously there's intersectionality here around gender.
You know another area of concern to us is that actually women don't have the opportunities in research and science perhaps that men do, they find it more difficult at different career points. They have families, they have to juggle priorities. Our research institutions, although they might be improving, have traditionally not been accommodating of that. So it's been more difficult for them to become senior researchers and professors and so on. And we've senior leadership patients. In that instance some a few years ago we established a skin called sustain which is really focused on supporting women and giving them the skills and the experience to help them feel more able to develop their careers and become confident in their research environment, whichever they find them, so you know that can be everything from mentoring or workshops to then they go on a media training session because they'll often be asked to represent their research in the media. And it's a very important thing to be able to do that confidently and clearly. So sustained a good example of the sort of innovation that we've done in the past in terms of gender there are obviously, ethnic minority women who are part of that, so we would continue to look for innovations. I think in how we how we do this, and we've just formulated a new equity diversity and inclusion advisory board for our council and I think that's gonna be very important in forming council about how the, the things that we should be doing in the future. I think good boards have seek good advice.
External advice to in order to continue to improve, and hopefully that's something that we're doing with our, with our new advisory group that will be formulated very shortly. So those are just some of the examples of how we take forward that agenda.

 **Anusree Biswas** 13:40
Yeah, it sounds really exciting actually. And to hear about sustain and I wondered, I'm gonna ask you the inevitable question around, will you have something similar for Minoritised ethnic people who are who might also be underrepresented? Cause that does sound brilliant. And while it might capture minorities, ethnic women, it wouldn't necessarily capture minorities ethnic men. And I wondered if you could tell us?

 **Simon Denegri** 14:01
Yes. Yeah, very good point. So we have talked and are talking about whether we might be able to do a sustain, you know the different context.
And I think we would like to obviously it's somewhat funding dependent for us cause we get funding from other people, but absolutely it would be our intent to try and think about how we could do the sort of sustain model in other areas. I think the important thing for us as well though is not just to lift and place something in another area and expect it to work. We're a great believer in spending time talking to that community adapting, tailoring, learning and piloting. So that it meets the needs of those individuals and that community and not expect something that worked in one area to automatically work in another. So I would hope we might, and I hope that people will make sure that we do by constantly badgering me about it.

 **Anusree Biswas** 15:06
It sounds very exciting and it sounds like exactly the right way of talking about it, so it's it sounds really good and exciting. I was also gonna ask about your early careerists as well. Are you seeing sort more minorities, ethnic people come in through there? Is that what's happening? Is there an intention, are you seeing that within your fellowship?

 **Simon Denegri** 15:07
Yeah so we are seeing both in terms of our fellowship and also our early career researchers, we are seeing more people with ethnic minority backgrounds coming through in our last round of fellows who were elected in May.
I'm probably gonna send you the figures Anusree because I'm probably gonna get them wrong, but overall our ethnic minority figure is around 17% I think in our last round of fellows. And so that's pretty good. But we are some way behind where we should be. If you look at our total fellowship. So if you look at women, for instance, this year 39% of fellows that we elected to earn are women.
But if you look at our overall fellowship, only 21% of the total are women and that's way below what it should be. And it's a tricky one because we only elect so many people each year.
And so making that change is quite can be quite slow, and one of the decisions I think we have to think about is whether we continue to go in this way and edge it open and overtime it will change or to try and do some bolder initiatives, you know to get more people in a more rapid way.
And I supposed to it's a live discussion. You know, it's not something we're constantly thinking about. We will be talking about it at our Council meeting in a couple of months’ time.
It always comes down to also, how do people who've come through that fellowship route feel about the system, and whether it feels fair or whether it actually perhaps shines a spotlight them in? The intention was good, but it actually shines on them in a negative fashion.
You know, that people begin to doubt that they're there for the good of their science, cause they want to be known as good scientists. Absolutely. So all these issues are quite an important and interesting balance I think.
So I think we're making progress. We would want to make faster progress. I think it's probably more apparent with our early career researcher groups, those who are coming through our schemes, who are benefiting from our grant funding. I think the picture is much more different there. I think in some sense it's perhaps the pool is different from which we are drawing upon.
And I think we are richer for it as an academy.

 **Anusree Biswas** 18:21
Thank you. That's brilliant



 **Lillian (Guest)** 18:32
I wanted to also add on a question there around researchers for minoritised communities. Would it also help if there was a bit more awareness within the minorities communities about research because I don't think research is seen as a career path that is easily taken by minoritised women is because of the West funded.
So if you are minoritised you need that constant flow of income whereby if you don't have a project in research you might not get that financial income coming in. So is it something that we might be also maybe needs to look at as to raise that awareness within the grassroots communities about research as a career path

 **Simon Denegri** 19:33
Yeah, I think we do. I think there's a lot of work to be done here. We have a scheme called Inspire, which we do in medical schools. So these are people already trained to be doctors and some of the new medical schools have been really focused on supporting doctors from minoritised communities but our INSPIRE programme is intended to excite and inspire and attracts young doctors into research to do research to think about a research career alongside their clinical career or whatever, and it's a very successful programme.
So we tend to think about it in terms of people who are from medical schools onwards, but I think there's a lot of work to be done much before that. You know, in schools, for instance, in universities. And there are some very good organisations like INTERSCIENCE that have traditionally been very, very, I think, important to give.

 **Lillian (Guest)** 20:23
Ohh.
Ohh.

 **Simon Denegri** 20:39
Young people exposure to a research career and how exciting it could be, but we've got a long, long way to go. It's something we also talk about at the Academy, whether we should be doing more with younger people. Is it worth than medical school students?

 **Lillian (Guest)** 20:46
Ohh.

 **Simon Denegri** 20:59
Around research, I suppose our challenge is that there are many organisations already active in that area. What more could we possibly do with our limited income and expenditure? So we've tended to focus it on where we think there's been an issue which is young doctors being educated, coming into the health service, understanding importance of research and being inspired by it, and actually one of our big policy problems, I suppose if you want it is that our NHS, particularly with all the pressures on it, it's not necessarily attuned to the importance of health research as it might be.
You know our belief is that a high quality health and social care system depends on high quality research and research needs to be embedded in the NHS. But of course although it's had some really amazing success during COVID.
Currently it's quite difficult I think for a pressured doctor to consider a research career or to do research because of all the other things that are on their plate.

 **Lillian (Guest)** 25:28
One of the things we found time on when we're doing reaching out a project with NIHR in the south east was the lack of trust between the community organisations and the world of research.
How are you working to build that trust and or how do you think we can build that trust?

 **Simon Denegri** 25:53
Yeah, I think this is one of the most important issues that science and health research really needs to grapple with, I think going forward because I think it's been there a long, long time. It has historic reasons deep seated ones that go down to history environments.
It was accentuated, highlighted, if you like by COVID and the experience of minoritised communities during COVID but I think even though it's been highlighted and underlined during that period.
I'm not necessarily convinced that the penny has dropped as much as it might do.
So I think it's a massively important issue.

 **Lillian (Guest)** 26:43
Yeah.

 **Simon Denegri** 26:47
I think there are some of the things that we can say are signs that things might be beginning to change.
So I've done some work, for instance with something called applied research collaborations, which are local parts, and again NIHR. I'm using a very simple term there, but they're sort of the local part of the research funding landscape that NIHR produce and particularly in the East of England and the East Midlands, the East England East of England ark we called them for short has a scheme which is all about populations in focus, which is looking at the research needs and working with communities who are marginalised in one way or another, and that's been very interesting.
The East Midlands one has black and minority ethnic sense of expertise, which is quite old in some respects, it started off probably about eight or nine years ago by focusing on diabetes in Asian communities and then, of course, the COVID experience, I think has it enabled it to transform into almost a sense of national expertise about understanding the needs of minoritised communities and the work that we need to do. And then I think there's also things like the NIHR now has a race equality framework, which I think is beginning to have some traction.
With not just public research funders, but also industry, for instance, particularly pharmaceutical companies. So I do see more focus being paid attention to. I do see some really, really amazing work being done.
It's probably a few things. One is it needs more resource. Two, it needs to be joined up so that people can learn from each other's experience.
And third, I think what I would like to see is more evidence of the Community voice being in there and driving the agenda as it were and it may be too early in for that to happen. But I think we will know success will partly be predicated I think on minoritised community voices leading that work and driving that work.
In our own case at the Academy of Medical Sciences what we've tried to do is with our COVID work, for instance, that we did, we did two big reports on the winter preparedness of the system.
And then we've just recently done a report about sustainability of health research in the future.
We've ensured that there's a minoritised community voice in that work, and I think that has to be a basic principle across all research funders and research institutions that we all need to be doing this. We need to make this, you know, the horrible phrase we need to make this business as usual, cause otherwise nothing will change.

 **Lillian (Guest)** 30:18
Hmm.

 **Simon Denegri** 30:19
So some early beginnings of good work a long way to change, I think probably the most difficult element of it of all of it will be the whole public trust, how his research perceived by the community, how it's reported in those areas.
I've always been really very struck by the work I saw in Australia and Canada when I was in my previous role at NIHR.
And the work they did with indigenous communities.
And the time and attention that they spend with talking to community leaders.
Before they even, you know, start to do any work in those communities, they spend time with community leaders. The community leaders are the ones that help the community feel ownership of it as a valuable thing they should be doing. And then only when they've gone through that route of conversation dialogue, agreements then, do they start work and I think we need to do the same process in building support and willingness and ownership of the work that we want to do and it's not been, I think as stronger part of our philosophy as a research.

 **Lillian (Guest)** 31:36
Hmm.

 **Simon Denegri** 31:45
Sector and the culture and the Community is as we should have been in the past, and I think we need to need to change that. The other thing is, I did quite a lot of reviewing for other countries and I noticed you review for Canada. They will have a section by law that researchers have to fill out which says how are you going to involve Indigenous communities in this? What are you gonna do?

 **Lillian (Guest)** 32:06
Ohh.

 **Simon Denegri** 32:07
And I think that's really important. You could say that you get a very standard response back and like, but I can tell you as a reviewer, you can spot a good response and you can spot a response that has literally been written by the PR department. You know, it's important. It's important that they are asked the question and made to consider their actions

**Anusree Biswas** 32:34
I'm fascinated with what you're saying, and I definitely recognise what you're talking about in Canada because I'm doing another project with Toronto and they definitely is a very deliberate acknowledgement of the Indigenous people's or fascinations people, which is just quite, I don't know, powerful, actually visiting.

 **Simon Denegri** 32:54
Yeah, yeah.
It's even down to when they start meetings and how you're knowledge, the people and the land you're on. It's a very important reminder actually we are only in this room in this place because of things that happened in the past and we need to pay respects to

 **Lillian (Guest)** 32:56
Ohh.

 **Anusree Biswas** 32:58
Yeah.

 **Simon Denegri** 33:13
That history and to the communities, I think that's a really important respect. It's a very important word, I think in this regard.

 **Lillian (Guest)** 33:19
Ohh.
Yeah.

 **Anusree Biswas** 33:20
I was also gonna say that both Lillian and I are part of the Kent Surrey and Sussex Ark. So we've sort and it's really great to hear about the East Midlands ark cause they seem quite a developed and mature ark in terms of minorities. I think people might be really good to maybe connect with them and understand better how they're doing things.

 **Lillian (Guest)** 33:21
Definitely.

 **Simon Denegri** 33:28
Ohh great.

 **Lillian (Guest)** 33:41
Hmm.

 **Simon Denegri** 33:42
Yeah, yeah.

 **Lillian (Guest)** 33:42
Yeah, especially that black and minority ethnic centre of expertise, because I think that would be a good thing for us to have down here, where there is that centre where, you know, if you want to know about those communities, there's some expertise there and maybe recognising that there is that expertise within, within our communities already.

 **Simon Denegri** 34:02
Yeah.
Yeah, well, I mean, it's very interesting, isn't it, we have lots of national, you know, I mentioned the Black women in science network. Why can't there be, you know, the Black community advocates and science network?
You know, whatever. A part of this I think will come from people coming together and forming national organisations and alliances.

 **Lillian (Guest)** 34:31
Yeah.

 **Simon Denegri** 34:31
I think it's a very important developmental stage. I think of what should happen next.

 **Lillian (Guest)** 34:36
Hmm.

 **Anusree Biswas** 34:38
Simon is really interesting what you're saying and it you've kind of answered a lot of the question I was gonna ask next about, you know, what do we do about EDI not falling off the agenda? How do we approach that? Because you're talking about these wonderful visionary ideas and you're putting things in place and maybe interesting to hear what you did with the Black women’s in science, perhaps cause it would great for us to hear about some models that we could share with others.

 **Simon Denegri** 35:07
Yeah. So I'll share with you a link to a podcast done by Vivian Kinko's (25:33), our equity diversity and inclusion manager. Cause she's done a really fabulous podcast for the black women's in science network about how that partnership develops, and it developed primarily, I think, from a belief that we had when we started off a few years ago to think about our EDI work.
There were very many models that we could have chosen and we were part of the, you know, equity, diversity, inclusion in science network and those sorts of bodies. But when you are an organisation with only so much money, you know, how do you, help make things change?
And um it my team were the ones I think he came up with their very bright idea, which is rather than try and bring people into what we're doing, how can we foster networks? How can we foster partnership? How can we support those in communities who were doing this. So we, you know, gave little bits of funding to people to help support that. And out of that emerged some stronger relationships. Black women in Science Network is one of those and then when they did their first ever in person celebrate events.
Partly because of the relationship between us and Vivian and them, they chose our Academy, our HQ London offices to do their events, you know, which was a fantastic celebration. It was, you know, it was lovely to be part of that, but I hopefully they also drew strength from feeling part of the Academy because that's what we wanted them to feel, that they were a very important partner of us. So I think a lot of this is about really just good, honest relationship building and I think the most important thing, probably at heart of that is just being honest and about expectations, you know, there's no way I can give you Anusree, you know, £1,000,000 to go and do your work that you need to do because I don't have that. But you and I can say I can do this and it will get us to the next step. So I'm a great believer in being quite pragmatic and opportunistic.
But having our ambition in mind and trying to find lots of ways in which we can support one another to do that.

 **Anusree Biswas** 37:34

Thank you very much.

 **Lillian (Guest)** 37:37
And as you say, a lot of the work it is opportunistic in that you find that opportunities where within those communities where you can then do your work and in a way that's how community organisations would work because they can value those opportunities. So that kind of collaboration as you say would work very well.

 **Simon Denegri** 37:46
Yeah.
Sure. And I think you're right and a really important element of that is I think trust.
So I can remember us talking internally about giving these small grants out and we were worried that people might react badly, you know, isn't it a bit risky? And we talked it through within the team. And our conclusion was that fundamentally this is about trust, is trust saying as a community, you know what's right, we're here to support what you can do to help. It's not about interfering.
It's about supporting you to do what you need to do, but also enabling you to challenge us and the only way that we can do this is perhaps by giving you some support in a monetary way or in client health to get things off the ground. So I think trust is a really important element and being prepared, to hear challenge and feedback on your organisation, that may not always be the easiest to hear or individuals. I mean, I can tell you my team would be very challenging to me when they think I'm not being very you know equitable and inclusive and quite right now, quite right too, absolutely.

 **Anusree Biswas** 39:16
And it's good that they can be Simon. That's so lovely. You must obviously have a good environment where people can have these conversations. That's good.

 **Simon Denegri** 39:22
Well, thank you. I hope so.

 **Lillian (Guest)** 39:31
So our last question really is that if the goal is around reducing health inequalities within a minoritised ethnic groups, what is the thing that you would change to help reach this goal?

 **Simon Denegri** 40:50
You would probably expect me to say this because of my background but my number one priority would be to make sure we involve people from minoritised communities in decision making about research.
What research is done? What the research question is, how it's taken forwards and how it's disseminated. I think that's the one that, although it may take longer to happen throughout the whole system, will have the longest lasting change for us all and will benefit us all.

 **Lillian (Guest)** 41:31
Sure.

 **Simon Denegri** 41:39
And I think I will know that when I stand up in front of a hall of patient and public involvement partners and not just see one, you know, group sort of community in the room.

 **Lillian (Guest)** 41:56
Ohh.

 **Simon Denegri** 41:56
But many communities represented and being able to feel confident and about reflecting on their experience and feeling supported in that room from others.

 **Lillian (Guest)** 42:12
Yeah, I think that's very good. And when you talk about seeing those communities coming together, I think it is going to take time it's going to take commitment and probably both in time and in funding, and I think many funders are not really ready to do to put that funding down. I think that's another thing that we need to maybe advocate for is that the results are more lasting than just dipping in and out because then those communities.

 **Simon Denegri** 42:49
Yeah.

 **Lillian (Guest)** 42:51
Will gain a lot of skills to those communities will understand more of what you're doing as researchers and probably will give you more information, more genuine information. I think this came out from our research Reaching Out when we reached out to their communities and we did discuss about you know, how putting your trust and your commitment into these communities can actually give you more back as a researcher because you're getting more genuine information

 **Simon Denegri** 43:30
Yeah, well, absolutely we produced a report this year called future proofing UK health research and again I can send you a copy of that and we have a section on public involvement in that.

 **Lillian (Guest)** 43:42
Please.

 **Simon Denegri** 43:46
With some key recommendations.
One of those is that funders need to fund public involvement properly and properly with regard to grants and research programmes and activity, they need to provide funding upfront for public involvements. So that people can have those really early discussions and you know and you and I can say to a research team, that's a really good idea, but it would be even better if you did this. So it would work even better. And I think that is something that's really missing.

 **Lillian (Guest)** 43:58
Ohh.
Yeah.
To.
Yeah.

 **Simon Denegri** 44:19
So I will send you that report, but hopefully that might trigger a greater move by research funders to start to think about how they future proof their work for the future by investing in public involvement because it's a very powerful tool,

 **Anusree Biswas** 44:41
Thank you so much for your time, Simon. I really enjoyed speaking to you.

 **Simon Denegri** 44:44
My pleasure. That's right. And I found the figures. I wasn't far wrong. This year we elected 59 fellows and 18% of those fellows were from minority ethnic backgrounds, compared to 12% in 2020.

 **Lillian (Guest)** 45:11
It's going up.

 **Simon Denegri** 45:12
It is going up.

 **Anusree Biswas** 45:15
Thank you it's been really helpful. I know you're very busy, so really appreciate your time and thank you very much.

 **Anusree Biswas** stopped transcription