Oral Health Matters – Episode 3

Engaging communities for better oral health.

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Richard Watt 00:04
Welcome to Oral Health Matters, a podcast that shines a spotlight on oral health and calls for it to be embraced as a key part of the global health agenda. I'm Richard Watt, a Professor of Dental Public Health at University College London. In this first season of our podcast, I'm in conversation with members of the Core Research Programme, a team of researchers and activists from around the world who are working to tackle the problem of oral diseases in Kenya, Colombia, India, and Brazil. In episode three, I'm discussing the meaning and value of community engagement in research and ways to promote meaningful partnership with local communities. To do this in this episode, I'm joined by Mirai Chatterjee from the Self-Employed Women's Association in India. And Blanaid Daly, Dean of the School of Dental Sciences at Trinity College in Dublin. Mirai has a wealth of experience working with marginalized and disadvantaged communities across India. And Blanaid is an experience clinical researcher who was focused on addressing the oral health needs of homeless people and people with special needs. So thank you very much, both of you for joining this podcast discussion. Oral health and dentistry have traditionally been very much dominated by professional perspective, with very limited input from local communities. My first question really is, is this a problem? Blanaid, do you want to respond to that initial statement?

Blanaid Daly 01:42
Yes, I suppose because I'm a dentist by training, I would say yes it could be a problem because how we are trained, and the notion of what a health professional is, or does, all influences how health problems are addressed. And the solutions that we come up with, and actually how health care is shaped. So that kind of training and background has influenced everything we've done as a dentist you are trained to fix things, to intervene. And we're not always as well versed or as confident about preventing things. And I suppose the other aspect is that when then health services are set up, we set them up to suit health care professionals, how we might like to work, you know, the opening times, the you know, we work during the week, not at weekends, whereas many working people working families would like to attend before work starts, after school, that sort of thing. Finally, I suppose professional perspectives tend to protect professionals and what you might call the status quo. So we might resist the fact that other, say in dentistry, other dental care professionals could address dental disease and dental problems. So there's this idea that you know, the dentist is at the top of the pyramid, and then all other health care professionals are around. Whereas if you were starting off in trying to address dental diseases, you probably wouldn't have a dentist. Well, you probably would have a dentist, but what you would probably look at as different types of healthcare professionals

Richard Watt 03:41

Mirai, from your perspective as a community activist, when you think of dentistry, we think of oral health, community engagement is really not part of their agenda is that your experience?

Mirai Chatterjee 03:54
As Blanaid said there is a gap currently between professionals' perspective and the reality, the grassroot realities we see on the ground, and particularly their needs, especially the need for oral health care. But having said that, I must say this is not a gap that's different from the gap that we see between other types of medical professionals and local people at the grassroots, particularly informal workers, who are the mass of the population, not only in India, but in the global south. So, there is this gap. But as I said, other professionals also we experienced this gap. And I think it's because their lived realities are so different. And so, you know, there is a need to bridge that gap and come together which we will be doing as we work together. And I think what we find is that oral health services remain inaccessible and unaffordable to most people in India. Indeed, in our early discussions with people at grassroots level, particularly vulnerable populations like our Adivasis, or Indigenous people, we find that they have never seen a dentist in their lives, let alone visit one for the teeth. So, this is the reality. And as Blanaid rightly said, we see the same, the systems, the services, they're all set up with from the point of view of the professional, what is convenient to them, the working hours, and so on, and so forth. So, all of this contributes to the gap. And I believe this is the same in the global south variable I have seen and asked people about their lived reality. And the other point is that there's big gaps in oral health literacy, people simply, you know their gaps in knowledge and simple preventive measures that could go a long way before they even reach the dentists are not known to people. And finally, what we find, and again, this is not unique to oral health professionals and dentists. But there is a lack or inability to acknowledge local systems and ways, traditional ways of taking care of oral health, some of which are really quite scientific in fact. But we see that dentists and other professionals tend to look down on these low cost and traditional ways as well. So, all these contribute then to the gap.

Richard Watt 06:24
Really some profound issues been raised there. And I think just hearing some of the points you're making, this gap we've got between the professional reality and the lived experience of communities is a significant burden. I wonder if it's also linked to the issues of equity, and issues of inequalities in terms of access, affordability, that seems to be an important agenda, and Mirai I really like your point about the lack of respect for sort of local interventions, local treatments, etc. And I suppose that links maybe to sort of colonization agenda and the need for a decolonization approach moving forward, so some big issues there. What would you both think are the benefits gained by meaningful engaged community engagement? Blanaid thinking about what you said, if we manage to establish trust and links with communities, what are the benefits do you think from such an approach.

Blanaid Daly 07:32
The solutions have to come from people themselves, there is a power imbalance that I think in the health professions, and as Mirai has pointed out, it's not alone within dentistry. But there is a power imbalance between, you know, the communities we serve and ourselves. And to me that the solutions have to come from people, and it's also important as well about raising awareness amongst people about what the problems are, and how to build I suppose demand for better information, better access to care and better ways to live the lives. Now I'm not saying that it's their fault, or it's their responsibilities. But we know that, you know, most governments respond to the political voices of their electorate. So, I think harnessing the community is very important. And then as Mirai had said, there's a huge amount of knowledge there about how to address some of the issues around, you know, managing food poverty, about cooking, about local solutions that we probably need to harness. And I think in terms of health care solutions, as Mirai has said, there's lots of things that you can build on within, for example, religious practices and the importance of hygiene for Muslim community, and that oral hygiene could be incorporated in to those sorts of things. We just haven't spoken enough to local communities I think, to actually draw on their expertise.

Richard Watt 09:29
Mirai, in terms of your comments about that gap. I suppose one area that we are hoping to move into with our research program is the ultimate sort of co-creation of interventions. What's your view that if we do establish meaningful engagement, can ultimately that leads to co creation of solutions?

Mirai Chatterjee 09:53
Oh, absolutely. I think so, Richard, but before that, I'd like to just speak to one of the other issues, which is the issue of effective community engagement and research and what benefits. I completely agree with the Blanaid. In fact, it's interesting our experiences in India very much mirror what she is sharing. And I think one of the important things that I've seen is that if communities engaged in research in a genuinely inclusive, respectful and participatory manner, then we get authentic responses, we get authentic data. Otherwise, what I've seen is that often times, people just respond either in a vague manner or what they think you might want to hear. So, if we want authentic responses, so that we get proper evidence on which to build our interventions and solutions, then you know, the best way is to engage with communities. As Blanaid said, once we win their trust, once we have that trust, once they understand. And once they understand that this could be of use to us beneficial, this research, then they respond, and they actively participate in research. And not only that, once the research shows that the evidence was up what's going on, then, as blended, said, they come up with feasible, and often low-cost solution, solutions that work in their context, and in their reality. And I will want to say that often, although people do know best, on the other hand, you know, most of the experiences may be limited to themselves, their family, their neighbours, their immediate environment. And one example is oral cancer, after our discussions with you, we've been talking more about oral cancer with the communities that we serve. And we found out that most people have no idea how widespread it is. And that, you know India is, you know, one of the top reservoirs unfortunately of oral cancer. So, you know, this kind of information is also important for communities to have. And then, you know, sitting together and co-creating solutions, is the next step.

Richard Watt 12:15
Through our discussion identified a sort of shared experience, whether it's in the global south or the global north, about this gap between this professional perspective and a community voice. And I think, although dentistry is not unique in this area, we certainly need to do more work in this particular field. So, thinking about the ingredients of success of effective community engagement, Blanaid what do you think, from your experience of perhaps working with homeless people, what do we need to do to set up effective community engagement? Particularly, if we're thinking about research. What would you say the ingredients are for success?

Blanaid Daly 12:59
I think the first thing is acknowledging that the voice of, for example, the homeless person is absolutely essential and needs to be heard. So, when we started research, and this was a long time ago, actually, back in the middle 90s, we were working in a really good Primary Health Care initiative in South London, where they were doing evaluation research. So, they had set up services to make them accessible to homeless people, but they wanted to know, were they doing what they had set out to do? And we started off with homeless people working on our research agenda. So, we asked for volunteers to come and help us decide, you know, what would evaluation look like? And what kinds of things they would expect from a service. And that meant, you know, and sometimes homeless people can be quite a desperate group. But there were people who were happy to stand up. And it also meant that we had to support people in giving them some training, and also to acknowledge that this was valuable work and to pay a small stipend to acknowledge that because I think that's very important that, you know, we're paid to be researchers, they should be paid to be researchers to. They helped in deciding what the evaluation would look like. And more importantly, they were trained to support the evaluation to by becoming interviewers, and sometimes, because there is that gap between researchers and health professionals. It was very, I felt very innovative, that homeless people themselves, were doing the interviews. So, they were able, as Mirai said earlier, to talk about real solutions and also then to challenge people about, oh well, you know, sometimes people say,

Oh it didn't work for me, and they were able to, I suppose glean and find out exactly what those reasons were. So, I think if you want engagement, you should obviously go out and seek it. But also give people the appropriate training, so that they stand with, you might call the professional researchers in researching the idea, but they must be involved in all stages, as Mirai said earlier, very participatory, and respectful. Okay, so that issue of sort of dignity, of rights of involvement, training resources, Mirai, from your experience, extensive experience in India, are things different from your experience, or would those principles apply equally to the work you've done with your local communities?

Mirai Chatterjee 15:52
The principles apply, they're quite universal, with perhaps a little tweaking here and there, for context. The main point that I wanted to make to add to what Blanaid has laid out so well, is that, you know, what do we mean by community? And what do we mean by communities? And in my experience, in our experience at SEWA, my guess is this is probably true of mostly all countries, is that communities are not homogenous, first of all. And certainly, speaking from the Indian perspective, diversity is the name of the game with so many castes, religions, ethnicities, languages, who are we talking about? If we're talking about reaching out to traditionally vulnerable groups, then the first step is to understand wherever we are working, who are these vulnerable groups, and in India, the vulnerable populations are Dalits, who are the so-called former untouchables, Adivasis. So, I've already mentioned indigenous tribal people of the subcontinent, religious minorities, and certain castes who are so called lower in the caste hierarchy. Of course, women across the board, and people with special needs, disabled people. And in our experience, it's generally these groups and populations which are excluded from what is normally called community, so they remain unreached and underserved. And I believe that when we are doing research, we have to proactively also reach out to these communities, these sub-communities, if you will, sub-populations within a certain geography to make sure that yet again, they are not left out, because usually what happens researchers not us, of course, but researchers, you know, will go to the village head man and it is a man. And you know, they'll usually in the Indian context, go immediately to the upper caste homes and sit there and, you know, fill up their survey forms. Will that's not the way we are planning, we are meaning the research that you are leading Richard. And I think a few more things in the steps for community engagement and research would be which would be helpful to us, is to link or partner, which you're already doing with SEWA with local community groups, NGOs, self-help groups, membership-based organisations who already have good rapport and understanding of local people. So, they can be helpful, of course, and then also engaging with local people. I've already mentioned the vulnerable communities, but also young people who are enthusiastic, to take up something new, and particularly what we in SEWA call in our language "aagewan", basically, frontline women leaders, in our case, women leaders, because they are embedded, they have lived experience, they know how to present things in simple language, which some of us are not able to do quite so easily. So those kinds of issues engaging with local leaders, local government functionaries, particularly the medical officers, in our case, in the public health system, we have primary health centres, and the medical officers sort of the king pin there. And then discussion and dialogue has already been mentioned by Blanaid, and getting people's inputs and so on. And then i think what's really important is also to go back to the community and share our findings. Often times we hear from people or so many people come and ask us so many things, and then they go, and we never hear back. So, people would like to know either through digital means like a WhatsApp group with a little, maybe a little video just a little, what are the main research findings and so on. And then finally, as Blanaid has already said how to discuss next steps, how to move forward with solutions.

Richard Watt 19:57
So that's a really extensive list of considerations and I think Mirai as you know, with our work so far, defining community has been quite an interesting process. And in the different countries we're working with, those communities that are being defined, are quite different depending on the context, and in terms of the culture, in terms of the population profiles, etc. But the idea of that you've highlighted about embedding our work with other organisations that already have those links with the community, clearly is so fundamentally important. Blanaid

thinking about your experience, what do you think are the main barriers or obstacles? Why haven't we done this before, when it's such an obviously important area of work?

Blanaid Daly 20:47
Because it's hard Richard, and it's much easier to explore something easy, like how much sugar somebody's eating, rather than talking to people about food choices and the reality of food choices. So, I think that's the first thing. And the second thing, it is a mindset around us health researchers about still thinking we are doing things to people, we come up with great solutions to the problems and then hand it to them, and then seems surprised that they don't want to take the solution or the way in which we shape healthcare. So, I think it is very much a mind-set. And I think Mirai is, you know, describe it so eloquently. It's about deciding that you want to engage with the community and defining that community and recognising that the groups that are you know, we call them hard to reach and it might be the fact that we're the ones that are hard to reach, and kind of reframe some of our thinking about that, and go to places that we would not normally engage with I think that's really important. Think about the groups that are underserved. And really the mindset is, and how do we specifically engage with that group, and there will be lots of other groups already engaging with people I think, probably piggybacking on some of those initiatives are very important. But we ourselves have to ask ourselves first, what we should do differently and how we should do things differently.

Richard Watt 22:37
And Blanaid do you think, is this threatening to sort of professional control? Do you think this, some of our professional colleagues might feel undermined by this type of working?

Blanaid Daly 22:48
Absolutely, because some of the solutions that will come from people will be radical, they will be saying simple things like we don't want to have to travel all the way across the city or 20 miles to see a dentist, we'd like somebody to come here locally to us. So, some of the solutions will challenge the status quo. Yeah, definitely.

Richard Watt 23:15
Mirai from your experience. What are the barriers to moving this forward? Maybe not so much just in dentistry, but in health in general? What do you see as the obstacles?

Mirai Chatterjee 23:27
The biggest issue to be dealt with is the issue of trust. As I mentioned, people at the grassroots, whether in India or Ireland, I would guess so anywhere else in the Global South, which I know better. People have now become a little bit wary, particularly very vulnerable communities are wary of people coming in from outside asking a whole lot of questions, as I said, and they don't see the benefit. They don't see any change at the end of it all. And they don't see their lived reality changing or their needs being addressed. So, they wonder why should they be involved in all of this anyway, so I think it's the trust to developing a rapport, which I mentioned earlier. And all of this, of course, takes time unless, as Blanaid said, you piggyback with organisations, but otherwise, it's time intensive. You have to be patient. You may have your protocol and you want to get started and be quick off the blocks. But that's not how it works. You know, I find where many times I've gone into the communities. I remember once I went to talk to some of our tribal sisters on sickle cell anaemia, when they wanted to speak about the fact that they had not been paid for two years from a government public works programs, we have to take that up. We had to change course. So you have to be flexible. You have to listen to our people. And of course in that case, once we addressed this gap that they had been not paid. And then we, you know, made representations to the government and got their payment done, then they were ready to listen to anything. All of this has to be done as per their convenience, not like well, now it's nine to five and that's all now, there, they have to be available as per our convenience. That's not how it works, particularly since most of the world's workers are informal, their daily wage workers, for them you know, being away from their field or forest, or marketplace means

that they lose that much daily income. So, they don't have the time to just adjust as per our convenience, we have to adjust to they're convenience. So, if it's after their work hours, it's at night so be it.

Richard Watt 25:48
Lets think about looking forwards and wonder what would be the take home message from this agenda to be able to create meaningful engagement? What would you take home message be? Blanaid any sort of final take home short-term priority you could identify? And Mirai for you, what would you take home message be for this as a priority?

Blanaid Daly 26:06
Whatever group you're trying to reach, always have representation from that group on your research team, because they may actually help you identify a problem that you're not even aware that needs researching. So to me, I think that's absolutely key is that they're involved from the beginning to the end, including the write up and authorship. Which I know that probably sounds very strange, but I think that's very important that people are involved throughout not only in determining what the problems are, providing the solutions and evaluating efforts made to address problems.

Mirai Chatterjee 26:56
You know, one of the things is, if we can, after we co create, after we do all this, findings can be built into Comprehensive Primary Health Programs, which are running in most countries, including like mine, to show how it can be done. I think one of the biggest issues we face is that professionals in the scientific community often dismiss citizen engagement or community engagement. They think, oh, this is all sort of, we don't understand all this. This is not scientific. So if we can show how it can be done, what is the methodology, and how it contributes so much to science, and well, moving forward in general, through journal articles through things that person's like yourself and planted right in scientific journals, medical journals, dental journals, I think that would be really important to validate the experiences and the contributions that local people will make to our research. Very importantly, finally, people want to see what is the solution. How do we move forward from here? We all know that we don't have dental services in most of the world. But then what happens, you know, from this research, could be some ideas like bring up dentists to do clinical work, rather than administrative work as they're currently doing in the Indian public health system. How to enhance the services, maybe train local frontline health workers like that, like the Hesperian Foundation has shown and where there is no dentist, I don't know if that's considered unscientific or not. But those kinds of approaches when local people are also involved in the solutions, part of the solutions, and actually carrying out the solutions those are my hopes for the future.

Richard Watt 28:51
Thank you, both of you. And if I tried to conclude, really, I think we've had a really fascinating discussion about what meaningful community citizen engagement looks like. Its profound importance to improving the quality of our research, the validity of our findings. And we've heard repeatedly about the importance of adopting an inclusive approach that really focuses on underserved disadvantaged populations, who are never given a voice or are never at the table of decision making. And as we've heard, this is not easy. But it has potential, the effect to make such a meaningful difference to what we work on and the solutions that we come up with. So, I think it's been a fascinating discussion. So I'd like to thank our guests Mirai and Blanaid, and to you for listening to this podcast. In our next episode, we'll be talking about developing and nurturing the next generation of oral health researchers in the Global South. And I'll be joined by Professor Lisa Jamieson from the University of Adelaide in Australia, and Professor David Conway from the University of Glasgow in Scotland. Oral Health Matters is produced by the Dental Public Health Group at UCL with production support from Research Podcasts, and funding from the UK National Institutes of Health and Social Research. Many thanks for listening.