**Listen to THIS - Episode 5: Co-design and engagement with service users**

Welcome to Listen to THIS, where we have conversations examining how we can improve the quality and safety of healthcare.

In this series, we'll dive into both current and long-standing healthcare challenges and we'll shine a light on some of the work that's being done to address them.

I'm Graham Martin, Director of Research at the Healthcare Improvement Studies Institute. You may have heard of terms such as co-production and lived experience and their role in improving healthcare services through research, but what do they actually mean? Who's involved in these activities, who should be involved and how can they contribute to making research about improvement better?

In this episode we unpack these terms and how they can be used and misused, how to put these concepts into action, the ways they can inform research in prenatal screening and other areas, and what to consider when thinking about whose voices need to be heard in improvement studies. I'm joined by….

Oli Williams: Hi, I'm Oli Williams. I'm a sociologist and lecturer in Co-designing Healthcare Interventions at King's College London. During my THIS Institute Fellowship I researched how the concept of co-production is theorised and practised in the context of healthcare improvement and applied health research.

Michelle Peter: Hi, my name is Michelle Peter. I am a THIS Institute Research Fellow and Senior Social Scientist at Great Ormond Street Hospital and UCL. I’m looking at the experiences of black parents who have been offered screening and invasive testing in pregnancy, and the reason for that is to amplify the voices of a group of people who are underrepresented in social and health research studies and to find solutions for the disparities that exist in maternal and pregnancy outcomes.

Nicola Boydell: Hi, my name is Nicola Boydell and I'm a lecturer in Social Science and Public Health at the University of Edinburgh. I describe my work as sitting at the intersection of medical sociology, critical public health and healthcare improvement studies. My THIS Fellowship concluded in 2024 and my work focused on using participatory approaches to service improvement within sexual and reproductive health services.

Graham: So, as I said at the beginning, we're going to be talking about co-production, related terms including involvement, engagements, co-design and thinking about how they are best realised in healthcare improvement research and what some of the issues and challenges and things to be aware of around that.

I'd like to come to you first of all, Oli, because I know that a lot of your research has focused on this and perhaps it would be useful to start with just to hear a little bit about what your views on co-production, how it's distinct or not from patient and public involvement, what the most pressing issues are, the big things to consider when thinking about how to engage people effectively in research around healthcare improvement.

Oli: I think what's true to say is that there are lots of different terms used in this space. If we more generally call this space, say public involvement, or we might think of it as participatory methods or participatory approaches…there are lots of terms, often beginning with ‘co’, that get used and I do think that there are certainly distinctions between them.

But over time so many terms have been used in so many different ways and often in a very ill-defined way, that all terms can mean the same thing at this point. You could always find for instance, a paper to cite what you think that term means and how you're using it.

It's fair to say a lot of these terms are contested and a lot of my work is around really trying not to get into that semantic war, if we want to call it that. So I think that often generates a lot more heat than light. It's not a particularly constructive space, but it is a space that a lot of academics feel very comfortable in.

So you could get a lot of papers published quibbling over what definition is used in what situation and whether somebody's done something properly or not. I think a lot of it comes down to explicit intention and being transparent about what you're actually trying to do.

And I'd say that is actually one of the bigger problems that we have. Not necessarily that there are different definitions that are used for the same term, but the fact that a lot of the time when people use these terms, they're not properly explaining what they mean by that term.

So if we take for example, there was a research team in Sweden, the Samskapa research team, that did a systematic scoping review a few years back that mapped definitions of co-production and co-design in health and social care literature. So that review, they found 979 papers that included these terms. They found two, I think, particularly interesting things. One, that there's been this exponential use of the term since around about 2011. So this is relatively modern, that these terms are used a lot more in this space.

But for me, what's much more interesting and related to what I was just saying is that over a third of these articles, so 352of these articles use one or both of these terms. So co-production or co-design, but provide no definition or explanation and relied entirely on the reader to understand what was meant by this term.

So what is theory that they were using and what is meant by what they did? So you know, what was the practice of what they did? So I think that's the much bigger problem that we have, is that people have started and I would say that this is a long-term thing, actually. People are using these terms as if there's an assumed understanding of what they mean.

And often this creates real problems in terms of where there's an expectation about what that might mean about who's being involved, how inclusive something is, how diverse something is, what sort of attempt has been made to address power imbalances.

And then in reality they might be using a definition which isn't attempting to make anything more inclusive or more diverse or challenging any sort of traditional power hierarchies. It's actually probably just a term that's being used that you could substitute for, say, collaboration.

Graham: So correct me if I'm wrong here, but I suppose the key distinguishing features that you're thinking of when you use the co-production term then is that it's not just researchers and end users.

I suppose the end users might be part of that, but you're including wider groups than that? Communities, dare I say, or certainly beneficiaries, indirect and direct stakeholders of various kinds. And you're trying to be inclusive, you're trying to bring all of those groups in and you're trying to do something about the power dynamics as well.

Does that get to the heart of it or are there other distinguishing features from your perspective as well?

It really depends on what context you're working in. So I think that there's no real value in criticising people for using a term like co-production and doing something that is different from your definition. Because I think there are legitimate definitions and etymologies of the term that predate a lot of these criticisms.

I worked with Brett Smith and colleagues and we did some work around this and we identified that there were three types of the way that co-production is used.

So we came up with the first one would be what we've labelled ‘citizens contributions to public services’. You then have ‘integrated knowledge translation’. There's been this big movement and one that I absolutely advocate for, trying to close this gap between research and practice.

And so that's much more about trying to get knowledge producers, as they're called, and knowledge users, as they're so called, to work together. So you're not creating knowledge in a vacuum, you're working together so that research is more helpful and evidence is getting put into practise.

And then the third category that we identified was what we characterised as being ‘equitable and experientially informed research’. And I think today's conversation, that's very much what we're talking about. And so in this space, what you see is that there is a commitment to people who have professional identities – so researchers, healthcare professionals, public health authorities, members of public health authorities – actively trying to form equitable partnerships with people who are typically understood as service users, patients, families of those patients, carers of those patients. So there's a real effort to try and form these equitable partnerships.

It's based on a premise that there is value in people's lived experience and therefore we should challenge what's often called a sort of epistemic injustice of where academic knowledge is considered to be above and more important than other people's knowledge, say lived experience, for instance, and therefore is always trumping that. Instead, in this approach, you would really value that knowledge and see that it has something to contribute to the research process.

Graham: So, equitable and experientially informed. That was the third category of the notion of co-production that you mentioned from your review.

Michelle, I'd love to talk a little bit about your research now, and in particular, if you could give us some background on that and tell us about it, but also tell us about the way you've tried to engage and involve the communities you're working with and whether that notion of equitable and experientially informed gets at the essence of what you're trying to do.

Michelle: Thanks Graham. And I think building on what Oli said about this kind of equitable partnership between the service users, the patients, the carers, the public and researchers is something that I think I embed within my research practice.

But I think there's that added intersectionality of including people who are typically underrepresented in research anyway, but equally disproportionately impacted by particular health outcome. And that's where the research that I do fits in with making sure that we have this active engagement with a population of people who often do not get their voices included, but equally are the most negatively impacted by adverse health outcomes.

And so if I think about the research that I do and my Fellowship, it's always been, for me, super important to make sure that the research that I'm doing is going to benefit the population that I'm looking at. And I think there's always been a very clear line that you can draw between the reason that I involve the public and the end goal of my research.

So my research is looking at the experiences of black parents who are offered screening or further invasive testing in pregnancy.

And the reason that's all come about, if I can go into that a little bit…so I work within a genetics and genomics research team. I've spent a lot of time on various projects speaking to parents about their views on the acceptability and the accessibility of current emerging prenatal, genetic and genomic tests that are coming in and being introduced into the NHS in England.

What struck me, as time has gone on in the various circles I've been in, is just how biased research participation is. And I found this in the work that were doing. But even when I think about the papers that I'm asked to review, the majority of people who are willing to take part in studies tend not to reflect the people who are going to be offered, for instance, in my case, these kind of different tests in pregnancy.

And what I noticed that I think is hugely problematic because in the UK and the US, but in the UK, black women face the worst maternal and pregnancy and neonatal outcomes, right? So they are 3.7 times more likely to die, they are twice as likely to have a stillbirth, they are twice as likely to be readmitted 28 days after birth. They are, I think, 43% more likely to have a miscarriage.

So these are disparities that have persisted and existed for a very long time. And actually, what we're finding then is that we have very little understanding about what these communities and people from other kind of ethnic minority cultural backgrounds feel about their maternity care, about the tests that they're offered at very pivotal stages in their pregnancy.

And so they're not included in the research, and they're not even included in the stages prior to the research even coming together. And so for me, it has always been very important that as well as amplifying the voices of a group of people who are often kind of underserved and underrepresented, that all the way through this Fellowship and even prior to that I included people from those communities to understand, am I asking the right questions? Are my materials that I'm using to advertise a project, are these appropriate? Is the question that the overarching research question that I'm asking relevant to you? Am I doing it in the right way?

And for me, it has always been very, I think, fundamental to this project to make sure that what I'm doing is going to benefit the population that I'm looking at. So prior to the Fellowship, I conducted some focus groups with parents from black communities because I wanted to better understand their views towards prenatal testing. I think there is this tendency to think that especially if you are from that cultural identity, from that have that shared cultural identity with the community that you know, you will know everything.

But actually, one thing I found was that quite a lot of the parents that I spoke to talked to me about premarital genetic testing and that being a prerequisite in some communities to couples marrying and having children together, and that actually this can even be ordered by the church.

So there's this idea of compatibility at a genetic level and these conversations happening in some communities even before pregnancy. And that's not something that I knew about, that I would even have thought about approaching when I'm having these discussions with parents in my actual Fellowship. So that already informed the way that I would conduct this research, and that wouldn't have been possible if I hadn't have involved people from these very communities in my research before I even started doing it.

Graham: Nicola, can I turn to you next again; a somewhat different area of healthcare provision, but another one where it's clearly vital to involve various communities in various ways, but which brings issues around, stigma, issues around power relationships, issues around actually quite fundamentally conflicting views of what a service should look like to the fore.

Nicola: Yeah, some really interesting points that I think speak to both what Oli and Michelle have both been talking about. I've been working broadly in the field of sexual and reproductive health for well over a decade, and thinking with a particular emphasis on how to work with different constituencies or groups. So whether that's individuals or whether we might call them patients, contested term, communities, healthcare professionals and other groups. And my research journey really started around HIV and HIV prevention, where a key tenet of the discussion would always be about ‘nothing about us, without us’, I would have described myself, and still do in many ways, as an engaged researcher, my work is engaged with community organisations in terms of both shaping the direction of the questions and in partnership, as Oli's described, that equitable and experientially informed partnership to actually do the work.

So when I came to this Fellowship, what I was really interested in, what my intellectual curiosity and puzzlement was around, was the ways in which participatory approaches were used or not when it came to sexual and reproductive health services more broadly.

Originally, the focus was very much on how that was enacted within young people's services. My project really rapidly changed because of COVID. Lots of my partners disappeared and I was invited to work on a project that was really looking about the rapid shift to the provision of abortion care through telemedicine delivery.

And as that project progressed, I became more and more interested in the parallels between the ways in which the talk or the rhetoric around involvement were not really then actually practised when it came to changing or improving or redesigning abortion care services. And that's really what the central focus of my work has increasingly become. So one of the things that I'm really interested in is actually around what we might describe as abortion identities. Often constituencies or people that we would want to bring in different publics coalesce around particular identities, whether that be gendered or sexual minority identities, or whether that might actually be to do with illness identities, which often how people think of themselves. It's a central part of how they might talk about their own experiences. And that's much less common when we think about abortion care.

It's an area that's a highly stigmatised practice. There's an assumption that people want to very quickly move away from. They wouldn't necessarily define themselves as being an abortion haver or an abortion seeker. That might not be part of an identity. And that makes doing community engaged and equitable partnership work actually really tricky. And that's what I'm trying to do and think through with my colleagues at the moment.

We've been doing some work thinking with different concepts around patient and public's involvement in engagement in abortion care redesign and to think about who and why we might be including different groups and where the boundaries around identities play into the work that we do. And that's really come to the fore in my more recent work, which following really follows on nicely from this Fellowship, which is around co-designing post-abortion contraception.

And we've actually found it really quite tricky to work with community partners because precisely the things I've just been describing, we've had people push back and say this is not a thing that our community would want to talk about.

We might talk about it individually, but it's too stigmatised, it's too sticky, it's too tricky an issue for us to engage with. And that makes the work really challenging in this area. So what we've been trying to think about is different approaches to thinking about what it means to have abortion experience that it's not necessarily the right person is somebody who has had an abortion. But we might extend, we might make the boundaries of that more fluid.

So it might be around people who have experience of supporting other people who have had an abortion, or it might be around people who've considered but ultimately chose not to have an abortion, so that we widen out that definition when it comes to thinking around the practises of involving people in our research and in our co-design work.

Graham: Oli, I'd like to turn back to you because I know that some of your research, including the doctoral Fellowship that you're supervising at the moment, speaks to some of these issues about the fact that some groups may or may not recognise themselves as beneficiaries. They may not even agree with the principles or the organisation of the service they're being asked to contribute to. So I wonder if you have any reflections on what Nicola just said?

Oli: One of the reasons we have this proliferation of the use of ‘co’ words is in response to where involvement begins to start, it's mandated around…the 1990s. Then you have a wave of essentially critiques of the practice that's happening, right? And in a lot of those critiques, people are saying there's tokenism, poor practice, just box ticking. These are things that people didn't used to have to do, but now they have to do it.

And what happens, mandates are both good and bad, aren't they? In some way it's saying we take this really seriously, so everybody has to do it now. But what that often leads to is the majority of those people not doing it very well because they don't actually value it and they don't want to do it.

And so you have this introduction where it's happening, then you have this wave of critique where it's like, well, the reality of what's happening is very tokenistic, a lot of box ticking. And I think a lot of that still goes on because there are still lots of people who don't necessarily either see the value in it or don't have the skill to do it, because that's often undermined as well. This idea that it's just simple to do is simply not the case. That's a real problem that we have in the field.

So you have that, you have this proliferation because a lot of the time people landed on these code terms as the solution, right? Oh, great. So PPI was bad. So actually these code terms are much better and they're going to help us to achieve all of these things.

So the NIHR, they rewrote their definition of what involvement was supposed to be, you know that about being *with and by* members of the public, not to *for or about* them. And then at that same time started to release guidance around how to co-produce research and they had this definition of what that is.

And I think it's quite telling to see in the foreword for that, for their guidance on co-production. You have this quote from Tina Coldham, who anyone who's been involved in this space will probably know Tina. She says, “I first heard the word co-production a few years ago. I have been embroiled in the involvement agenda as an activist and working as a consultant on it for many years. And all of a sudden there was this new word and perhaps aspiration.”

And I think that's actually really telling. Like it was seen as a saviour for a lot of bad practice. And I think that's really important to understand. When people start to be very critical of you have…now a whole wave of again, similar critiques because this new wave of the code words are going to save us all. And guess what? They didn't.

Because again, you still get lots of poor practice and they become buzzwords. Sarah Carr had this really lovely saying where she said a lot of…because they became buzzwords that people use in the language of radical power sharing…but they didn't actually do the radical power sharing bit. Right. So you still have this problem where okay, we know now it sounds better if we say these words and we're more likely to get funding if we say these words. And it sounds like we're doing better work if we say these words.

But the reality is, are they doing something that is different from what went before? And I think there's a huge thing here around expectations. And you see these in the critique. So these two terms come up. People often start saying we really, “we need to do *true* co-production.”

And then, and as the opposite of that, people say, oh, what this is actually is faux-production. It's not real. And what you're seeing there is that there's an expectation, the expectation has shifted. So when people are using these ‘co’ words, the people who are being involved, who have typically been excluded from these decision-making processes, there's now an expectation that this is going to be more than just giving me a seat at the table. I'm supposed to be meaningfully engaged, I'm supposed to have a meaningful contribution, I'm supposed to have some power in the decision-making process.

And often actually people are using these terms again really without any clear definition of what it is, what they're doing. And essentially it just becomes maybe a slightly better or friendlier version of the poor practice that was happening when people were just doing involvement.

So I think that's really important to pay attention to is the shift in expectation. And so when people push back again, I've sort of pooh-poohed the sort of semantic war and I think that is happening, but this is where you can take it seriously, is when you use that word because of the context that this was brought in, these ‘co’ words were brought in as saviours of bad practice.

So this is now going to be a new dawn, a dawn of a new era where we're doing more involved work, we're actually doing this properly. And then when we don't do that, then people voice all of this criticism and have this, I think, very fair criticism of what's happening. And I think both Michelle and Nicola spoke to that.

Graham: Michelle, I'd love to hear your reflections.

Michelle: I think that whilst a lot of funding bodies now have made it, it's fundamental that you demonstrate how you have involved the public. I think there's limited funding and resources for this engagement in the first place. A lot of funders are requiring you to have conducted meaningful engagement with patients with community organisations before you submit your application for the very funding you're seeking.

So where are you getting this money to compensate people? Where are you getting the money to pay yourself for your time to do all of that? It's kind of a backward step where you have to do all of these activities prior to receiving the funding that you're applying for.

And I just think there's a wider issue and maybe, I don't know, is it little understanding from funders about the time that it takes to build relationships? It takes work, it takes effort to develop these relationships with different parent support organisations and different trusted advocates within respective communities.

It's not just; I just turn up to a group and say, “hey, I want to do some research. Do you know any people who might be interested?” And they just send me the people. You need to…there needs to be that trust there within those partnerships that you're making.

And maybe this is putting a cat amongst the pigeons, but I don't feel that enough respect is given to the time and dedication that it takes to build up that relationship before you even apply for funding in the first place. So that's me being a bit controversial maybe.

Graham: Well I don't know that it is to be honest; funders seeing these things as transactional and universities which are not exactly awash with money right now being reluctant to find the funding to do this properly and to build those foundations from which great co-produced research might follow. Nicola, what do you think?

Nicola: I couldn't agree with Michelle more, so I'm really glad it's not putting the cat amongst the pigeons at all for me!

I think just to build on what Michelle said there around the funding and the resource…The other thing that I've often noticed and I don't know what others’ thoughts are on this, is that often this work is delegated to younger, more junior colleagues, often they come from gendered and other minority groups and there's a sort of assumption that they will have the skills to be able to develop this work, when I don't think that's the reality.

Because for all the reasons that Michelle's just described, that the funding isn't there, that the training isn't there, that the safe space in which to explore new and different ways of doing this work is not also valued. And I think it's really hard, often because we're having to sit with real uncertainties and real discomforts around a topic and holding those, often sitting in quite a liminal space if you're doing this work and that is not an easy thing to do. And I think that a problem is then assuming that it's going to be quick, also that it's going to be easy when it's really not.

And I think there's something here for me about really what it means to value this approach and what it means, what good looks like is actually investing in the resources and the humans that actually do the work in this space.

Graham: So those are hugely difficult challenges, they're structural challenges and they're not easily overcome and I don't want to marginalise them at all. But nevertheless I would like to start to finish on an optimistic note and a practical note as well. Putting those challenges to one side and how it makes it really difficult to develop those trusting relationships, those long-term relationships, those genuinely partnership-based relationships whereby not just researchers but others are setting the agenda and the right others what can be done to try to make that a little bit more possible and get a little bit closer to that ideal despite all those structural challenges.

Oli: So Graham, I was going to say that it isn't all doom and gloom because I think a big part of the solution is not to oversimplify this work. This work is challenging. It takes time. It's like a lot of it's relational, right? And building, if anyone's ever had friends or been married or been in a relationships aren't easy, right? You have to build these relationships that take time. There are ways of approaching this work that make it better.

So one of the things I've been advocating for in the papers that I've been writing is that there should definitely be an expectation, if you're reviewing funding applications or if you're reviewing published work, that people can't just use these terms now and not really define them.

I think we really need to set an expectation within the field that these terms need to be defined so we can properly judge them. These people said they're doing this. Did they actually do that? So that's one thing. There's real positives around people acknowledging this stuff and how important it is.

So there's a really great paper, I think, by Rochelle Burgess and Natasha Choudary where they write about a ‘phase zero’. So this is exactly what Michelle was talking about. This understanding that you need to build relationships with people. This often happens prior to any sort of funding or any idea of this is what we're going to do. And then certainly in the work that I'm doing, we're starting to. What we're really pushing for is, okay, there is real positives for doing this work, and so we should all be positive.

Oli: I think there is this ethical reason of why we should do that. So that's brilliant. But then also acknowledging, but it's not easy and it can often go badly. And if you do it badly, you can have very negative impacts on those communities and the people that you're involved in.

So we should think a lot more about this. So one of the things we're doing in our research group is developing resources that help people to do this work well, and particularly with the I-2 people don't necessarily need to be highly trained, but we want to create these resources so that even people who aren't highly trained are going through a process that people who are trained and have thought about these things are supporting them through that process, through this resource. We're going to be piloting that resource next year.

So there are definitely green shoots. Graham. It's not all doom and gloom!

Graham: Nicola…

Nicola: Yeah, I certainly don't want to give the impression that I think it's doom and gloom or that it's all too difficult. That's the absolute opposite of what I think.

So, to echo Oli, I think it's really important to make the work visible. One of the things that me and some of my colleagues have been doing, particularly thinking around patient and public's involvement and engagement in abortion care, is actually advocating within professional practice spaces for making the work visible through different forms of scholarly writing, so that actually does place the emphasis and value… so when in some journals that I've published with…they have these better ways of working-approach papers which are really short but focus on practice and changing practice.

And I think that using things like that or comparable ways to make visible the excellent work that is going on and that is possible is another way in which we can really reinforce the importance and value of this work.

Graham: Thanks. Let's have a final word from Michelle.

Michelle: There are really good examples of how researchers have involved patient and the public in their research. So it definitely isn't all doom and gloom.

I think we have as researchers a moral imperative to make sure that our intentions are the best when we are conducting our research and we want to do it well. I think that means that we do need to have some form of training and guidelines and I know there are many workshops that you can go on to understand more about how to…how to do this work, but it can be very overwhelming. I think if this is not your background, if this is not something you've ever had to do before and this is not the perspective you've ever approached your research from before, it can be really scary.

So if you've got support and guidance about how to do that, I think that it can be done really well. And like I said, there are already great examples of people who do this.

Graham: A big thank you to all the guests who joined us today. Oli Williams, Michelle Peter and Nicola Boydell. I've been your host, Graham Martin, and I hope you've enjoyed listening to Listen to THIS.

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