TRANSCRIPT

Episode 11 – The future of patient and public involvement LIVE!

[INTRO MUSIC] This is Not A Consultation.

Caroline Latta - I'm Caroline Latta.

Paul Parsons - And I'm Paul Parsons.

Caroline Latta - And welcome to Manchester for our very first ever Not A Consultation LIVE!

Audience - [CHEERING]

Paul Parsons - Yes, it's a double first for us tonight, a double first for our podcast about all things patient and public involvement and NHS service change. It's the first time we're recording Not A Consultation in the same room as our guests and it's the first time we're recording in front of a live audience. You are live, aren't you?

Audience - **[CHEERING]**

Paul Parsons - There we go.

Caroline Latta - Yes, live. What could possibly go wrong?

Paul Parsons - Yeah, all sorts, but nothing that Callum can't edit out.

Audience - [LAUGHTER]

Caroline Latta - So we started recording conversations for Not A Consultation at the height of the lockdown. So the idea that we might be one day sitting in a room with an audience like today didn't even enter our minds.

Paul Parsons - And now here we are in a room in Manchester, about to talk about the future of public and patient involvement with an esteemed panel of expert guests.

Caroline Latta - Shall we get going? Lots has changed for patient and public involvement in recent times. And if you believed some of the blogs about the technological future, we'd be worried that AI (Artificial Intelligence) is going to take over what we do. It's all going to put us out of a job by this time next year.

Paul Parsons - Our priorities and objectives are ever changing and the people we know that we most need to hear from face ever increasing barriers to participating. This promises this evening to be a fascinating conversation and please do take part by getting your questions ready.

Caroline Latta - So let's start, as we always do, by asking our guests to introduce themselves.

Rory Hegarty - Hello, everyone. Rory Hegarty, Director of Communications and Engagement for NHS Northwest London.

Karen Coleman - Afternoon, everyone. Super excited to be with you. I'm Karen Coleman. Very proud to work for West Yorkshire Health Care Partnership in Communications and Engagement.

Frances Newell - Hello, everybody. I'm Frances Newell and I'm Head of Partnership Development at NHS England.

Caroline Parnell - Hi, I'm Caroline Parnell. I'm Director of Communications and Corporate Affairs at Stockport FT (Foundation Trust). And welcome to the Northwest!.

Audience - [LAUGHTER]

Paul Parsons - Thank you very much Caroline. We thought we'd start by looking at what's changed since the new legislation came in last year. And Karen, can you tell us how working in these new ways has already changed the way that West Yorkshire does involvement, if indeed it has, and what benefits you expect the changes to bring over time?

Karen Coleman - Thanks, Paul. Gosh, what a big question. Has involvement really changed? Not convinced, if I'm totally honest. I think the legislation has changed the governance around it, but I think what we're trying to achieve doesn't change, does it? So, for me, really, it's all about building on involvement. That track record we've had as an integrated care system to 2016 and we serve a population of about 2.4 million. That covers two big cities. We've got Bradford District and Craven. We've got Calderdale, Kirklees, Leeds, and Wakefield District. So we've got a huge population and really proud because 20% of our population actually comes from minority ethnic community groups. So I think involvement is a challenge and I think involvement is a challenge before you even get to the legislation. So when I look at some of the work that my colleagues, my expert colleagues, who work in engagement involvement on them local communities, neighbourhood level have been doing, we have things like Bradford Craven District

listening events, we have things like Wakefield Big Conversation, Leeds The Big Chat, Calderdale Engagement Champions, Kirklees Community Voices. And I think, really, when you get into what it really means to people, the health and care, it's not about the legislation, it's about what does it mean for my little ones I'm bringing up, what does it mean for me as a single mum, what does it mean for me as a carer of an older person with dementia? That's what really matters to people. And I think until we get them conversations going and we can get pushing all them views and concerns that they've got right to the top table, then we're not really going to design services that are fit for the future, let alone now.

So I think what has changed, actually, is the legislation. We've got an integrated care board, haven't we? We've got a wonderful Chair, Kathy Elliott, we've got our integrated care partnership, which we call a partnership board, which isn't new, but them statutory elements make sure that we're actually getting them voices right to the heart of them decision makers. So some of the examples I can give you, really is that, for example, Bradford District and Craven, they do the listening events and their views of them people from all of these sessions that they talk to out in people's communities, they're not called conversations they're called listening in, because they actually take the time to listen to people. And then what they do is they push them into the local ICB committee and then their views come up to our integrated care board at a West Yorkshire level. And to make sure our Chair, and Rob Webster, who's amazing, who's actually at the Expo today, speaking with his son George Webster, there's a little plug for Strictly Come Dancing!.

Audience - [GIGGLES]

Karen Coleman - If you look at Kathy and you look at Rob, this isn't lip service, this is absolutely not lip service. They want services that meet the needs of people in communities. Whatever your background, wherever you live, whether you're rich or you're poor, they want excellent quality services. But throughout all of that, of course, is this tackling health inequalities. And we know we've got people living in 10% of the most poor areas in the country, and we know that we've got issues against things like people being able to access an NHS dentist, for example, people on the elective waiting list with learning disabilities. I mean, it's multifaceted, isn't it? It's not as simple as somebody's got

dementia, but what about their care? Or what about the housing they live in? And I think that's what's really great about integrated care systems. When we're involving people, we bring all of that conversation together in one place and we push them views right up to the top of our integrated care board. We have engagement sessions and we've had one on dentistry, primary care, access to GPs ahead of them board meetings so they can hear live them concerns that people are raising. And then equally so for our partnership board. And then of course, really, is that we have our West Yorkshire programmes, we have a Cancer Community panel, we have the Youth Collective Voice, and it's only really then can you really look at it altogether, map out what we know, where the gaps are, then we can really do involvement.

Paul Parsons - Thank you. Rory, does that sound familiar for Northwest London?

Rory Hegarty - Similar, I think. I think West Yorkshire have always been a little bit of a trailblazer in this area.

Karen Coleman - I did pay him.

Audience - [LAUGHTER]

Rory Hegarty - So I think we've developed our system. What we started to do when ICBs were first announced, we were a collaboration of CCGs merging into a CCG and we had a conversation with local people. And it was open sessions, about 200 people turning up to these sessions, on average, talking about what would good public involvement look like in a future system? What would be ideal if you had a blank piece of paper? And it was going extremely well, then, of course, we ran into the Pandemic. And during the Pandemic, a guy said to me what we did during the Pandemic was we really targeted because we knew that vaccination in particular, take up was really low in particular communities. So we worked really hard through WhatsApp groups, through grassroots community organisations, to target some of those communities. And somebody said to me in one of

these meetings, "the problem with the NHS is you come and talk to us when you want to shut something. You come and talk to us now because you want us to get vaccinated, but when do we get to say what we want? When do we get to set the agenda?" So that was our sort of starting point.

Having done all this co-production work, we thought, actually, we really need to look at this much more through an inequalities lens and we need to be going out and talking to and understanding our communities much better. Which I think we always thought we did, but I think we really realised at that time, everybody realised during COVID, there was a trust issue among some of our communities. Didn't trust public information, didn't trust public services. So we went out and we really re-devised our programme then and thought about outreach as the real centrepiece of it, what we do now. We talked, I think, between 20 and 60 community groups a month. We got a huge patch, as well as 2.1 million people. There's over 200 community languages spoken, for example. So, again, like Karen's, very diverse. So we started to go out and talk to communities and it was very much on that 'what matters to you?' type approach, rather than just going out and saying, we want to change this, or this is our strategy for XYZ, it was about what matters to you, what's working for you, what's not. And we've got a whole load of stuff.

We publish all of this data raw, so we publish now every month what people are telling us, and that then goes into our programmes, it goes into our board and people get to see that. And then the other bit, so there's loads of other bits, as we have over 120 lay partners, so the more traditional patient representatives who come and sit on groups and talk and provide that resident voice in the room. We have a citizens panel, which I think lots of places do, which broadly represents, which we use for surveys. And we also have something which we've called collaborative spaces, which is probably jargon, so not ideal, but we have open meetings, anybody can come, staff, residents, anybody can come. And again, it's a co-set agenda, so we still do all the traditional service change stuff. But I think our approach, and very much based on what people told us, is much more about listening first and getting the information in and publishing the information. Because the other thing, this sort of goes into a black hole stuff. You come and talk to us and then we never hear anything. When you do publish it, it holds you to account in a very different way because obviously everybody then sees it, local governments see it, the public see it, people see their own words published. So I think it's a really interesting approach. I don't

think any of the rules have changed or anybody's intentions have changed, but I think the way in which we do it in Northwest London has changed.

Caroline Latta - Thank you, Rory. I love that. I mean, anybody who knows me knows here at Stand, I'm obsessed with reporting and publishing what we've heard, because you're exactly right, it provides that transparency, that reciprocity, and it does hold organisations to account. So thank you for that. I'm going to come to you, Francis Newell, if that's okay. So, in this brave new world of integrated care systems, we're hearing lots already from Karen and from Rory about working in partnership more than ever before. I'd be interested to hear what your perspective is in terms of the opportunities and the aspirations there are for bringing partnership working to the fore as part of integrated care systems.

Frances Newell - I think there are great opportunities and aspirations. So the legislation last year that established integrated care systems, it builds in a legal duty to involve people and communities that existed already. So that's not new in itself, but I think where the opportunity comes is the partnership working that Karen and Rory have spoken about. So it brings the NHS together, it brings local government together, partners, social care partners, voluntary community, social enterprise partners, housing providers, and in an area like Northwest London or West Yorkshire, all of those organisations are working with their population on the same patch. So, I think aspirations for collaboration and partnership are absolutely at the heart of integrated care systems and that's where the opportunity is for how all those partners work with people and communities.

I think we see really good practise around those partners joining up and saying, okay, what is it that the NHS does well? There's some great practise in the NHS in really understanding patient experience for particular services, working with people that use services, things like maternity services, service redesign, which our friends at Stand know all about. The local authorities, kind of, have got all that experience of engaging with residents across a particular population. We've got our partners in the voluntary sector that have got expertise in the Trust with many of the different diverse communities that we really need to work with if we're going to tackle health inequalities and different outcomes in health. Social housing providers are engaging with their residents and so

there's a great opportunity to come together and say, what do we all do well? What are our shared priorities? And together, where do we want to target our efforts? Because there isn't enough time, there aren't enough people. And I think the partners working together across the system can really make two plus two equal five when it comes to working with people and communities in a way that makes a difference.

Caroline Latta - Thank you, Francis. Caroline Parnell, are there any different aspirations from provider organisations? What opportunities are there for involving patients, carers and communities and partnership working, do you think these new integrated care structures bring?

Caroline Parnell - It's interesting because I think we've got some great examples on the panel of how it's working. I suppose I'm going to be a bit of a negative Nelly here, if I'm being honest. So before the change in the ICBs came in, we had really strong partnerships in Stockport between ourselves and the local authority and the CCGs. What happened is that resource, certainly from the health, went into the centre and we're still doing that forming and norming stuff, so we're still trying to work out what resource can we tap into. So what we've done is essentially filled the gap ourselves and are working even more closely with our local authority colleagues, who were brilliant, actually, at getting out in the communities far more than we are. And we're a combined Trust of community services and a bit bigger DGH, really. And I think we've still got a bit of way to go to work those out. And because of that churn, we've lost good people who have moved on to other things, who had the contacts, who had those relationships. And I think, actually, what we've all been talking about is the relationships we build with individuals and communities and actually the opportunities for Trusts like ours. Is there's no closer relationship than a midwife with a lady who's in labour, there is no closer relationship between a nursing assistant looking after someone with dementia. So we have, in a sense, I don't want to use the phrase captive audience, because I actually would like them to go home..

Audience - [LAUGHTER]

Caroline Parnell - quickly, please!. But we do have this great group of people who are really interested in our hospital, and I'll focus on the hospital. The one I'm in is over 100 years old and unfortunately, we're not part of the 40 new hospitals, as you can tell it's 100 years old. But people are, local people are, incredibly proud of it and want to have the best, want to support us. So they do that through our membership. And we've got a group of really engaged governors. And what I'm hoping from this, is actually to see the promise that FTs had originally, when they were set up, about really engaging with members, about what's important to them. And certainly we've just been doing a piece of work with Stand where the minute we sent an email out to our members, within an hour we were getting responses back. And a Trust that we're working with who doesn't have that, was really struggling to get responses. So, the people that we have in our hospital are really proud of the hospital and want to be absolutely integral in how we develop for the future. And I think we shouldn't forget, actually, that in a hospital like ours, the vast majority of our staff live in our patch. So they're not only staff, they are service users as well, and they're really interested in where we go and how we develop.

So we've almost got a two pronged approach with what we're doing and we've got some great examples at the moment about how we're engaging the community, particularly around deprivation. So we've got a lovely new project. Stockport is a great place, but there is real pockets of deprivation and people who don't have the aspiration for a career. So we're working with the local authority, with the local council, on a programme where we, in one specific neighbourhood, where we're asking people, have you ever thought about a job in the NHS? Why don't you come and have a placement, four week placement with us? And if you really like it, we can get you straight on the access course. And that relationship is actually making people think, "Oh, Gosh, I could have a career. And then actually, if I have a career, I've got more money coming in and what does that mean for me and my family in the area?" So I'm hopeful. But I just think at the moment we're still in that forming and norming stage. And until all that settles, we're actually just continuing with the relationships that we've still got there.

Paul Parsons - Yeah. Thank you. We've already heard a bit about health inequalities and reaching those communities that we wouldn't normally hear from and you haven't

historically heard from. Caroline, you mentioned it there. So I wonder if we could carry on? If we can think particularly about digital exclusion as well, because been some great work done in Cheshire and Merseyside on mapping digital exclusion recently, and I hope to see that spread out across the country, because for people who do our work, it's going to be incredibly helpful. But what expectations and aspirations do you have for involvement helping to reduce those health inequalities, which we've seen rightly promoted in profile, over the past year?

Caroline Parnell - I think the example I gave, that's a really sensible, let's try it out, how does it work? And actually, it's got the opportunity to really grow. We have a very high population of elderly people in Stockport. It's got the highest proportion of elderly people in a GM, and with that comes people with lots of complex illnesses. It's interesting you're doing this in the Northwest because actually, the Northwest is one of the most digitally poor places in the country. And I read some staggering figure the other day that people who have an income of less than £25,000, actually half of people over 65, have no internet connection at all. A third of disabled people, none, and one in five young people. So we do a lot of our work, don't we, thinking that we can send an email, but actually, if you can't afford internet access or you're just actually a bit frightened of it, what do you do? So, for us, we're doing a lot of work with the community hubs and working with our local council that way, really, and trying to do projects together.

I mean, Stockport has its pockets of deprivation, but it's got real ambition, so it's just got Town of Culture. So GMs, Town of Culture. So we're doing some work there around engagement in the arts, because there's lots of work, isn't it about when you get people doing something like an art project, they also start to talk to you about their services? So that's a project we've got going at the moment. But I want to learn from other areas because we certainly haven't got this cracked. And frankly, I have a really tiny team, so I'm hoping that by doing the partnership stuff, we can work together on tackling the deprivation, but also the ambitions that we have across the patch.

Caroline Latta - Rory, how are you tackling this in London?

Rory Hegarty - I think for years we've been talking in the NHS about tackling health inequalities. It's been in every NHS strategy I've ever communicated and it's always been an aim, if it was an aim of PCTs, CCGs, every generation of kind of commissioning organisations and system level organisations. And we haven't really shifted the dial at all. And I think ICSs are an opportunity because of course, you really have got the partnership with local government. So all of those wider determinants of health like housing and environment and all those things that affect people's lives are part of it. We absolutely recognise that. We have an inequalities programme in Northeast London. I still think the challenge is, so you can talk about you're not going to tackle an obesity crisis by talking to people who come to NHS meetings, because the reality is the vast majority of our population are not going to come to NHS meetings. So the digital question is really interesting, because I think actually there's a real opportunity in digital technology, you can get a lot of people into a virtual room and have conversations about things. It can't become the default, because what you really have to do is go and talk to people. And if you don't understand your communities, I think the thing is, the data will tell you all sorts of things about what the problems are. It won't tell you the why. So if you don't understand people's lives, you understand the lives that people are living. And also that is how you work with other people. So if I went and walked into a traveller's site in Northwest London and said, "Hi, I've come to talk to you about the NHS", I don't think it would work. You need to work with grassroots organisations, the people that work with those people. So it's a long term thing. And I think the other thing with it is that, so I had a conversation the other day with somebody who said, "this inequalities programme is great, but what are you going to deliver in twelve months? Are you going to deliver in 24?" That's a very, very simplistic way of looking at it. You're not going to change public health in a year. These are really long term generational challenges. But where you have to start, I think, is by talking to people and understanding communities, understanding the challenges that they live. So that's our approach, but I think it has to be a long term thing.

Caroline Latta - Karen, what are your thoughts on this?

Karen Coleman - I found this all fascinating and just picking up what Caroline said, because my background actually as I worked for a local authority for about 17 years and

some of the best work I've ever seen, and I'm sure a lot of you in this room won't remember this because I'm probably a lot older than you, was the single regeneration budget round five. And the single regeneration budget round five. What it did is it gave money to communities to develop an action plan to meet their neighbourhood needs. And it was fantastic. And some of the best community involvement we ever did was sitting in a laundrette all afternoon just chatting to people. And then the even better one was when we went to The Harp pub in a place called Fartown, sitting, talking to men who were from the Black Caribbean community. Amazing. Just amazing. But of course, that's expensive, let's be honest about that. We just don't have the resource to get out and do one-to-one or one-to-ten or one-to-twenty. And I think sometimes that's where we squeezed by budgets.

Absolutely picking up on what Rory was saying, he's so right. You need communities in VCSE organisations or community peers or neighbourhood peers to talk to the people who live in their neighbourhoods don't you. And a really great example is for people who are really big into health inequalities the core 20 plus five money. And that's enabled my colleagues in West Yorkshire to be able to buy in that specialist support from organisations like Solace who work with refugees and asylum seekers, because you don't need to look far from the news to see that we've got a crisis, haven't we? We've got people entering our country who were really poorly, not fit to work, some of them, after all that long travel across the open waters and putting their lives at risks. And that really gets to the bottom of what's important. And we're really proud to be an ICS (Integrated Care System) as sanctuary, the first in the country, and that's done with meaningful action.

I think the other piece of work that I always shine a light on is, we talk a lot about ethnic minority communities, but we don't explain who them groups of people are. And I think there's this massive assumption, isn't there, that they're Bangladeshi, South Asian, Eastern European? But actually, if you look really under the skin of it, some of the big health inequalities, just like them groups experience groups of population and people like Gipsy, Travellers and Roamers. And we know that the average life of a man from that community is very low, probably around the mid 50s. That can't be right. That just cannot be right. And when you look at Leeds, if you travel from one area, affluent area of Leeds, from, say, round Hare Park down to another area, there's ten years disparity in the length of time that that person will have a good quality of life. That can't be right. And I think the

other thing that's taught me from my council days, and unfortunately, a lot of that stopped, if you get in early, if you really get in early and do early help and intervention and preventing that sort of thing, it costs the state a lot less money in the future. But of course, what we've seen is sure start centres close, which I absolutely adored, and unfortunately, I did some work around that for communications. You've seen all of these things close, where that early help really, really mattered because council and NHS budgets have been squeezed so tight. But, yeah, I think we need to reverse that if we're going to tackle health inequalities, we need to pump more into that health and equalities lens to prevent it for future sustainable communities.

Caroline Latta - Thank you. Francis, you get to look at this from an England wide perspective. What are you seeing in terms of the reducing health inequalities agenda?

Frances Newell - So I think there's some great work going on across the NHS on working with communities to understand what are the barriers to access, what are the things that make it difficult for people to live more healthily, but you can get great insights, actually, from existing data. So one of the things kind of over 20 years of doing this work in the NHS is sometimes I think we do a lot of going out and talking to people about plans and strategies and asking them questions that perhaps we might have asked before and we might already have some answers on. But we're not so good then at actually sitting down with diverse communities to design the solutions. And we can't design solutions to everything. And the NHS also finds it very hard to prioritise. And I think there's something about working with the partners across an integrated care system, agreeing the priorities in an integrated care strategy and saying, these are the key inequalities for our residents that we want to focus on in this place. And we're going to work with communities to design the solutions. And we're going to draw on the wisdom of those communities working with the partners that they trust to put some services in place that will really tackle those inequalities in a way that's going to be effective. And we're going to measure what works and what doesn't work. And I think that's something that we saw work well when partners were working together during COVID to really roll out the vaccination programme. And there's been some great work done across the

country, actually, on building on that experience and transferring it to other areas of services. So I think that's encouraging.

The other thing I think that the NHS and public sector bodies can do is we can say, are we challenging ourselves to bring in those diverse voices that can challenge us, challenge our thinking and get us thinking in new ways and developing new solutions together? And are we recruiting teams that look like our diverse populations? Because we know that one of the biggest drivers of health is employment status, and do we really think about that as a route to tackling inequalities? And do we work with communities to get their advice, actually, on how we reach out and employ the parts of communities that are not very well represented in our workforce? I think that's an interesting and undeveloped area for working with people and communities. We're all very focused on workforce and that's something where I think we could be working a lot smarter with communities to find some answers.

Paul Parsons - I think that's a good point for us to take a quick break.

[MUSIC]

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Caroline Latta - And now, back to the show.

[MUSIC]

Caroline Latta - Before the break, we heard from Francis about how co-production and other ways of involving people is going to make a real difference. And we know that guidance encourages us to involve people early and to involve them continuously. We look at lots of involvement strategies from the integrated care boards across the country and we see them heavy with terms like co-production and co-design. So we were wondering what impact you think these approaches will have on how local people get involved in shaping health services in their communities?

Karen Coleman - Yeah, I think because I cover communication engagement, I might take a slight different approach, if that's okay, to this. I think where you see really good involvement in communications is in campaigns. And I think when campaigns are done properly, when they're co-produced and they're built from insight, they really have that impact that wows people and want to mobilise and get it into their communities and homes and neighbourhoods. So when we've co-produced some of our campaigns, for example, I don't know if any of you heard of our Looking Out for Our Neighbours campaign. I mean, that was such a great campaign and it was award winning, and that was actually built from local insight and involvement of lots of different community groups. And that included people living in high rise block of flats over in Leeds, right through to somebody living in rural Halifax. Not in Happy Valley. I'll just say they weren't from Happy Valley. And we got out and we asked people "what would make you look after your lonely neighbour?" and things like that, and they came up with some brilliant

insight to do that. And when we actually launched that campaign, because it was built from them and they became community champions for us, putting flyers through the door with little "Hello I'm here if you need anything". It was just great. And in the first week, we had 46,000 acts of kindness. Now, that's not 46,000 hits on a Twitter or social media account. That's 46,000 people who got off their bottoms, who moved somebody's wheelie bin, who took somebody a cup of tea, who they knew lived alone. And actually in that first week, just by noticing, because they'd seen the campaign, that somebody's curtains were still shut, they went round to see an elderly neighbour and he'd had a stroke and they actually saved his life because that person lived on his own and never really saw anyone.

I think other examples where the insights really made a difference is around suicide. So when you look at suicide in men, particularly in West Yorkshire, it's higher than a lot of our other population areas. But what we actually did is we got out there and our colleagues and our suicide prevention specialists, we brought together a community project, like a co-production project. And it was really hard, I'll be honest. It was really difficult because you start with a blank paper and you've got 40 people with different views. But I think with patience and with kindness and giving everybody that respect to say what they feel about it because they've lived that experience, you get something really amazing. And that campaign won a national award as well.

And then again, I mean, I could go on forever. But the one I will shout about, which was particularly challenging, anything that's worth doing is challenging. I think that's my tip. But the rewards are greater. So in West Yorkshire, I talked a little bit earlier, around 20% of our communities are from minority community groups. And we know that we have to do something to help our colleagues get past that glass ceiling if you come from a minority group. And also to try and eliminate racism that we know is still happening to today. So we produced the an anti-racism movement in West Yorkshire called 'Root out Racism'. And that was built from about 120 colleagues coming together about what it feels like to be in their community and experience racism. What does it feel like to work in a council or a health watch or a hospice or a hospital? What does it feel like to experience racism? And it was just amazing. The impact of that was amazing. And some of the quotes that I'll always remember, I'll take them to my grave. And I'm a grandmother of mixed race grandchildren. But I'll take to my grave the very fact that somebody says the fact that somebody who takes money for a bus ride will put the change in the holder

because they're black, it feels because they're black, if somebody gets on behind them who's white, they put the money in their hand. Somebody also said they went to Selfridges with their friend who was shopping and you know, the alarm goes off, they search their black friend's handbag, but they didn't search theirs. Racism is still alive and unless you can involve people to really get to the heart of what really matters to all of us, then I don't think we can make a difference.

Frances Newell - So the NHS has had aspirations on co-production for many years now. It's not always done well, but the aspiration has been in place for a long time and I've seen it work really well. When different parts of the NHS work with communities to sort of really understand the issues and design out those barriers to accessing services, I think we have to be realistic and say it can be very hard to achieve a decent co-production in the NHS. It needs time. We're quite a top down centralised service and that often doesn't sit comfortably with co-production, because co-production done properly does involve a shift in power and that's challenging. As Karen says, everything that's worth doing is challenging. The NHS is also often like a lot of public services asked to deliver to really challenging timelines and to do co-production properly, to work with communities and to work with staff, you've got to give it time to build up the relationships and actually do something decent together. Again, that can be very hard in the context that we work in. But I've seen great results, especially when you get people from local communities sitting around the table with the staff and the clinicians that deliver a service and really looking at the issues together and designing something better together. And I don't think co-production is always the Holy Grail. I think it's one of a range of methods that can be used. And I've seen again, great results where a proposal has been developed with intensive work with a smaller group of people and then it's taken out to a much wider cross-section of the population to kind of test those proposals with a wider group.

Paul Parsons - Thank you. In case we get done by the Trade Descriptions Act, we're going to talk about the future of patient and public involvement. How are you using and how do you see technology changing involvement, and not necessarily technology related, but what excites you about the future of patient and public involvement? Rory, can we come to you first?

Rory Hegarty - Yeah. The technology question is really interesting. Maybe all the insights that we publish will be written by AI Bots in the next couple of years, I don't know. But I think technology is a really big opportunity and challenge. So, as I said earlier, there's the whole thing around. You can get many, many more people into a room. If it's virtual, you can reach people in many different ways, but when you also have to go out and talk to communities. So I think technology is a threat to that in a way, because you could easily just narrow down and start, say, well, we get 200 people at these meetings, we're getting loads of people and you could stop doing the really important stuff which going out to talk to communities. I actually think the future of resident involvement I try to say resident now, because I'm working with local government more. I think the future of that is actually about community development. It's about going out and really working with different communities. You're not going to solve an obesity crisis by talking to people that come to your boards, but you might do by going and talking to different communities directly. And I think actually developing those communities and working with them. Why do people not turn up for their appointments? Why do they turn up for A & E when they perhaps shouldn't be there? And all those challenges and what we've tended to do is just tell people that they're doing it wrong. And I just don't think that's it we need to understand why and then we need to adapt our services. So I think it's a long thing, a long term thing, but I think the future of public involvement has got to be around how we develop our communities.

Paul Parsons - Thank you. Francis, can I come to you for that?

Frances Newell - I think one of the most interesting and exciting areas of public involvement is where we look at deliberative approaches. So some areas have done quite exciting things with citizens assemblies looking at climate change, for example. Our colleagues in Gloucestershire have worked with citizens juries on a couple of occasions. So where you get a group together that's broadly reflective of the population, they have got the opportunity to really review and understand the evidence and the context. They can sort of cross examine colleagues from health, from local governments. It's a really thoughtful process. It builds in time for people to understand, look at the issues, look at

the evidence. I think they're working on a much more level playing field and through that kind of dialogue and the mutual respect, you can arrive at better solutions together. I think it's an approach to involvement that strengthens civil society and really feeds into more democratic processes. And I think it's got a lot of potential and I'd like to see more parts of the NHS and the wider public sector using those approaches.

Paul Parsons - Karen?

Karen Coleman - Yeah, I absolutely agree. I think the secret, though, is going back to what Rory was saying. Isn't it's all about you can get the same faces and their faces and their views are no less important than anybody else's. What we're trying to do in West Yorkshire is taking on that I love the citizen jury stuff, I absolutely love that around deliberative work that Francis was saying. What we're doing in West Yorkshire is that we're working with health watch and we're setting up West Yorkshire Voice and that's been a co-production exercise where we started with a blank piece of paper. Now, the success of that for me would be that you had 4000 people registered on that database. Some like you to speak to them face to face. Some like a telephone call, some just want to have an email from you now and again. But what that really should be doing for us, if we do it right, is it's representative of our communities and we're speaking or communicating in a way that suits them. I hope it happens. I really hope it happens, because I just look at my family, none of them speak to the NHS. None of them. Would I speak to NHS if I didn't work in it? Probably not. Do I value my NHS. I love my NHS. But there's a difference.

Paul Parsons - Thank you. Caroline.

Caroline Parnell - There's always a place for technology. I'm a bit of a luddite, its my age, but there is always a place for technology. I think it is about tailoring it to your audience, the audience that we have. Big population of elderly people not accessing internet, etc. So even, I'm going to pick up the comms stuff actually, even in our own organisation, I've got a lot of staff who don't use the staff app, don't use the staff intranet. And actually,

when you go on the ward, the Ward Manager says, "just give us one side of A4, please, because I can stick it up in the staff room". And I think we have to accept that that's sometimes what our populations say to us as well, "please don't ask us to do another online survey". I think the other thing for me, that just thinking about that is one of the other challenges in it, is actually educating our organisations, because when money's tight, the easiest thing is the cheapest thing. So for a lot of our boards at the moment, money is really tight. So if you're trying to do involvement, "we'll just do a survey, we'll get our volunteers to take it out if they're not going to do it online". But actually, the stuff that we're talking about, to get real value takes money and it takes time and it takes resource.

So one of the best things I ever did was actually looking at re-building a mental health hospital. And we did fantastic work. It took a long time with our patients and things like the local council wanted us to preserve some of the old building and the mental health patients were saying, "absolutely not. That building has awful memories for us". And we were able to use that to actually challenge the council on some of their planning. But one of the things that we had a bit of a laugh, someone said, "oh, I'd like a swimming pool", and someone else said they wanted a nightclub and we didn't have money for either. But actually, what came out of that was the fact that what they were saying is, when you're in hospital and you're not very well, the days are really, really long. And if they could have a swimming pool, they felt better in water. It kept them busy. It tired them out. So actually, we hadn't thought about really anything more than physio, really, but we built a bigger gym, we built more exercise space because that had come from them. But actually, for a lot of our clinicians, they were like, "yeah, we know what's best". And their voice actually shaped that hospital. And I'm really proud of that work we did, and particularly things like the rooms where our estates people wanted to put mirrors in and our patients were going, "but if you put a mirror there when I'm in a paranoid moment, I'm going to think that someone else in the room with us". We hadn't thought of that. So a lot of our work, I think, is actually challenging some of our clinicians and some of our managers to say, actually, this is worth doing. You get a better product in the end, but it takes time and you're going to have to invest some money in it, which isn't always easy.

Paul Parsons - Thank you. We could honestly carry on this conversation all evening, but time is short. Thank you, everybody, for sending your questions in. Caroline, I'll leave it to you to choose one.

Caroline Latta - There's some great questions, but I'm going to go for the one from Mike Thorpe, who I know because we've spoken to Mike today. You are a patient rep and it's a really good challenge. So you said, Mike, "we're hearing the views of people in the system about how they think involvement is working, but do the patients that are involved think the same? Do they think they are influencing matters in the way that they would expect?" So I'm going to go to you, Rory, first.

Rory Hegarty - Okay? I hope so. It'd be my very short answer. So, the last conversation we had, we have a co-design advisory body which is drawn from people who work with communities we traditionally weren't very good at reaching and some members of those communities, and they absolutely have fed back that they're feeling more involved. But there's a long way to go and they still feel a lot of it is still the NHS presenting to them and then asking them to comment rather than there is a journey to go on so that people are able to set the agenda themselves. And that's where we're trying to get to.

Caroline Latta - Karen?

Karen Coleman - I doubt it. And I think the legislation's, I think, created a little bit more uncertainty when that moved from the CCGs (Clinical Commissioning Groups) into ICBs. I think some of them relationships may have got lost. I hope not, but I think maybe they did.

Caroline Parnell - I think if it was your annual school report, they probably would have said, could do better. Shows promise, but could do better, which is what they used to say about me when I did P.E.

Audience - [LAUGHTER]

Caroline Parnell - They were right. But I think there's a lot of promise there and I think the passion on this panel today tells you there's lots of people who really want to do good work and I just hope we can fulfil that promise.

Caroline Latta - And Francis?

Frances Newell - So people who get involved in health and in public services do it because they want to improve things, they want to make things better. They're ambitious for the NHS, as we all are. Often therefore, they are dissatisfied because they would like to see more progress being made. They would like to have more influence, they would like to have leaders who listen really well and act really well and they don't always have that experience and so they continue to challenge us and that's fine because that's why they're there.

Caroline Latta - Thank you, everybody on the panel, and of course, we could continue this conversation all evening, but I am really sorry to say that our time is up.

Paul Parsons - Yeah. Thank you so much for joining us for the discussion this evening. Thank you all for joining us this evening.

Caroline Latta - So our thanks to Karen Coleman

Audience - [APPLAUSE]

Paul Parsons - Rory Hegarty

Audience - [APPLAUSE]

Caroline Latta - to Francis Newell

Audience - [APPLAUSE]

Paul Parsons - And to Caroline Parnell

Audience - [APPLAUSE]

Caroline Latta - And thank you to the whole Stand team for putting this event together on top of exhibiting today at NHS Expo. Thank you very much, team. You're fabulous.

Audience - [APPLAUSE]

Paul Parsons - And thank you to our friends at Tractivity for sponsoring the event tonight.

Audience - [APPLAUSE]

Caroline Latta - We'd love to hear your views on the future of patient and public involvement. Join the conversation by following us on Twitter @notconsultation or emailing us at listen@notaconsultation.com.

Paul Parsons - So that's it for this episode. There's loads more learning in our other episodes, all available on our website, notaconsultation.com. You can find us as Not A Consultation wherever you get your podcasts and hit subscribe to be the first to get all our new episodes.

Caroline Latta - And Not A Consultation is powered by Stand, experts in involving people and communities and delivering service change for patients.

Paul Parsons - And this live event is sponsored by our friends at Tractivity, the UK's leading stakeholder management software.

Caroline Latta - So thanks for listening and remember,

Paul Parsons - This is not a consultation,

Audience - It's a podcast!

Audience - [APPLAUSE]

[MUSIC]

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