JB: Welcome to Listen to THIS, where we have conversations with people taking all sorts of approaches to studying how to improve the quality of healthcare. I’m Jenni Burt, senior social scientist at the Healthcare Improvement Studies Institute.

Today, we’re taking a deep-dive into why and how to engage and involve people, other than researchers, in the study of healthcare improvement and in improving healthcare itself. I’m sure that everyone listening is well aware, how over the last couple of decades, there have been multiple efforts to widen involvement in healthcare and healthcare research and for really good reasons. Academics and their funders have traditionally decided the research priorities and you might say, held all the power, whilst the people who will potentially be affected by the outcomes of the research, rarely got a look-in.

However, with the rush to ensure the perspectives of patients, carers, healthcare professionals and the public are incorporated into decisions about research, there comes rising concerns about tokenistic and formulaic engagement approaches. I’ve got loads of question around the current state of engagement and involvement, fortunately I’ve got some back-up with me in the form of my two expert guests.

First, I’m really happy to welcome Anna Burhouse to the podcast. Anna, you lead the external quality improvement arm at Northumbria Healthcare NHS Foundation Trust. So, you’re responsible for the training and coaching of NHS staff from across the UK to lead complex quality improvement work. You’re also a Health Foundation Improvement Fellow, an Ashridge Business School Alumni in Leadership for Improvement and an Honorary Senior Research Fellow at the University of Bath Centre for Healthcare Innovation and Improvement.

You also maintain a clinical role as a consultant clinical child and adolescent psychotherapist and you’ve been working in that field since the late 1980s. So, Anna, what led you to focus on how to engage staff in healthcare improvement initiatives?

AB: I think for me, it was hearing about the work of Marjorie Godfrey from Dartmouth Institute and her premise is that quality improvement is twenty per cent technical and eighty per cent about people. So, that to do improvement well in the NHS, we have to get serious about engaging people in improvement.

JB: I’m also delighted to be joined today by Lisa Hinton, Lisa, you are a Senior Researcher at the Healthcare Improvement Studies Institute and over your research career, you’ve both used many different approaches to staff and patient involvement, but you’ve also researched the topic of engagement and involvement itself. Alongside this, you lead social science research on understanding patient and staff experiences in improving care. One of your particular areas of focus is maternity services, where patient and public involvement can be particularly important, but also particularly sensitive. Lisa, why are you particularly interested in the role of patient and staff in improvement studies?

LH: I’ve been involved in researching and understanding more about patient experiences of their health and illness over a number of years now, I’ve been involved in a number of projects, specifically around maternity care but also in intensive care and critical care. For many, many decades, we developed medicines and developed operational procedures and thought about how we’re going to design our hospitals based around the perspectives of the clinician and the medical treatment. We have been playing catch-up really, in understanding the perspectives of the other individuals involved, what motivates people to come to the hospital, to take their medicines, to engage with healthcare is absolutely vital if we’re going to improve outcomes.

JB: Welcome both, to the podcast. This won’t surprise anyone who knows me but I did want to start with a little rant. So, over my research career, I’ve sat in so many really massive project meetings, professors and clinicians, arguing about really geeky things like power calculations or step-wedged trial designs and there is one or two patient representatives plonked at the edge of the table and they’re valiantly trying to find the right place and supporting document number ninety-seven.

The research funders are, on the surface happy because there are patient representatives on the steering committee and engagement is therefore happening. I’ve never imagined the patient representatives are very happy, even if they get some nice tea and biscuits out of it and I know I am potentially exaggerating a little bit, although in some meetings really not very much. But I think everyone who has ever attended one of these research meetings will recognise this scenario. I wanted to know from both of you, what do you think we ideally mean by the term, engagement?

LH: Not what you describe, because if you just continue that thought process a little bit, how has that patient representative been selected to come and sit around that big table. How representative is that person of the full range of experience of, for argument’s sake, living with multiple sclerosis or having experienced a maternity complication. So, there are lots of issues around how we select that person to be in the room in the first place. But then there are issues around what that person is contributing to that meeting, in that moment and we need to be thinking about conversations outside of those big, formal meetings and thinking about really creatively, when can we get patient, carer involvement.

JB: And Anna, you will notice that I described patients plonked at the edge of the table, the clinicians in those rooms are there with their academic hats on as co-investigators on the study and I have tried, in the past, to get people like practice managers or GPs to attend meetings and it’s really hard for them but also, we don’t tend to think of them in that kind of role. So, what’s engagement for you?

AB: So, I guess engagement for me is a very wide term, I still find it helpful to go back to Sherry Arnstein’s work around the ladder of participation because I think it still is relevant today as it was in the sixties when she came up with it. It’s a series of steps, I think she had eight in the original model but it describes going from a position where you’re not really engaged at all, it’s a political process, you’re kind of like, brought in but you’re not heard.

It’s a bit of pseudo-engagement, right through to really proactive, at the top of the ladder as she puts it, where the power basis has shifted and it’s much more a sharing of power between the people that want to do something, for her it was about civil rights but it’s been applied in lots of different settings now, where you’re seen as equal partners, equal contributors with experience to share and equal validity around your opinions.

JB: So, I’ve been asking about engagement, anyone who is familiar with the field will know that lots of other terms fly around, we have involvement, we have user experience research that has popped up now, we have co-design and there has been quite a lot of debate in the academic literature about whether these are all the same thing, whether there are boundaries being put up, slightly artificially between these fields. What kind of language do you prefer to use, what should we use, going forward in this discussion, are they different things?

AB: I guess what I’ve learnt is not to make assumptions about what people think engagement is and almost, this builds on what Lisa was saying, right at the beginning of this process, to almost have a conversation about what do we mean as a group of people that are coming together to do this thing, whether it’s research or applied improvement. What do we mean about involvement and how will we know that we have achieved it, as a group.

LH: I think what you’re saying there is about trying to reach a collective agreement about what a particular group means about engagement and how they define it, which is one step. There is another step, one of the big problems, I think, in this field is there have been multiple attempts to develop blue prints and frameworks to guide people and all of those have come out of really good motivations to try and upskill it and improve it.

But it's led us to think that there is a way of doing engagement or involvement and I think for me, one of the key things is to understand at the beginning of any project, that it will have its own individual peculiar and particular needs. There is no blue print that you need to follow and you need to work as a group to scope those out and work out how engagement is actually going to work for that project.

JB: And across those development of the broad principles, are those broadly similar, whether you’re talking about engagement in healthcare improvement efforts and engagement in research about healthcare improvement. Do they need very different endeavours?

AB: I think they’ve got a lot of similarities in terms of the values that you need to apply them but I think there are some differences too. So, to get on and to do quality improvement in action, you don’t need to go through ethics, you don’t need to show that you’ve considered engagement but in order to do it really well, in a practical way, of course you should have thought it through. So, I do think there are some structural and process differences but the values, I think, should come from the same kind of place where, why are you doing engagement in the first place, what’s it’s value, what’s its purpose.

LH: I think philosophically, they come from a very similar place in that understanding the prospectus of patients, of carers and of staff, whether it’s in undertaking a randomised control trial of a new intervention or its engaging in an improvement project. Incorporating their perspectives is highly valuable to the authenticity and the outcomes of the research or the improvement.

AB: Yes, and I guess the other thing that might be interesting to explore as well is, when you’re doing quality improvement in practice, sometimes when you’re thinking about engagement or co-production or co-delivery, you’re thinking about what somebody might bring about their lived experience into the room that will help you to deepen your understanding of what the needs are. But you also might do engagement or co-production or co-delivery when somebody has technical skills that you need and they might bring them to the table. So, in projects I’ve run, for instance, with quality improvement, one of the people that was involved in helping us, had legal skills and that was how they contributed.

JB: So, you’ve both helpfully already moved onto something that I was going to flag up to go back to basics and say, why do we do this, why do we try and engage and you’ve already started talking about authenticity and outcomes but do we know that this leads to better results?

AB: I think it’s an area that needs more research in its own right, I’ll answer from a very personal point of view. I know from the projects that I’ve been involved with over the years, that there has been something really unique about the contribution of people with lived experience that has made me think about things in a completely different way and has altered the course of the roll out of the programme. It has helped us think through about the evaluation and what’s important to measure and has really helped us to think as well about dissemination and spread and how we do that. So, on a personal level, I would never now do a quality improvement project without engagement and without people alongside me because for me, the benefits have been incredibly huge.

LH: It’s self-evident, to anyone who has been involved in research or improvement activities that engaging and involving people improves and enhances both the process but the results that you get at the end. But it’s really, really hard to measure engagement, we quite like to have a little tick-box exercise at the end of things, we like to be able to show things and demonstrate things in numbers.

A couple of years ago, we tried to collect together and evaluate the frameworks for evaluating involvement and we thought we would hire about ten and we found over sixty. They’re just being repeated and redesigned and not really reused by other people, I would encourage people to think about evaluation as a way of just encouraging them to up their skills, up their game but not get completely high-bound by making sure that they’ve got every box ticked because I think that can just be counter-productive.

JB: So, there is a general sense that for anyone who does it, it does feel different if you are engaging, if you are involving, co-designing, it feels different. We shouldn’t be trying to give that a nine out of a ten or a seven out of ten. We’re talking through around outcome focus, does it change the path, does it change outcomes, are there other reasons for engagement, for example, just that it’s the morally right thing to be doing?

AB: Absolutely it is, but I think it’s deeper than that too, engagement helps you to know whether you are researching or putting things into practice that are meaningful and are relevant to those people. So, there is something about how it connects you to the deeper purpose of what you’re doing.

LH: But it also can direct you to where the real squeaky wheel points in a service are. I mean I was involved in a project a couple of years ago about trying to understand more about noise levels in the intensive care unit. So, researchers observed that patients are very disturbed by high noise levels and they have very poor outcomes as a result of the high noise levels because their sleep is disturbed and they develop more delirium which is a very harmful thing for ICU patients.

But it required engaging with patients and with their families to understand what noise was, where noise came from. So, there was this problem that had been identified and articulated by researchers but it actually required people who had lived experience of being in those units from a patient and a relative point of view, to help guide the research towards the squeaky point that actually needed addressing.

JB: And you went about that in a different way than say, qualitative research approach, which might do formal interviews?

LH: In that project, we actually had the luxury of both, I’m really pleased you’ve raised this, Jenny, because I think this is a really grey area in this whole field. There is a rich tradition of qualitative research to understand patient experiences of their health and illness, that’s done with rich governance and ethical procedures and it’s a very labour-intensive process and it gives you very, very rich and valuable insights.

JB: But there are a lot of rules to follow.

LH: But there are a lot of rules to follow, to do the qualitative research in the intensive care unit, you go and you interview one person at one point in time and then that interview is done. There is also the approach of engaging patients and relatives in an engagement or an involvement process that is might lighter touch, it doesn’t require ethical approval but it still gives you access to the perspectives of the people in the bed, in the intensive care unit or by the bed, if it’s the relative.

You can get hugely rich and valuable insights from engaging with individuals who’ve got the lived experience of a particular setting that you’re interested in understanding more about. You can go back to them again and again, it’s much more of a conversation and an iterative communication process.

AB: I’ve got an example in mind, when I was at the West of England Academic Health Science Network, we started a project, again in maternity, to help prevent cerebral palsy in pre-term babies and we contacted the charity, Bliss and said we were looking for some mums with some lived experience, in particular that could join us in this quality improvement programme. Those two women, amazing women, Monica and Ellie, not only did they help us in the moment, to think about the co-design of the project and how we should get up and running, they also went on to develop a leaflet for mums.

They have been absolute cultural champions of that project going forward and now, we’re in the lucky position that through the AHSN networks, that piece of work has been rolled out to every, single maternity unit in England. They have become these incredible spokespeople for the project, they continue to input into the design and Ellie has got involved in inspecting maternity units, writing about it, they have made films, they have got hot on Twitter for us around it. Honestly, I can’t say enough, that none of us at the beginning, when we sat down in that first meeting would ever have predicted where that engagement would have gone and how it evolved over time.

JB: What did you do differently in engaging Ellie and Monica, that was different to the assumptions that would have got those patient representatives around a big table with all of the clinicians pouring over subset document seventy-nine or whatever it was.

AB: Yes, so I think the only thing we have in common with that original description is biscuits, we still have biscuits but…

JB: Everyone needs biscuits.

AB: [Laugh], yes, I was working with a wonderful neonatologist, Doctor Karin Lloyd and we thought very much, at the beginning that neither of us had had a pre-term baby, so we were lacking a skillset within the team and it’s really thinking about how you build a team right at the very beginning and recognising the value of lived experience. Whilst we were both passionate about improvement and Karin Lloyd, she’s got an incredibly rich history of saving so many babies lives over the course of her career, we didn’t have that.

Then I think it’s not just a matter of recognising that you haven’t got that skillset, it’s also being very open to the fact that you don’t know where it will go. So, not trying to have control over the process and being genuinely open in a very transparent way, being open to changing your original ideas.

JB: So, what you are describing is a really different model from, I think how engagement in research often sets out where a research team, through no fault of their own, through often the structures that we are trying to fit within will set out to feel that they are the research team and they need to find some patient reps, they need to find some patients reps and so they’re the add-on, they’re not part of the team from the very beginning.

LH: There was something really central, I think, in what Anna said, in describing that project, in terms of the flexibility and that’s very, very different in research where we have designed, whether it’s a five-year randomised control trial or a year study. With regard to applying process, means that we have designed that research timetable, we have a plan and there is very little flexibility within our research timetables often. I think that is one of the structural problems around engaging in healthcare research and improvement research and absolutely where we need to try and develop ways of, I think, flexing and giving ourselves the space for more flexibility so that we can evolve and absorb new ideas, potentially new directions that you might want to go through along the way.

JB: So, maybe time for me to have another little rant, just because it’s popped up into my head, from what we’ve been talking about, the conversation has been talking around patient and by extension, we can maybe say patient and carer involvement so far, I was trying to get a really geeky project funded that was so specific to staff needs, none of us could work out what patient would be a relevant member of the team. Not in any way that they didn’t have valuable experiences but because it was just this really geeky, nerdy staff thing.

So, our grant application had involved staff, GPs were the ones that we were targeting at, GPs, practice managers, we’d had lots of conversations, we’d got people onboard and the funder, a well-known national funder, who I’m sure everyone can guess, rejected it on the basis of there was no patient and public involvement. I remember that day, possibly even kicking the office wall because I was like, because we’ve got the relevant involvement, we’ve got staff involved and they’re the ones who we need to be taking on this journey with us.

I felt that that really showed the tick-box exercise of, tick you’ve got your patients on your steering committee, they’re going to check your consent forms and your information sheets, help a bit with dissemination, job done and staff just seemed to be a completely ignored group. So, Anna, we all talk about how overwhelmed staff are all the time but I think it’s really obvious that they are central to this engagement journey as well, how do we do it?

AB: I think it’s a really interesting question and up at Northumbria, under the work of Annie Laverty, Northumbria has got quite a good reputation of having tracked patient experience really well, for the last twelve years.

JB: But that was quite modest, you’re legendary in-patient experience.

AB: But actually, Annie started work, well over a year ago now to start to track staff experience too because there is a really huge evidence-base that patient experience and staff experience is a proxy measure for patient safety. So, we’ve been on a bit of a journey in Northumbria over the last twelve months where we’ve been really trying to track staff experience and to learn from it. We can show, in the last twelve months that we’ve made a statistically significant difference to staff wellbeing. It hasn’t been easy, it’s a journey of discovery for us but I think what we’re learning is there is some really huge themes that are coming out.

So, staff are not reluctant to engage when they’re being asked the right questions, I would say. Staff are open to giving you very clear feedback about what they need to do their job well, the clarity that they want, in terms of their role and also how important the relational side of work is for people. Engagement with staff has to be relevant, it has to be about things that staff really passionately care about, either because they care deeply about patient outcomes or because they care deeply about their work environment and their colleagues.

JB: So, Lisa, what’s your experience of both the structures for getting staff involved in research but also the meaningfulness and how we do it well?

LH: Well, the structures first, I think there’s been such a drive to engage with patients and when you fill in grant forms, there are big boxes and you need to have at least four hundred or five hundred words to say about your patient. I think we’ve just been missing a trick in trying to think about the staff experience for so many different reasons, absolutely philosophically we would need to be engaging going forward with staff in the same way that we have been engaging with patients.

Practically, there is, I think a very exciting development and movement increasing discussion around co-design in both research and in improvement activities and at the core of co-design is bringing people into the room who are able to work together as a team, to improve a particular service or a particular care pathway. So, that may well be the surgeon, the physician but also the porter or the physio. So, I think giving more oxygen to co-design approaches has to be a good thing, going forward.

AB: I think also it’s got to be easier to do than it is now.

JB: I was just going to ask, for anyone listening, they just think, I’m so busy already, this all seems like so much effort. I mean obviously you’re saying it’s really worth it and morally we need to be doing it anyway but what do you mean by it needs to be easier, Anna?

AB: Well, I think we have to find ways of making this just standard work in the NHS. We have a staff survey once a year but that means that we’ve only got data to look at that is already out of date by the time that we get it. So, thinking really clearly about how do we capture both patient and staff experience in real time, in order to make improvements, I think is a really huge challenge but one that we should be embracing.

JB: What about freeing up staff for research involvement, staff are so committed, so busy?

AB: But staff are generous, I would say, on the whole, we obviously don’t want to abuse that generosity but people are always willing, I think to get involved with something that they think is relevant. So, for me it’s how do you convey the message that this is really important work, people want to know that their contribution will make a difference and that’s really important. So that also means feeding back to people about what you’ve found.

LH: I agree with you Anna, staff are very generous with their time and do give a lot to research collection activities but I think we could probably do better at thinking in a more creative and iterative way about how we might engage with staff on particular improvement projects. So, rather than collecting data across every staff member and every Foundation Trust, actually we want to solve this problem, who do we need to involve and how can we genuinely engage with them.

JB: And for those people who have been listening to this and are thinking, oh my god, last week we had a meeting where our two patient reps were stuck at the table eating biscuits and looking a bit confused, what can anyone do, small steps to try and slightly change the way they’re going about this whole endeavour?

AB: I think just open up a conversation, just say, how are you finding being involved, is there anything we could do to make you feel that you’re more fully engaged in this process.

JB: Should people be trying to evaluate the impact of their engagement, at a project level?

AB: There are quite simple ways that you can check-in regularly, to make sure…if you’re having a meeting, you can have it as a standing agenda item to have a discussion about how it’s going. Reflections on the roles that you’ve taken in that meeting and that day. I think the main message would be, don’t be scared of having a go because I think a lot of people are almost scared into passivity because they’re worried about getting it wrong. I would say, you will get it wrong, embrace that and learn from it.

I think also, when I do co-production with young people, with sixteen- to twenty-five-year-olds, I’m doing a project at the moment, we’ve got between six and eight young people actively involved in it, you can get it right for two or three people round the table but you might equally get it completely wrong for five or six. So, I think what we’re describing is, this is not a static process, this is a relational process which is dynamic, that you have to keep working at whilst you’re in the middle of it.

JB: So, it’s not any surprise to anyone but I think we all agree, around the table, that engagement, involvement, co-design, all of these activities are really crucial and even if the evidence-base hasn’t caught up yet, that they are making a real impact on both healthcare provision and research about that healthcare provision and that we should just be doing it for morally good reasons.

Try something, try that one conversation, that it’s really important that we speak to staff and actually for the researchers who are listening, pushing the fact that the structures need to take more account of the importance of the staff voice. There is just no right way of doing it though but everyone always needs biscuits.

Thank you so much Anna, for all of your contributions today, it’s been great having you. Thank you so much Lisa, as well, I’m Jenni Burt and you’ve been Listening to THIS.

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