Transcript of podcast episode 4:

Involving children, young people and their families in making healthcare safer

with Jane Runnacles and Victoria Dublon

Natalie Wyatt

Welcome to your RCPCH patient safety podcast, where we delve into the successes and the challenges of creating a healthcare environment that is safe for children and young people. I am Natalie Wyatt, Paediatric Registrar and Quality Improvement Fellow at the RCPCH.

Jonathan Bamber

And I'm Jonathan Bamber, Head of Quality Improvement at the RCPCH. In this episode, we're going to focus on how improving how we engage children and young people in their care can positively impact patient safety.

Natalie Wyatt

Say, for example, if we help patients to self-report any harm that occurs when they're in healthcare settings, this can triple the rate of detecting adverse events. And also we've seen that if we involve patients in co-producing interventions to improve safety, there's up to a 40 percent reduction in harmful events. So it's imperative in our effort to improve patient safety that children and young people are at the heart and central in the co-design and co-production of patient safety improvement interventions.

Jonathan Bamber

In this episode, we're talking with Dr Jane Runnacles, consultant paediatrician at St. George's Hospital, and Dr Victoria Dublon, paediatric diabetes consultant at the Royal Free Hospital. Both Jane and Victoria are champions of improvement work that puts the young person and their needs first.

Natalie Wyatt

So welcome to you both, Jane and Victoria, and thank you so much for joining us today. It'd be great if you could just tell us a little more about yourselves and your career so far?

Jane Runnacles

Yes. Well, thank you for inviting us. I feel really passionate about this as somebody who has always had a real keen interest in quality improvement, having had an amazing opportunity during my training to work with the patient safety team at Great Ormond Street for a Darzi Fellowship, where I first experienced and learned from Peter Lachman, who was a wonderful mentor who always championed the importance of engaging a young person and their families in improvement work. And then I went on to work with Victoria at the Royal Free, where we were actually a pilot site for the RCPCH SAFE collaborative. And we had some really interesting work where we were looking at, um, implementing safety huddles on our ward and really thinking about how we could identify parents' concerns around deterioration. So, totally recognising actually a parent knows best when their child may be deteriorating and trying to understand how you can capture those concerns. And I think that's something that's come out of many very sad sort of stories of deterioration in the past. That actually a parent reports that they often have, have watched their child deteriorate. So that's where I met Victoria. So Victoria's always championed the work brilliantly. and had a really amazing enthusiastic approach to actually how we engage children, young people and their families.

Victoria Dublon

Oh, thank you, Jane. I've been at the Royal Free for 16 years and Jane mentioned Peter Lachman and I was also going to mention him because he really was the first person to open my eyes to QI and I was lucky to work with him and learn with him at the Royal Free. And I was able to put this in place within the diabetes world and the acute paediatrics world. And then Jane came along and got me involved in SAFE, the Royal College of Paediatrics program, which I think we're going to talk a bit more about later.

Natalie Wyatt

And for those listening who might be kind of new to this, this whole topic of child and young person engagement, um, Jane, would you mind telling us a little bit more about what it means to you, what is patient engagement and co-production in a healthcare setting?

Jane Runnacles

Well, I think we're all familiar with patient centred care and hopefully that's something, I think as paediatricians, we're actually very good at thinking about shared decision making with our patients. So, with the children, young people, and obviously their parents and carers. But I actually really like the term, uh, patient centred safety, really thinking about developing an equal partnership, um, with children, young people and their families around sort of creating, um, a culture for safety, but also understanding that. really they notice safety issues that often healthcare workers miss. And as you've said before, but actually we know that a positive patient experience is associated directly with improved clinical effectiveness and fewer adverse events or harm. And I actually at this point would like to reflect on, um, something I heard, uh, the wonderful Don Berwick say in a, in a talk, and I know it's been quoted and referred to many times, but, and I may not get this exactly right, but his sort of challenge to healthcare is, are patients and their families someone to whom we provide care, or are they active partners in managing and redesigning their care? And I think that's really important. sort of concept, that actually the whole aspect can start on an individual level actually with your patient. But really we should be looking at the system as well and thinking about how we can actively involve children, young people and their families in actually designing a safer system, a safer healthcare system on quite, you know, it can be on a, on a smaller ward or departmental level, as well as thinking about patients as leaders in healthcare, which is obviously the ultimate, uh, sort of at the end of the continuum, as it were of, of person-centred safety.

Jonathan Bamber

I think that articulation of patient-centred safety is really interesting. I mean, obviously with both quality improvement and patient safety there's a residual perception that, oh, I should involve patients in this process, or it's something I should do at some points and some people are very good at doing it, but I think there's something interesting there around in order to lead to a safe environment and high quality, safe care. It's not an add on, it's something that's essential to have the children, young people, their parents engaged in, in that process. It's interesting you use that phrase of being patient centred. Often there's other language that people use around, is it engagement, is it involvement?

Um, have you a view on whether it matters on the language that we use or is it sort of more around what happens in reality?

Victoria Dublon

I think language does matter so much, doesn't it? It's something Jane knows that I go on and on at almost every handover that we have at the Royal Free, because if we're using the wrong, wrong language together that can make us come over quite patronisingly when collaborating with young people. And I, one of the words I really try and get us away from saying is patient, because why should they be patient? It's us that need to be patient.

Jane Runnacles

Yeah, I was going to say that's exactly what the challenge is, isn't it, around involving children, young people and their families because actually it's, it goes against the kind of traditional hierarchy of healthcare, which, you know, absolutely needs to be disrupted. I mean, it's all about, um, listening and being respectful and having an equal partnership. So I think actually how we think about truly collaborating and partnering with our children, young people and their families is so important. So, yeah, moving away and actually thinking about that patient as a person and how we really, truly partner with them to, to think about improving patient safety.

Natalie Wyatt:

And this might be a great moment actually for you to tell us a little bit more, maybe starting with you Victoria, about what benefits you've seen in bringing the people that you're looking after more into the centre of the care planning and the creation of their care pathways?

Victoria Dublon

I think one of the things that we found when we were rolling out whiteboards at the Royal Free is by getting feedback from young people and families, it actually spurred the whole project on because people started to see immediately the difference that this was making. So I think that young people can be the best champions of these types of projects, and I think that's something we need to remember.

Natalie Wyatt

Will you tell us a little bit more about your whiteboard project?

Victoria Dublon

Jane, you started it out, didn't you? I was just the first champion.

Natalie Wyatt

So this was part of your SAFE programme, Jane?

Jane Runnacles

Yeah, so I first learned about the concept of daily plan whiteboards, I think it was from Yincent actually in Newcastle who presented his work about improving the communication and having shared goals on ward rounds initially, so having a whiteboard next to the patient's or young person's bed space and being able to agree goals and plans with their parents and carers or with the young person if it was appropriate. You know, on a very basic level, thinking about planning for the day ahead. If we knew the time of a scan or if we had an idea of when we would be able to do the blood tests. And it was amazing the feedback we had from parents and carers that really helped them to organise their day and be around for a time when they needed to catch up with the medical team or when they needed to be there to, to support their child having a blood test. And actually as Victoria said, it really helped engage other members of the team because the parents and carers could really see the benefit and they would ask for other team members to contribute to the whiteboard and they could contribute as well when they perhaps weren't going to be available if they were doing a school run. And that's on quite a basic level, but on a kind of a larger scale it was it was not just about having those shared goals there was more about - and it makes me think Victoria about our project, ‘what matters to you’ - because it wasn't just about goals, we could talk about concerns or challenges. It helped them to be able to raise their concerns if they didn't think their child was getting better, and it just opened up that conversation, being able to think more widely about the care of their child and the direction of travel in terms of their hospital stay.

Victoria Dublon

I was going to say, you know, if we went back in time, this is what we'd call the doctor patient relationship really, isn't it? It's an alternative way, a modern approach to building those bridges and like you say, it really helped them to get to know who their team was.

Jane Runnacles

Yeah, exactly. And I suppose it was a way of co production because it helped us work with them to design sort of how the care was going to be delivered, but also think about sort of safety measures actually. So thinking about how they would escalate their concerns. And this was, it fed into the project with safety huddles. And I always loved the example at the Royal Free about using our wonderful housekeeper to connect with parents on a daily basis, because we recognize that actually, she got to know the families really well. And she was going in before we did in the morning to take their orders for breakfast or lunch. And parents and carers will actually connect with her in a way that they don't with the medical or nursing teams, really, and have much more of an informal conversation. That really came out of talking to some of the parents and carers, and also talking to the wider team to see how we could listen to concerns from parents as well. And I think it all kind of linked in, didn't it, with the whiteboards.

Victoria Dublon

It did and it enabled her to become a real champion within the team and everybody, maybe the junior doctors in the past didn't really know who she was, she was just another person on the ward, but it really brought us all together, which is another way of promoting safety, isn't it?

Jonathan Bamber

This is a fascinating conversation in that this example touches on one of the other podcasts that we have done as part of this series around psychological safety and the importance of all team members and, including children and parents, people involved in care being included and being able to contribute and be involved in making sure that that care is as high quality as possible and you can introduce changes. And you mentioned old fashioned patient clinician relationships, that drawing in the fact that there are loads of people involved in that, in those interactions and to get that better communication is really powerful. It's a really interesting example.

Jane Runnacles

And it's all about sharing situation awareness. So obviously this was part of the RCPCH SAFE program. And I always found that fascinating to think about the concept that the shared situation awareness across the team and the parents and carers and the young person is so much greater than all the parts. So, you know, it really absolutely would lead to improvements in patient safety and awareness of those at risk of deterioration and understanding who your watchers are on the ward.

Jonathan Bamber

It's, I guess, important for listeners to understand that often good co production comes out of part of a broader quality improvement or patient safety piece of work. So maybe this would be a good time just to explain a little bit more detail around the SAFE program in that, as you mentioned, it's initial drive in my understanding around situation awareness, which as people would know is an aspect of patient safety. Traditionally, we would focus on past harm and looking at past harm, but that importance of monitoring and being aware of our current situation in order to avoid harm in the future is really fundamental. And so the SAFE program that Peter Lachman led with the RCPCH, looking at situational awareness in my understanding, but then this aspect of co production. It'd be interesting to know, was it originally within there or did it grow as this amazing flower as part of the program as it developed?

Jane Runnacles

Well, I absolutely think that it was, it was there from the start in terms of Peter Lachman's kind of vision for the program. And all of us were encouraged to think about right from the start in the design actually, how we would be engaging children, young people, parents and carers. And actually it was strongly linked to thinking about our early warning systems within our trust and obviously now with the national pews it's become recognised really that actually listening or identifying parental concerns should be part of that early warning system.

Victoria Dublon

And that's on our whiteboards isn't it?

Jane Runnacles

It is and we had it in part of our safety huddle was actually talking about parental concerns but my worry was always, are we truly identifying them? You know, we, we talk about it and we know some of the parents who may be quite vocal in expressing their concerns, but are we really listening to everybody and, and, and hearing those who may not be expressing their concerns or not understanding how to raise concerns. And that's actually, that was a big part of what we were thinking as, as, you know, as part of our SAFE programme. Um, and actually more recently, in my current trust at St. George's, we revisited this issue around asking about parental concerns, and we actually thought about the young people as well, because although, obviously, some of the younger children may not be able to articulate this certainly some of the younger people would be able to tell us if they felt they were not improving or not getting better or if they had concerns that they weren't sure quite how to, to bring up with us. And I worked with a fabulous junior doctor who we engaged with our children's council at St. George's and they really helped us design some information, some leaflets, posters, which we give out to, um, we've been testing it on one of our inpatient wards to see if it helps, um, parents, carers and the young person. It's quite age appropriate. And it was, it was co designed actually with a parent who's an artist, which was a really lovely way of feeling that we are listening to the, to the parents and actually, taking on their perspectives on how to actively engage them in, in safety work, which I think can be really challenging. And it's, it's not an easy approach and it does obviously take a bit of time and effort, but it's certainly worth, you feel then you have something which is, is appropriate and, and actually will be used in a positive way.

Victoria Dublon

Great to hear you've got a children's council at St. George's. That, that sounds fantastic.

Jane Runnacles

It's really lovely to have an engaged group of young people who've experienced care at the Trust. You know, they've probably noticed safety issues that maybe we haven't noticed, but they just come with a different, it's that fresh eyes and a totally different perspective and really challenging in a positive way what we're doing and why, why we're taking these approaches. And really, you know, they made us think that actually the word deterioration is maybe not understood in the way we may understand it and actually, you know, it goes back to language like you mentioned before Victoria, thinking about what language we use and it's it's been a really great experience, but I know you've engaged a

lot of your young people though in your diabetes work as well. And actually, you know, that's another way of thinking about it.

Victoria Dublon

I was thinking about all the different ways over the years that we've engaged young people at the Royal Free, both through diabetes work and what we've done, but also for what advice we can give to other places who, who want to do some collaboration. And many hospitals have a hospital school. And when we were doing the whole SAFE project with huddles, et cetera, that's when we really got to know our hospital, the hospital school at the Royal Free. I don't know if you remember all those years ago, Jane?

Jane Runnacles

It was so valuable having the teachers coming and that they were part of our team for the collaborative.

Victoria Dublon

Yeah, they continue to collaborate with us more and more. And for me, that makes sense because children spend most of their time at school, but most wards, I mean, I think all the hospitals I worked in as a SHO and registrar, do have teachers on the ward that help engage the children, say if they're trying and carrying on the topics that they're doing at school, so that they feel they're not totally missing out on school. We found it was a great way to access young people to collaborate because teachers are experts in language as well with children. And I work now with our school all the time on projects. So the Royal Free School works on the ward but they also have an ongoing school where young people don't necessarily have to be on the ward, they're just a part of the Royal Free School. So that's a great pool of young people to get their feedback about projects. But as Jane says, in the diabetes world, it's become our everyday, every clinic way of working that we're continuously having feedback and input from young people about what they want from clinic and how we can improve clinic for them. And in that way, it makes it safer. Because they're more likely to come and more likely to engage. So it's self perpetuating really.

Natalie Wyatt

And what does it look like on a day-to-day basis, Victoria, when you say about getting feedback, getting input, how are you doing that? Is it, are you just having conversations? Have you got youth workers involved? Is it surveys? Like, what is the practicalities of how you're doing it?

Victoria Dublon

So we'd love to have a youth worker but unfortunately I was turned down for funding for that so I continue to use the resources through the Royal Free School and they usually have interns who, well all the time they have interns, that are visiting teachers in training. So similar skills to youth workers and whatever QI project we're doing, so at the moment we're doing about healthy futures so that's a. a great safety project for the future of young people. And the interns come down and help collect data and feedback from the resources we're using.

Jane Runnacles

And Victoria, they also helped you run specific educational days for your young people with diabetes, I remember. So they actually designed, you know, they could actually help you educate the young people on things like um, carb ratios and calculating insulin doses and that kind of thing, isn't it? So one of the,

Victoria Dublon:

So one of the, the hurdles that the teachers helped us realise on the ward was that many young people, not actually only the young people, the parents as well, don't have the maths skills to be able to, it can be quite complex working out insulin doses. From that we, we then went on to have regular. educational evenings, afternoons, and indeed we got funding to collaborate with young people and turned the educational evenings into a series of puppet workshops where young people produced their own films about diabetes with script writing and input from WAC Arts, so they also learnt production skills. They really, really enjoyed that and not only did it help us build bridges with them and understand what they want at the service, they produced these lovely films that they wanted young people to see when they were diagnosed with diabetes. And we've had marvellous feedback. We still use these films all the time with young people and families that are newly diagnosed, and they love them because straight away they see young people talking about what they've just been diagnosed with and can identify and feel they're not on their own.

Jonathan Bamber

So it sounds as if from a range of different directions, be that the use of the whiteboard process as part of the safe program, the hospital school, the work on your diabetes work, they're building a culture of acceptance and support that supports true co production and engagement with people and in processes of care and improvements of care has become the norm. Would that be fair to say?

Victoria Dublon

I was going to say the word is normalisation, isn't it?

Natalie Wyatt

I love as well that you've, that specific example that you've given as well really fits with the kind of the RCPCH ethos around children young person engagement in that you're not just taking from the children in terms of going and seeking their feedback and seeking their guidance and asking for help you're actually giving them something back as well, which is, you know, the skills around production, something fun, something entertaining. So making sure that, you know, all of the rights of the child are respected in, in that process, which I think is, that was a really lovely example of doing that. I think that's really important when we're thinking about engaging children in this kind of work, is that it's not all about what we want from them. It's what we can give to them as well.

Victoria Dublon

Yeah. And I think that's also something colleagues might worry about in the current financially challenged climate as well. So it's not just time that you need to do these things, but finance. And in order to get the finance, you need to have the time to apply for that. And again, that's where other colleagues came in, for instance the interns at the Royal Free School, because they were able to send off the letters etc. for finance for us and we managed to get finance for that film quite easily. So I think collaborating with young people but also your wider team and thinking who is on that periphery of your wider team that you could bring in can really help with all this collaboration.

Jane Runnacles

I'm always, um, talking about that aspect, actually, that we're not always very good at looking outside of our immediate team or department, and actually there are so many wider resources, not just within perhaps your hospital trust, but from third sectors and other organisations, that it's really, it's, it's sometimes difficult to know where to turn, but actually the, the benefits and the gains you get from working across a much wider stakeholder group to help. And it makes me think, actually, I was reading about the, um, WHO World Patient Safety Day, which this year is all about engaging patients in patient safety. And their kind of slogan this year is about elevating the voice of the patient. And it's all about thinking about opportunities to engage, um, patients, in our case, children, young people and their families. And actually these are just all examples of ways we can kind of raise their voice in order to kind of think about partnering with them for, for improvements.

Jonathan Bamber

Have you had particular examples where you've had challenges to that, that people would say, yes, yes, yes, that's fine, but I'll do that at another time. Or it's, it's that. peripheral thing. How, how have you dealt with people who provide a bit of a pushback to say that's a nice to have, but we haven't got the time, et cetera?

Jane Runnacles

It's, it's a really common scenario. And also there's sometimes a fear of actually bringing young people into improvement work, which, you know, often I, I get pushbacks, not from my immediate team, but I mentor quite a lot of paediatric trainees and quality improvement work through an education program that I lead. And often they'll come back and say, Oh, my supervisor didn't think it appropriate. It's not really something they should know about if there's an issue here, or, you know, we don't, we shouldn't be sharing this, this problem with them. And we always challenge and say, well, actually, not only will they be able to identify and help you understand that problem better, because obviously the first step to quality improvement is really understanding the problem and where it lies in the system. And absolutely, your patient should be part of your process map to, to really understand that process better. And there are huge gains and benefits from involving them in that process mapping, because actually it will help you understand it so much better. And then there's also the gains from co design. I mean, I've had some, you know, real nuggets of a parent coming to me saying they're a graphic designer and could they help actually with some of the resource that, you know, would have been really tricky to, to find or to, finance even, or a young person who's very creative

or who really want, you know, is amazing with their words and their writing who, who's wanted to help. So I think, you know, just showing examples of where the benefits have been is, is hugely helpful. I don't, I, I'm guessing you're, you've had a similar experience, Victoria, in that as well?

Victoria Dublon

Well I was thinking it would be unusual not to get pushback occasionally because sometimes it is surprising and you do feel slightly shocked that people are pushing back. But it's the old sort of, it's all often the things like contraception and so Healthy Futures is all about preconception advice and paediatric teams can still be quite old fashioned and think, well, what's that got to do with us? So, but as we always say, those that challenge most, once they're on board, they're often the most on board, I find. It's just you have to find a way of convincing them and be patient.

Jonathan Bamber

So taking that particular example. So, Jane was mentioning, it sounded to me as a combination of providing the examples of where it's helped, but also where there are opportunities to make things to use resources that are available to make that process easier can be helpful. When you have someone turning around saying I don't see how the value of that engagement, do you use a combination of those approaches? Can you think of an example of where you've managed to turn someone around to become that champion when they were previously a blocker or a constipator in the system?

Victoria Dublon

Well, as I mentioned, the um, preconception advice, Healthy Futures, I think even by promoting that everybody does have the right to that information and, and showing that actually that's what young people want. So then getting those questions and, and answers from young people and showing the team. that that is actually what they want. They want to know what the risks are, even if they're not sure that they want children now. It's on their periphery often, you know. Am I going to be able to have children if I've got diabetes with high blood sugars? Once you broach those subjects with them and ask them if they do want to know this sort of information, and you have those facts that they do, and you present that to the team, that was the way we turned it around, and it's been a highly successful project actually.

Jonathan Bamber

Brilliant, thank you for that, that's uh, it's really interesting and um.

Victoria Dublon

It's something very neglected is um, still is preconception advice and contraception in paediatrics.

Jonathan Bamber

But it’s interesting as an example of something where there's sometimes a disconnect between what people genuinely want and a cultural perception or maybe a historical perception of, as clinical experts, we feel as if...

Victoria Dublon

Exactly. It's a bit like you were saying earlier, Jonathan, because they don't feel the experts of that, you know, then they think that probably it's better done by somebody else. But that's not always true. Actually, it can be better sometimes if you're not the expert because you do it in, And maybe you think more about what you're doing when you're doing it, I don't know?

Natalie Wyatt

And perhaps you're more likely to truly work together if you're, you know, both you, the young people and the families are all sitting there on the same page saying, we don't know how to approach this and planning it together. It's more likely to create a situation where things are truly created together.

Jonathan Bamber

And like any quality improvement. or in patient safety work, following that quality improvement methodology, until you start testing something in, trying something out in your own context, then you might just assume that, oh, it's going to be more work and it's...

Victoria Dublon

Well, I'd be kidding if I don't sometimes think, oh, actually, maybe this is going to be too much. Maybe this time I've chewed off too much. And I'm very lucky to have colleagues that I can go and chat with, and I particularly go and talk with the head and the deputy head at the Royal Free School, because they remind me why I'm doing this project and trying to get whatever it is at the time off the ground. It is for the young people.

Natalie Wyatt

So just linking back to what we were talking about before about creating an environment where children, young people and their families feel that they are able to raise concerns about their health, about their safety within healthcare settings. For somebody who is looking to start out doing this, how can people take those first steps to support children, young people and their families to raise concerns?

Jane Runnacles

So I think on a basic ward or individual level, most paediatric departments do use an early warning score system. And actually, we do recognise that, um, there's very good evidence that some children do deteriorate and actually their scores on the systems don't always reflect the fact that they're deteriorating. And we all know that as a parental carer, they know their child better than any of us. So it's so crucial to listen and respond to their concerns. And, you know, this sounds quite obvious, but sadly, looking at past history and hearing patient stories and events that have been analysed, actually on many occasions, a parental carer has recognised at an early stage and their concerns aren't always listened to. So thinking on, on a ward level, even thinking about an individual nurse, being able to escalate concerns and being empowered to escalate those concerns. to, to the medical team and something we do at our trust is, is having safety huddles, which specifically ask whether there are any parents who have concerns. And I do think it's a challenge to actually, as I've said before, actually know that you're, you're capturing that, um, and that you're really responding, but that's something which could be relatively. easy as an improvement work and link it perhaps to some information for parents and carers, just as we've produced a leaflet. And actually we're inspired by the Listening To You project at Birmingham Children's Hospital. And as I said, we worked with young people to actually design something that. We hope they would read and understand and know, um, a way of, of escalating concerns themselves. So I think that's, that's one approach.I mean, obviously with the new NHS patient safety framework, there's a lot of emphasis on learning from events with a real kind of culture of, of engaging patients and families to

learn. And. You know, we always find a patient story incredibly powerful, but actually how we truly listen and learn from deterioration events and actually put that into practice in our own departments, you know, is again another challenge, but so crucial and really something that we should be thinking about as well. I don't know if you've got any other thoughts than that, Victoria?

Victoria Dublon

Yeah, I think starting simple and starting with a multidisciplinary team of, of how you're going to do that, but make sure early on you're, you are involving the families and young people, right from the beginning, really. A bit like how we started doing What Matters to You Day, Jane, at the Royal Free and having families and young people's feedback on those days gave us a focus.

Jane Runnacles

And it was creating that environment, wasn't it, that was safe for them to raise concerns or, you know, as well as hearing the positives. It was a safe place where they could actually discuss some concerns or some challenges to their care, which, you know, as we all realise, even some of the negative patient experiences would have an impact on on patient safety as well.

Victoria Dublon

And huddles are a good way of starting and and promoting the fact that within that huddle, parents concerns feed in, and they do really really count and if you've got huddles twice a day then you've got parent's concerns being fed in twice a day and young people's concerns.

Jane Runnacles

And just also as challenging some of those, um, misconceptions about there being a difficult parent or a stressed and, you know, and actually truly listening to concerns, because I do think there is still sadly that sort of hierarchy and, you know, view of some of the parents or carers that, you know, actually we should learn from and listen to them.

Victoria Dublon

Goes back to language matters, doesn't it? That that's not a phrase allowed in our department. It's not necessarily that, that clinician's fault that they're using that phrase, they've learnt it from somewhere else and, and having an open discussion regarding language matters.

Jonathan Bamber

To follow up on that, so there was some really fantastic examples that both of you have talked about of where someone could take their first step. A lot of these, like the use of huddles and having specific days for people to have their voice are... Firstly the separate days are particular events that you arrange and the huddles are a mechanism for communicating the people's voice into decision making, but you touched on there Victoria around the challenge of that hierarchy of: are people going to be listening to the parents, the children in that conversation? And you mentioned keeping it simple, which I suspect is really important. What mechanisms do you use at the Royal Free to, to keep it simple, to support the ability for clinicians to have that conversation in a truly co-produced way and enable people to be able to raise concerns?

Victoria Dublon

Well, one of the tools we have is actually on our whiteboards that there's a three face picture. A smiley face, a straight mouth and a downward mouth. And there's one for parents and one for young people. That's embedded into our use of whiteboards. And sometimes it may have been filled in by the nurse coming on on shift. Or if it hasn't, we tend to fill them in on the ward round.

Jonathan Bamber

So this is the whiteboard process which was introduced as part of SAFE and has now become normalised as normal practice?

Victoria Dublon:

Yes.

Jane Runnacles

In a similar way with the early warning systems, we thought at length about an easy question that a nurse could ask a patient, um, you know, or, or a carer saying, are you concerned your child or young person is, is not getting better? Or is, you know, it was a really interesting conversation we had with them about the wording we'd use. But making that a normal part of when they came to do observations, that this would then be scored on the, on the early warning system. And again, you know, having a structure, having a tool that, that works so that it's part of what, what you do, you know, this is part of your, part of your daily work so that actually you have a system in place to help identify those concerns. So kind of again normalising what we do but then making sure that that's escalated in a structured way as well so that that warrants a review.

Victoria Dublon:

And I'd say out of everything at the Royal Free that has really been embedded. So much so that it's just the norm at huddles that the nurses feel really open to say the family have concerns.

Natalie Wyatt

And in terms of looking at outcomes, have you been able to collect any data or find any correlations or associations with safety outcomes from implementing or normalising this practice?

Victoria Dublon

We haven't done anything recently, but we probably should actually.

Jane Runnacles:

It's really difficult, isn't it, to, to measure, um, when you're looking at, a lot of this is about changing the, the culture around safety in a department. We did actually, at the end of the SAFE collaborative, we looked, we had safety culture questionnaires for the wider team. So, I feel like we weren't asking the, the young people or the families directly, but

we were certainly asking a wide range of staff. And we were able to measure and demonstrate an improvement in their, um, attitudes and, uh, in the safety culture. So that was an interesting bit of work. But be, be interesting to revisit that actually, Victoria, looking at what's been embedded and what's, um.

Victoria Dublon

And the beliefs of families as well. Whether they feel that their concerns are being heard?

Jane Runnacles

Yeah, and we did get feedback that, you know, just seeing these, this information when you walk into a ward reassures you that this is a safe culture, you know, this is a place which, which recognises, which sees the importance of safety and patient safety, which I think is a really positive aspect as well.

Victoria Dublon

We're doing some work in A& E about This, at the moment, we've just started a new QI project in A& E capturing why families and young people have come to A&E and their level of concern at the time regarding symptoms and just their overall feeling of concern, which will also be really interesting work.

Jonathan Bamber

And I, I wouldn't beat yourself up over that question of impact and evaluation in the, although it's really important to be reflecting and learning, there are some aspects of if you are doing good quality improvement and measuring, okay, has this change been an improvement? And it sounds as if with the SAFE program, you built up reasonable evidence around that, that we built that up that once something becomes normalised, then it's, by definition, it's going to end up needing to be proxy measures to realise, okay, are we still improving? Are we going in the right direction as opposed to some kind of attribution of trying to pull out that engagement is the point that's going to define that improvement. I'd like to turn the conversation to one aspect that I'm actually quite happy that we haven't been focusing that much on, but I think is important to, and I think Jane, you mentioned it in passing around often when we talk engaging public, be that children or parents or others, we focus on catastrophic events. And there are examples where

focusing on terrible examples of where harm has taken place can galvanise people to be motivated to pay attention to it. However, a lot of our conversation so far has been around in normal care. How can there be co production and true engagements?

Jane Runnacles

It makes me think about, um, how you bring other people on board in patient safety work and how powerful it is to start with a real patient story. And I, you know, personally think back at conferences and even part of the SAFE collaborative where a parent came and talked about an experience they had, which, as you say, often you hear the stories that are, you know, tragic stories where actually their child has deteriorated and died. But there's been so much learning and a sort of positive approach to how others can learn from from these events, but also how that learning is shared more widely, and what systems we can put in place. And actually, having some really helpful, structured stories like that can be really powerful to engage others as well in your whole team.

Jonathan Bamber

There's power behind patient stories and they tend to be examples of where things have gone wrong. However, sometimes because they are by definition, the 'safety one' example of looking at where there has been harm, that that may not be the best way to focus on how do we create a safe culture, safe environments. Without belittling the idea of patient stories, do we still think there is a role for that, as long as we do take into consideration culture and change overall?

Victoria Dublon

There's a massive role for that, I think, and that's something, as Jane was saying, that's really pushed on quality improvement, I think, and the power. of a parent's voice. And that's the whole movement, isn't there? #NotaNurseBut.

Natalie Wyatt

One thing I was thinking of, you've actually referenced so many individual hospitals' excellent pieces of work. So you, you talked about Yincent Tse introducing the whiteboards. You've talked about great programs of work at the Royal Free and St. George's, you mentioned the program, the Listening program at Birmingham Children's,

and there's all these great little pockets of work going on. I mean, how can we do better at sharing what we're doing so that every time people aren't reinventing the wheel. that clinicians around the country can take this learning?

Jane Runnacles

Well, I think there are some fantastic toolkits and I think through collaboratives, work is sort of designed and shared in a really positive way. And obviously with the RCPCH patient safety portal, it would be lovely to have a central place where people can access some of the tools, but also share resources that they've developed and then they can be obviously adapted to the local context. I mean, conferences are a great place to share your work and it's sometimes difficult or perceived to be difficult to publish some of these improvement initiatives when they're quite small scale. But I've come across so many examples where great projects have been spread that way. And, you know, I would encourage people to put pen to paper and write some of these up or produce posters that they can share. But having, you know, having a, a sort of network or collaborative approach is, is, is really helpful, I think. And, you know, and I always say to many of the doctors, the trainees, as well as nurses, actually, you know, we're quite a mobile workforce. We move around different departments and, you know, do share and learn from your department and take it to where you work next. Um, and think about ways you can engage the wider team, because often some of your wider team are more established in, in the workplace and be there for a longer period of time and can provide that sustainability. Because that's sometimes quite challenging actually keeping something going once you've, once you've started on some improvement work. So I'm all about sharing seamlessly and I think in quality improvement that's so important. But having some of the toolkits or resources available can really help give a bit of structure to a project.

Victoria Dublon

And there's so many resources out there, aren't there, and ways of, of getting involved. I got very involved as well and with the Me First, Team at Great Ormond Street who rolled out education regarding young person-centred collaboration and care and they do study days, which are a great way of seeing what other places are doing and like Jane was saying, they're very into shamelessly stealing, um,

Jane Runnacles

And seamlessly sharing?

Victoria Dublon

Seamlessly sharing.

Jonathan Bamber

Seamlessly sharing. There's a slogan, if ever I've heard one.

Victoria Dublon

And, and actually even just looking at their website, there's some great tools there that you can use. There's the Royal College Recipes for Engagement, which is a great booklet and is online as well, isn't it? We've used that within our diabetes team. Lots of ways of getting involved.

Jonathan Bamber

Food for thought.

Jane Runnacles

I mean, clearly another, taking co-production further is the concept of experience based co-design using much more structured kind of design techniques to improve experience. And actually those kind of toolkits could have more of a structured approach to co-design improvements around patient safety. Um, and it's not an area that actually I am very experienced in, but I suppose it's something that is important to, to think about in, on this topic.

Jonathan Bamber

And it's when we're talking about that, this, this topic of co-production that there's the important role of young people and parents in the problem identification process that kind of within QI, we call it around the diagnosis or problem agreement process. Then there's the involvement of young people and parents in their day-to-day care, which

we've talked about quite a lot. Then the, that co design process in improvement, you're right, we haven't spoken about it. And it is, it's an extra area of challenge. I've been involved in quality improvement programs, which have managed to have non clinical members of the public involved within that safety or improvement team. It's an additional level of challenge to have that pragmatically. And I don't know if you've been involved in any programs that way? I mean, the Health Foundation had their whole co creating health program, which got to a stage where there was reasonable improvements and you're right you mentioned toolkits. Do you see that as something that's under focused on and is important or do you think that it's more that because it's complicated we should focus on standards of care and listening to, having that engagement within other patient safety projects?

Jane Runnacles

Well, I think, I do think it's really important and I do think, you know, we're not very good, there's often just a token patient representative on, and I do, I mean, I suppose I have, um, experience from joining the Q community as one of the, well, I was part of the first cohort and the Q community was brought together with QI enthusiasts and across the healthcare sector, but also with patient and, um, representatives, but, but more as, as participants and partners rather than as representatives. So that's again, use of the wrong word, but as true partners in helping design the Q community and, and working out how as a group on a more national level, work could be shared and there could be a much more focus on how we could work together for, um, larger scale improvement as well as collaborating on smaller work and projects. And I always think that they bring such an important perspective and I could talk before about that challenge. And I suppose at St. George's we did have experience of co-production with the Children's Council in developing that information and leaflets. Um, it's quite a small example, but it's somewhere where you can start. And actually if you, if you work in a department where there isn't a children's council, that might be a nice way to start thinking about how you could co produce improvement work. Invite them to be part of of the process of testing out change ideas or coming up with ideas, you know, acknowledging that, you know, sometimes that is difficult, but it's not something you should ignore if just because it's difficult.

Jonathan Bamber

Thank you so much both of you for sharing your experience and knowledge today. I hope that your practical examples of how you've included children and young people in improving how safe they are in hospital will inspire those listening.

Natalie Wyatt

I think it's clear from our conversation today that if we're going to make improvements in paediatric patient safety, we need to keep children and young people in the heart of what we do. We need to find out their views and create the improvement work together. For more information about how to engage children, young people, and about paediatric patient safety in general, please visit the RCPCH Patient Safety Portal, our brand new online resource full of learning resources, safety alerts, and more. You can find links for this. And for the research and projects that we have discussed in the episode notes for this podcast. Thank you for listening.