Written evidence submitted by Group 3 (PSN0033)

Transcript of roundtable meeting with patient representatives held on Tuesday 30th January 2024 to inform the Health and Social Care Committee Expert Panel evaluation of government progress on implementing patient safety recommendations.

Start of transcript

David Pearson: Hello everybody and welcome to this this group, which is for patients and service users, or patient and service user advocates. So welcome to this discussion. I wonder if we could just introduce ourselves to the other people on the call. We're quite small and perfectly small in this afternoon, so it will be a relatively intimate conversation. So, if I could start by asking Participant A, would you mind introducing yourself, please?

Participant A: Sure. Hello, I'm Participant A, and I came to be here, I suppose, because my child died in negligent circumstances from sepsis. I've campaigned tirelessly ever since for better awareness and recognition of sepsis, and have worked in the patient safety arena I suppose. That encompasses anything to do with sepsis, patient safety, and also the culture and toxicity within the NHS and the investigation process too, so I work alongside stakeholders as well. Thank you.

David Pearson: Thank you very much, Participant A. Participant B?

Participant B: I'm Participant B. My child also died of sepsis, not so long ago, just showing that very little has been learnt. So, ever since then I've been trying to talk about, weirdly, my focus is less on sepsis, but more on the culture issue, the arrogance of doctors not listening because I actually talked about sepsis and was ignored, so it wasn't as if people didn't know or think about it. And so, yes, there are lots of things within this framework that I think I'm not an expert on. I don't know the intricacies of maternity care and things, but I do feel very strongly about the service that we receive, and my eyes have been slightly opened as to the realities of our healthcare system in the worst possible way. So, that's why I'm here.

David Pearson: Thank you very much. So, we did have more people originally, but a number of people gave apologies or weren't able to come, but nevertheless I'm very grateful to you for giving up your time to have this conversation. And I suppose the first thing I want to say, is that I'm very sorry to hear about your losses of your children and just very sorry to hear about your experiences before we start.

Participant B: Thank you.

David Pearson: I think that it sounds really difficult, and my heart goes out to you for that. So, I'll just say something just sort of by background. So, if you'll bear with this, it just explains the context. Really, the background reading we have done so far suggests that public inquiries and reviews often make recommendations to improve patient safety, and although the Government accepts these recommendations, when it comes down to it, the recommendations may not always be implemented very well. Which plays to your point Participant B really. In a moment we are going to ask you some questions about some specific recommendations, and we'd like to hear your views on it, and how these recommendations have or indeed have not been implemented in practice. And in that context, I suppose, I think, although you might not be involved in the particular area where the recommendations have arisen, there are some common themes in this and so there are some broader issues which can be applied from the position of the lens that you bring to it. And if we feel like there isn't much to say on this particular topic, well, that's fine. We have lots of other ways of gathering evidence and this is part of

a process, so if it's not your thing or you feel uncomfortable about saying anything about it, that's fine too. So, whatever you say would be appreciated by us. And I suppose the other thing is, well in some ways you act both as people who've been affected personally and to a certain extent now, as advocates for people in receipt of health and care. So, I think you probably have both of those hats, but the questions are obviously directed slightly differently. So, is that OK? Is anything else you'd like to ask me before we kick off, or say about what I've said.

Participant B: I mean, as I said when I replied, I haven't used maternity services for a long time. So, I can only say what I've read and heard through and about maternity services, not my own personal experience. I can talk about things that I know were recommended that we're not in place. Things that I was like, why don't they have this? And it turns out they were recommended as part of some review somewhere that hasn't been followed. And I'm sort of shocked that these things happen, that there are recommendations that aren't then followed, and nobody really holds anyone to account until someone died and then they say, "oh, you should have been doing that thing that was in that 2014 review". But what I worry about is, I'm worried that this would be quite specific stuff that I have no experience in, I guess.

David Pearson: Yes, and that's very good of you to say that. And, I would say, don't worry too much about that. We have ways of weighting the kind of evidence that we hear. So that's our job, to do that. But we're just grateful for the fact that you're here and yes, you will have broader experiences or an understanding of stuff, I suppose, partly because of unfortunately, the world that you've entered, which makes you think more broadly and that's fine too. So, on that basis, we'll keep going, and the other thing to say is though we've allowed quite a lot of time for this, if we finish beforehand, I'll profusely thank you and then we can go off.

David Pearson: So, the first recommendations that we've highlighted are, and if you'll bear with me while I read them. And some of them are quite wordy but forgive that. And then we'll come on to some key questions. One is maternity care, and the other is leadership. So, you've got experience as you say, personally in the past of maternity, and obviously leadership is something we all experience. The recommendation one was: "There is no mechanism to scrutinise perinatal deaths or maternal deaths independently, to identify patient safety concerns and to provide early warning of adverse trends. The shortcoming has been clearly identified in relation to adult deaths by Dame Janet Smith in her review of the Shipmen deaths, but is in our view, no less applicable to maternal and perinatal death and should have raised concerns in the University Hospitals of Morecambe Bay NHS Foundation Trust before they eventually became evident. Legislative preparations have already been made to implement a system on medical examiners as effectively used in other countries, and pilot schemes have apparently proved effective. We cannot understand why this is not already been implemented in full, and recommended that steps are taken to do so without delay". This was from the inquiry into the Morecambe Bay investigation in 2015. The second recommendation is a common code of ethics standards and conduct for senior board level healthcare leaders and managers should be produced and steps taken to oblige all such staff to comply with the code, and then employers to enforce it. And this is from the report of the Mid Staffordshire NHS Foundation Trust Public inquiry, as we know, conducted by Sir Robert Francis. So, two slightly different things, but some common features. So, the first question is, how confident are you that NHS leaders will identify and act upon potential or actual unsafe care for mothers and babies?

Participant B: Well, I will answer that. I'll start by answering it: not very is the answer. After my child died, I thought about having another baby. I tried and failed, but increasingly as I was thinking about it, because as I said, my eyes have been open to patient safety issues, all I could see again and again, were headlines saying how terrible maternity care was in this country. The numbers of unnecessary maternal

deaths, and I don't know how much has actually changed since the Morecambe Bay scandal. I do think, I can only say anecdotally from what I see in the papers, I do think that the state of maternity care in this country is very, very poor. Some of that will be down to a lack of staff. I think some of it's just down to a lack of empathy and thinking that women are of hysterical. I think that there is a built-in sexism in the country in healthcare towards mothers….

Participant A: I would second that.

Participant B: …Acting hysterical and, “it's just pain, suck it up”, and, “they can't tell the difference between childcare pain and something going wrong”. And that's not true. And my answer to all of these questions will be, these recommendations happen and even if they happen at a senior level where the NHS dictates this needs to change in the culture, it goes to a board and then, whether a board ever actually changes anything on a ward level when there is an inbuilt culture… Maybe sometimes, but it's very sporadic. And I'm sure there are wonderful pockets. I’m sure there are pockets of good maternity care in the country, and I'm sure that there are absolutely terrible, and I worry that that none of these recommendations ever really have a huge impact if a hospital is going to allow a culture to exist and doesn't or can't change it. I don't know if I've been very articulate there.

David Pearson: No, that is very articulate. So, I think what I'm hearing you say is that you don't have confidence that they’re implemented, and that where they are, I think you used the word sporadic, so there is a kind of issue of inconsistency implied in that. Participant A, you chipped in to second what Participant B was saying, do you want to expand on that and give us your thoughts?

Participant A: I've seen some progress over the last decade, nearly. But every time we take one step forward, we seem to take two steps back, and when I started doing the work that I did, there was very much the onus on patient centred care and patients designing their care. Patients being part of, especially with maternity care, choosing the birth that is right for them and not being told what is a normal delivery by people in Whitehall. And now what I see ten years later is every other conference that I talk at, I'm asked to talk about compassion in healthcare, because it's lacking, rather than actually focus on what my day job is, about sepsis care. It's actually about, you can't deliver the right care whatever illness you have, unless the person that's delivering it has empathy, has compassion, shares in your crisis.

And because I think there has been a significant sea change in the understanding, or moving away from that when people go to hospital, when people go to their doctors or visit, maternity services in this aspect, they’re at one of their most vulnerable times. They’re at one of the most important junctions of their life, especially with childbirth, and I just don't feel people are given enough time and we can talk about system pressures, we can talk about not enough staff, we can talk about all of those things. But, actually, I find that when you spend the 10 minutes you get with whatever staff member it is, that it's not helpful, because it's fraught. It's fraught, you can see on their face that they're thinking about the next thing that they've got to do, or the 10 things that they haven't done, or that there's no one coming to take over at the end of their shift or whatever it might be, and the problem is, that gets pushed on to us as the ‘service user’, terrible term. I just don't think that we're in a better position now than we were ten years ago when my child died. I work with [an organisation], and we see a lot of - I say a lot - we see maternal deaths from sepsis, we see neonatal sepsis which would cover this area, and a lot of it is due to mums obviously not being listened to, because they're saying, “something's not right, I don't know what's right, but something's not right”. I know that there is a huge strength of work going on with maternity Transformation Board in terms of national news and things like that, but ultimately, at the end of the day, you can change and embed systems and processes and protocols, you can even mandate, but unless the person that is on the front line wants to do that, it's not going to happen. And so it's the

same old adage, ‘you can lead a horse to water, but you can't make it drink’. And unfortunately, as Participant B has experienced first-hand, and as I have experienced first-hand, we see day in, day out, people not being listened to, or not being part of their care. Almost like a transaction. It feels transactional in the NHS at the moment. I think it's very difficult. I have been through maternity twice, and I do have some peripheral understanding because of the work around sepsis. But as Participant B said, I don't move in those circles, so to speak, so I wouldn't want to tar a brush anecdotally over something, like Participant B says.

Participant B: All I could say is when you said how confident would you be?

Participant A: Not.

Participant B: Because I'd lost a kid, and because I was reading all these headlines about how terrible our maternity care was, it made me scared to have a kid, especially as an older mum. I was scared, which I wasn't the first time around, because I knew too much, and I thought, if I do get pregnant, I'm going to go private. I would throw money at it, because then I could control the situation more and I could have a relationship with a doctor in advance, and I could feel like, I can demand something of you because I am paying for this. I've no experience of working in maternity, but as a consumer of the industry, if I got pregnant, I would crack myself and I would go privately. And that's a sign of lack of confidence in the system.

Participant A: So after I lost my child 10 years ago, I did go on to have another child, and we had him seven years ago, and the care that I had when my first child was born was fine, but that was because [the child] was an unremarkable baby. So I went in, I had the baby, and I went home. There were no complications. When I had my second child, it would be because of the knowledge in the healthcare arena of who I was, and indeed the investigation that we had endured, and the work that I did alongside the NHS and the Department of Health, I had exemplary care. But I did feel for the lady in the room next to me, who didn't have that same level of care because she wasn't known for having dragged the NHS across the coals for their failings. It just feels like there's a big disparity, and it's a postcode lottery. As Participant B says, there's pockets of excellence but unfortunately, the good things look after themselves, it's the bad things you’ve got to worry about, and I feel that there are too many of those at the moment.

David Pearson: Thank you both. Very clear and very powerful. If I just develop this a little bit further: so you talked about compassion and various other cultural things about attitude. The recommendation two that I read out was all about having standards of care for mothers and babies, that senior leaders are required to comply with codes of ethics, standards and conduct. How important do you think that is? And I suppose I'm conscious of what you were saying, that this is partly that behaviours are one thing, and attitudes are maybe another, or maybe not? What would you say? In your work, since your terrible losses, have you been able to see standards? I know I'm broadening this because this is for mothers and babies, but you could say, well actually that would be a template event which we could hold people to account or to develop that confidence, Participant B, that you don't have.

Participant B: You go first with that.

Participant A: The difficulty that I see is that when things do go wrong in the NHS, and they will go wrong because everyone that works in the NHS is human, they're not infallible, and when there is a breakdown of trust, what happens is it becomes a ‘them and us’ process. So, there's no ‘joined-upness’, if that's a word, we don't sit around a table like adults and talk to each other about what's happened, and how that's made us feel, and the impact and the consequences of that. What happens is you are left with no choice but to go down a litigation route, because they just will not talk to you. They will not

answer your emails, or they give you the least amount of information to make you go away, or to think that you'll go away. And unless you sort of become a sleuth, you just don't get to the bottom of anything. I was horrified when there were a number of recommendations made in my child's report following the death, and I said to the coroner, "who oversees these recommendations being embedded?" And she said, "well, no one". So I said, "well, what's the point in your existence then?" Because we're all sorry that my child died, we all know how he died, we all know where he died, which is what the fact of an inquest is. But following the protracted investigation, and it's the same with the Ombudsman, they make recommendations but there's no regulatory body that oversees the implementation of those. It's left up to organisations essentially to mark their own homework, and do they do that? Is that in their best interest? There is a particular case in Sheffield, where there has been a marked improvement, I would say, where a death happened and the hospital were told to work with the family, and they have put that family at the centre of every single recommendation that they have done, and they have seen it through, and it's now live. And we've been part of that because it was a sepsis death. That gives confidence back to that family because they feel like they've been listened to. And I'm sure Participant B probably agrees, all I want, well, everything that I want, I cannot have, and we are doing this knowing that we have already lost, and all I want to know is that what happened to my child is not going to happen tomorrow. But I could probably categorically tell you that it will, and Participant B, your child is an example of that. And so unfortunately, it's too siloed, the NHS, and unfortunately unless you've lived through an experience such as ours, you see the NHS as one. It's just one NHS, until something goes wrong and then you realise, crikey, this arm doesn't talk to this arm, no one knows over here what this one's doing. Yet, everyone is supposed to be caring for my child, or whoever it might be, but they can't do that because they can't see their notes. Why can't you see the notes? Well, because the NHS designed a system that doesn't talk to each other and you go down a rabbit warren of so many things, and the problem is there's also too much turnover in staff. So, for example, one of the stakeholders that are involved in my child's death, by the time the report came out, it was a new managing director or a new senior manager at the surgery. So, they have no idea, they're so far removed from me and what originally happened, that it almost becomes like they don't really care. It's just like a piece of paper with lots of words on it and well, 'we better show you that we're sort of doing this so what we'll do is we'll release a statement to say this, that and the other, but actually we don't really do anything'. And you can find that out, because quite easily a year down the line you can ask the surgery under Freedom of Information exactly what they do according to this, this, and this. You just feel like, what was the point of two and a half years of me not being able to grieve, being hauled over everything for the recommendations to be made and for them not to be implemented at the end because there's no process for that to happen, or oversight. But, they've just spent £1,000,000 to get rid of me. If they'd have put that into the safety of that GP surgery well, it'd probably the best GP surgery in [region]. I mean obviously this is sort of digressing slightly, but I think it's really dangerous territory at the moment with the Supreme Court ruling that we had a couple of weeks ago.

Participant B: Yes.

Participant A: Do you agree?

Participant B: Yes, something really shocking. Can I just ask you something? Did you get £1,000,000?

Participant A: No, I didn't. My legal fees were over a half a million and their legal fees. No, I didn't get £1,000,000, the cost of the whole case was seven figures. No, I didn't quite get that. And yes, the Supreme Court ruling of a couple of weeks ago, which means that people like Participant B and people like me, who've witnessed the most horrendous death of their most beloved child, we cannot claim for our psychiatric damages. I cannot get treatment like EMDR [eye movement desensitisation and

reprocessing] therapy for my significant PTSD [post traumatic stress disorder] and I think that's really dangerous because a lot of the learning comes from litigation. Unfortunately, we have to be pragmatic, a lot of the learning comes from litigation as a result of findings, and now there's a huge inequality of people that simply won't be able to go and ask a solicitor whether their loved one has died in negligent circumstances because they don't have the money, because their cases won't be worth anything, because they can't take it to the court. I think we're in dangerous territory, and I think we're going to be moving even further backwards. I'm sorry that digressed slightly, but it has a bearing on what we do.

Participant B: Can I ask a question? What was the question, how confident are you in the leaders being able to put this in? Is that the question? Can you just remind me of the question before I answer it?

David Pearson: Well, the questions I've got it written down, I slightly amended, because it was flowed from our conversation. The question was, is rather, how important do you think it is the standard of care for mothers and babies that senior NHS leaders are required to comply with the code of ethics, standards and conduct? Which of course was in the recommendation of the Mid Staffs inquiry.

Participant B: Sorry, it is such a wordy question. How important is it that the leaders are required to…?

David Pearson: So, it's about the standard of care for mothers and babies and senior leaders needing to comply with a code of ethics standards and conduct.

Participant B: OK, so the first thing to say is obviously it's very important that they do. But that they don't. One of the things that I've been in many meetings since then, all the way up to Amanda Pritchard [Chief Executive of NHS England], I've had a meeting with her, and the head of patient safety, Aidan Fowler [National Director of Patient Safety in England], the chief nurse, Ruth May [Chief Nursing Officer for England]. And there's words that they use all the time, which is, "How do we make this not just a box-ticking exercise?" And so, if the answer to those questions is how confident am I that they will do these recommendations: not very, because they say all the time, this becomes a box-ticking exercise. And that comes down to what Participant A was saying, which is that the NHS ultimately has no power over any of these hospitals and no way of enforcing it. And this is way beyond the scope of this committee, but the creation of the foundation trusts, in my opinion, is a huge mistake, because now you have a government and a Health and Social Care Select Committee and NHS England trying desperately to make maternity care get better and the foundation trust going 'ah'. I mean, it seems to be a really awkward and unpleasant relationship between most foundation trusts, whose only interest in NHS England or the government, and the only relationship, is financial. They want to take the money and then they want to ignore the recommendations, or only do them as a box-ticking exercise. They're not my words, as I say, they're words all across the NHS. They can recommend things all they like. They can say, "you need to do this with maternity care", but if they can do it in just the way that looks like they're doing it, that's what they will do.

Participant A: Yep, and can I just expand on that as well?

David Pearson: Yes, sure.

Participant A: I've found that there's a lack of willing to want to spend money now, because we don't know who's going to be in power, and that has been for the last 10 years. It's almost like if we spend £10 million doing this, whatever it might be, there's no point because we're not going to see the benefits of that now, if we're not in power in three or four years. I've seen that time and time and time again, and the revolving door at the very top of the government doesn't help, because if there's no certainty in the top, then there's no certainty in the bottom. It's like the duty of candour about saying sorry - well everyone is sorry my child is dead, but what does that mean to you? What does it mean in real terms?

Of course you're sorry, but what does sorry mean to you? And I think it is the same with the ethics, we can instil rules, and plans, and tick box exercises for people to follow, but do they actually follow it? And who follows them up to know that they're following it? It just doesn't happen, and it just feels like more and more bureaucracy layered upon more and more bureaucracy, and I feel really sad that we're in a world, in the 21st century, [this number of] years after my child's death, that we are having to put in a rule to mitigate against not being listened to. What is that? I almost feel dumbfounded to the point where I just can't do this anymore sometimes because you bang the drum every day and all you're seeing is, all they're doing is chasing their control totals. And now there's obviously ICB [integrated care boards] and all of the council and the foundation trust and stuff. It just becomes too… it's a machine. It's a machine and it's got this command-and-control vision at the top and that doesn't work. It just doesn't work.

David Pearson: Participant B, you were going to come in, I think.

Participant B: No, I was just simply going to say that the thing about the turnover… So, you've got turnover of Health Secretary, something like 6 or 7 in the last two years, something insane in the last two years, each with a different kind of priority, and now you've got a change of government coming up, so if they can ignore the Tories right now, they will. Plus, you've got this massive changeover of CEOs in individual hospitals, which, I think that on average they stay something like 12 or 13 months or something; Henrietta Hughes [Patient Safety Commissioner] told me some crazy figure about how little they stay. So, if this is about the confidence of them to enforce these changes at that level, partly box-ticking, partly change of leadership and partly just the structure of the NHS, which is just like Participant A says, everyone thinks there's one NHS and there isn't. You just have so little confidence. It's like total potluck and we got unlucky, and that's what I would say happens in maternity care. You can't say it is better or worse, or if they are following it or they aren't, or these leaders will do it, or they don't, because the structure of it lends itself to not being able to follow any new recommendations, except in principle, but not in practice.

Participant A: Yes, I agree.

David Pearson: So, what I think I'm hearing is that you're saying that these things are important, the ethics standards and conduct, but you don't see it happening. And you've gone on to give some analysis why you think it isn't happening.

Participant B: Yes.

David Pearson: The things that you've both said, latterly, I'm inclined not to ask you the next question because I think you've already answered it fully. It's not because I don't want to hear the answer, I am very interested in what you're saying, it's because it says: 'How effectively do you think standards are enforced among NHS senior leaders and managers, and what impact does this have on patients?' So, if you've got something to add to what you said that's great, but you've been hugely clear.

Participant B: They're all small hospitals where they do these things well, like I say, the one I example always give is Royal Berkshire, where at some point somewhere, someone decided to introduce something like [a patient and family escalation system] and in the first instance, the doctors pulled down the posters because they hated the idea so much. But now they've built it into the culture, and it seems normal to listen to patients and expect that kind of thing. But that's one hospital in one place. And do I have confidence that it will happen in Leeds or in Loughborough? No, I mean, these are all different places. There's such a lack of enforceable-ness, there's such a lack of accountability. People don't know that things go wrong.

Participant A: Unless they're told, how will they find out?

Participant B: I used to be completely disgusted by the American system, and it's kind of gross, the money, but at least you can kind of identify and work out whether…

Participant A: There's accountability because it's all about the money.

Participant B: The thing I say to my friends now is, "there is no such thing as the NHS". It doesn't exist. What you have is a series of hospitals that behave in different ways, and sometimes wards within hospitals that behave in different ways, maternity wards that behave in different ways. They all have the NHS badge on them, but they all operate in completely different ways, irrespective of whatever this government mandate is. The only thing that forces them to do it, is the CQC. That's the only thing they care about at all.

Participant A: Yes.

Participant B: They will do everything 'box-ticky' unless it's CQC, because the CEOs only really care about their CQC ratings. So that's the only way to enforce anything at all, and even then, they will do it in the most lenient way. So, that's my answer.

David Pearson: Thank you. And Participant A, anything you wanted to add, or do you feel you've covered it?

Participant A: No, I pretty much echo what Participant B says. That's my experience of it, and obviously, I mean despite the fact that I've been so badly harmed by, I say the NHS, I haven't, I've been harmed by certain people within it. I don't want to tar everyone with the same brush, because there will be people that are working hard to fight against this narrative and the problem is they get sucked up into this machine and the NHS, like Participant B says, it is a victim of its own success because 50 years ago we weren't replacing 90-year-old Doris's knees because if you were 90 and you needed a new knee, you were on your way out anyway, we won't do that. We live in a world where if we order something online and it doesn't come tomorrow, we're angry. We want it now, and the NHS does not position expectations of us, the people that use it appropriately, and it gives the wrong expectations. I think going back to the fact this is maternity care: maternity care is almost completely out of everyone's control because a baby is just going to do what it wants to do. If it's going to come out, it's going to come out and there's nothing you can do about it. Well, there's sort of some things, but I think we try so hard to control and tell people what they should and shouldn't do and pigeonhole, certainly in maternity care, that we've just lost sight of what that journey is for that mum, that family, that baby. I just feel like we've lost sight of why we have the NHS in the first place, because doctors and consultants are so far removed from the patient, even when they're at the bedside. And I sit on a deteriorating patient board and there was a huge hospital survey done for patients and then doctors, and workers and whatever. One of the topics asked to the patients was did you feel listened to? Did you feel like you were able to raise a concern, or raise a worry? Resounding across the board: No. With the doctors, they said they felt that they did give their patients opportunities to speak up or worry or concern, and they did this when they did their ward round. And I said, "but why are you doing that at the ward round? You've got a patient that is likely to be on their own at their most vulnerable, laying down. You've got six people suited and booted around you at the end of the bed. That's not the appropriate time to ask." But it's the only appropriate time to ask, because they haven't got any other time. I just think gone are the days of that homeliness about the NHS, about having a doctor-patient relationship. And it's transactional. Now everyone is a job. I just think that goes right from the bottom all the way to the top, unfortunately.

Participant B: Sorry, David, can I just say one more thing?

David Pearson: Yes, sure.

Participant B: It's an example of the box-ticking thing, and I just want to say that I know this isn't a maternity example, so this probably isn't one for you, but in the Francis report it recommended that there needed to be a lead consultant - or a named consultant is the word - for every patient so that if something was going wrong, you had one person you could return to time and time again. When [my child] died, we'd seen a different consultant almost every day for the past week, a different person, and this was insane. Nobody could tell that she was getting worse and worse and worse, because it was a different person every day.

And they said, "oh, well, you know", but then I discovered afterwards that there's supposed to be this named consultant and they said, "oh you did have a named consultant, look, it's here on the top of her medical records. It's right here, main consultant: [name]". I've met this guy once for literally 3 minutes, about two weeks before she died. But if the CQC or anyone came along, they could say, "oh look, here's our named consultant", because there's a name at the top of the of the medical records. But that meant literally nothing and it was not what the Francis report was recommending, they were recommending I have a relationship, but I didn't. But they could say, "oh yes, we definitely do the named consultant thing". So, although that's not what you're checking out, what I'm trying to say is that would apply to every single maternity recommendation there is. Which is in principle, "look here it is, it's happening, it's happening, look" - but it doesn't actually happen on the shop floor. They will carry on exactly the way that they're doing it before and show that they're doing it, if they have to for the CQC, but often not. And now that [my child] has died they're like, "yes we're doing that thing that we should have done from 2014 because we can see that there's a reason for it, but we have to wait for someone to die first".

David Pearson: It is relevant, in the sense that when we talk about the standards, about what might the standards be, but if you're the named consultant, it is pretty important that you have a direct dialogue and you're abreast of the situation, you're in in dialogue with people. I'm not saying that is the standard, but that might be it. I think the other thing I'd observe from what you said is that - I mean you both expressed a degree of sadness, I think, and balance in the sense of saying, "well, I don't want to write off the whole, it's not everybody, it's not all bad everywhere" - and you cited the example of Royal Berkshire and Sheffield, which is, which is interesting to hear. But I think you're also saying very clearly that it's too inconsistent. It's too sporadic and it's difficult to understand how it's systemically applied. I think that's what you're saying and correct me if I'm wrong.

Participant B: And I think the two things that push things through, the things that make a difference, are someone dying. So, the Sheffield case, it's like something that might have already been a recommendation. When someone dies, they suddenly go "oh yeah, we definitely should do that thing", or, "we should change our culture". So individual hospitals, they don't do it because the government or the health committee tells them to, they do it when they're caught out, because someone died and that shouldn't have to be the case.

Participant A: Yes.

Participant B: And sometimes just extremely powerful, persuasive people who don't mind being very unpopular on the shop floor, just making it happen and just really pushing things through against things. So those are the two things. But I don't think it's because the Health and Social Care Select Committee or the Health Secretary or NHS England say, "by the way, you need to be working like that". Those are the only two things I think make a difference.

David Pearson: Right. Participant A, you were going to say?

Participant A: I was also going to add to that, that when organisations, i.e. CQC, PHSO, or whatever it might be make a recommendation for a change to be made to something - I'm going to give you a prime example, tomorrow NICE [National Institute for Health and Care Excellence] publish their updated sepsis guideline. Now, the Sepsis Trust have been going backwards and forwards, backwards and forwards, backwards and forwards with them about this guideline, because they've written it, but you try and get a nurse on the front line to actually do what they've written in that guideline, there's ones over here, and ones over here because it's not realistic. And so when they put this tick box in, and it could be related to anything, you know, obviously the NICE guidelines, there's pregnant people in it as well, so it's very relevant. They don't make it pragmatic. It's not realistic. It's not relevant to where healthcare is on the frontline right now. It might be how we'd like it to look in reality, but it's far from what it plays out like in real life, and I think that's where it's just so far removed now.
We have policymakers, we've got people that write guidelines, or do the research. Actually, I think they just need to go and say spend a month on the front line and try and do exactly what their guidelines say they're doing, because it's almost impossible, but you can't make these people listen. It's very, very difficult.

David Pearson: OK. Well, thank you. I'm going to move on if that's alright. But I'm very interested in what you've got to say and it's all very cogent and powerful. We're halfway through, we've got a couple of other areas to cover, well, actually three. But there I think there are themes that are laced into each other. So, the next recommendation is targeted interventions on collaborative leadership and organisational values, including a new national entry induction for all who joined health and social care. And this is from the Messenger review of leadership in the NHS and social care. That was 2022. So this is about collaborative leadership, organisational values, and there's a plan in this for a recommendation for national entry level induction. So, the question is, is it your impression that NHS and social care staff provide care that is based on the values of their organisation? I don't know how much contact you've had with social care either of you, but you may or may not be able to refer to that, but interested either way. So, it's about how people provide care, and is it based on the values of their organisation?

Participant A: I feel like a lot of the people that work for social care don't actually work for the NHS, and so the values of their organisation will be vastly different to those of the values of the people that work for the NHS. And as sort of side note, I chaired the Primary Care Commissioning Committee, and I sat on the CCG governing body when it was a CCG. I ended my tenure with the creation of the ICBs as I didn't feel confident enough just to move across. But we found down here - [region] is where I am - that the health and the social care staff that were on the frontline felt much more rewarded and part of a group when they were able to say that they worked for the NHS. And the organisations that sit sort of on the peripheral outskirts of the NHS that deliver a lot of our social care, they don't have that, and they're almost treated like the dogsbody and that's reflected in news that we see, in news that we hear. But yet, they're doing exactly the same job as their counterpart, who works for the NHS, and has a pension and has X and has these other benefits and wears the NHS lozenge with pride. I think also with the number of bank staff and agency staff that are working within the NHS, I think you remove that continuity of care as Participant B says - how many consultants and doctors did you see with your child?

David Pearson: Thank you. Participant B any comments on this?

Participant B: Some people do, and some people don't.

David Pearson: Yes.

Participant B: It's all I can say. What was the question?

David Pearson: Is it your impression that NHS and social care staff provide care that is based on the values of their organisation?

Participant B: Yes, like at [hospital], some people did, and they were great, and some people were rude, awful, dismissive and arrogant. That applied to nurses and doctors, I mean, probably less nurses. But yes, some people do, some people don't, and I don't know, I don't think that's something that can be mandated at government level.

David Pearson: Yes.

Participant B: Not everyone was absolutely shocking at [hospital]. Some people were great, and some people were terrible and that will be the case everywhere.

David Pearson: Yes.

Participant B: I think at the moment it's worse. I think it's gotten worse even in the last couple of years, because there's such anger in the system, absolutely everywhere. But I think the anger is placed not just at the government level, I think nurses feel angry with consultants, and consultants at junior doctors for carrying on this strike. So there's a lot of sort of rage, and that is sometimes taken out on the patients…

Participant A: 100%.

Participant B: …who are just there not knowing half of this is going on. I didn't know there was all this sort of weird internal politics of the place, why would I?

David Pearson: Thank you. Just in terms of follow up, there's a few questions I've got here which I'm going to - some of which I'm going to skip because I think you've covered it. So there's one, has it been your experience that those caring for you or for your child in your cases have treated you according to values of respect and equality?

Participant B: No.

David Pearson: Well, I think you've answered that.

Participant B: Emphatically not.

Participant A: Can I just say though, I think the one doctor that sent my child home when he was dying: I think he thought he was, but he wasn't. And it's a really weird position for me to be in, because he wasn't acting intentionally and I almost feel like there's an element of the NHS is so broken down, that people are acting based upon the ethics that are instilled, because the ethics are so bad. So, I almost feel like they're doing what their predecessor has done, because their predecessor was doing it badly.

Participant B: Yes, I think that's a really good point because actually, and people who wrote the external reporting into what happened to my child said this to me, which is that you can have a system where you train people and say, "listen to the patient, listen to the parents, blah blah blah". And you can say what you like, but if those people then go on a hospital ward and train with consultants who don't do that because they've been in the system a long period of time, who themselves trained with people who, well… They learn much more from copying the people they are with than they learn from an induction video and what they're told in medical school. They learn by imitation, really.

Participant A: Yes, and hierarchy.

Participant B: And you still have a lot of people, you still have a lot of bad actors, 60-something year old consultants who are very old school, and doing it the old school way, and that is being passed on and

passed on and passed on. And I don't see a solution to that really because so much training happens on the job. It's like they're told one thing and then they see another and then that's how they act.

David Pearson: Yes, so, in your experience, do you have a sense, or did you see staff groups working across health - or indeed, health and social care if that applies - where people did seem to work well together, collaborate well as a team. Or indeed in your other experiences of the sort of work you do with others, have you?

Participant B: My child's death, I would say, they couldn't even work collaboratively between a ward that was next to the ICU. This came across in the serious incident report.

David Pearson: Sure.

Participant B: They said that there was a difficult relationship between this ward and ICU. I work at an [organisation] and there has always been competition between us and [another] part of the same organisation. This happens here, but I never in a million years thought that kind of competition would happen within the NHS. But then you also see it just in trying to make changes, like trying to introduce [a patient and family activated escalation system]. There's a kind of competition between them, like, "we don't want to take that person's safety law because it's theirs and we want to do it better, and we want to do it our way so we're not going to copy them". And [the Patient Safety Commissioner], who has been leading the law stuff, she asked people to come to a meeting to talk about it and she said somebody said the people that can come to this meeting is inversely proportionate to how important they are or something like that, some sort of rude thing which basically says, if you're there, you're not important. There's not a sense of learning from things, there's a huge sense of competition between individual wards in hospitals. Not every hospital, but it can happen. Individual wards, plus hospital to hospital within a trust, plus trust to trust. Unfortunately, I don't think that they do learn from each other enough, partly because of this hospital trust system, which ultimately, was brought in for competition. So, it's competition, and competition doesn't breed collaboration.

David Pearson: Sure. So, Participant A.

Participant A: So, I work at [organisation], and we had one particular trust, and I will name them because they've done really well, [hospital] specifically, they came to us to say, "our sepsis care is shocking". Case after case of serious incidents, things are going wrong at the front door, they're going wrong through the flow of the hospital, outreach, critical care outreach, everything. So, what they did is, they created a collaboration, and they wanted me to come and sit on the board as someone that works at the trust, but also someone with experience. They had someone from the lab, they had someone from pharmacy, they had someone from ICU, they had someone from admin, they had someone from A&E, someone from everywhere in the hospital. Because they knew that the only way that they could turn this around was by having everyone that had their hand in the trough, at the table, and they worked tirelessly for 18 months to change systems and processes that were local to them. Because obviously what is happening at [hospital] might not work well for them for a number of reasons, and they did this right through the flow of the hospital, out of the hospital into critical care outreach and on discharge as well. And they've worked with us. And now what I do, because they have seen so much success, when I have other hospitals approach me because of the same reasons, I put them in touch with Blackpool and I say look at what they're doing. Let's all have a meeting, lets share best practice. What is good? What didn't work? What might work well for you? X, Y & Z. So, for me it's not all bad. The problem is they've got be willing and there were people that sat around that table, like Participant B just said, whose paycheck probably didn't say that they should be sat around that table, but they cared. And they wanted change because it was happening on their doorstep. So you've got to have the buy-in from

everyone within that organisation to make it happen. And that's one particular place that I can give an example of where that has worked well. And I'm not to say that someone couldn't die in a negligent way, because obviously everyone is different, but they're doing what they can do within their remit to make that change. And it's hard work. It takes a long time.

David Pearson: That's a good example, and thank you. I suppose the final thing I want to ask on this section before we move on to the final one is, do you think it would benefit patients and people in receipt of social care if all new health and care staff received induction training in values, well it says organisational values, but of course it depends what that means. So, I think it could be of the NHS. It could be though, universally polite values. So in other words, if you're saying compassion is important, can you teach it?

Participant A: Is the question saying do you think it would matter to the patient? Because it would only matter to the patient if it wasn't happening to the patient. So if the person that they're engaging with, whether that be in their home or in the hospital setting, or wherever it might be, was compassionate and kind and all of those things that we've talked about, then it wouldn't really matter because it's already happening. Does that make sense?

David Pearson: Yes.

Participant A: So it would only matter to them if they had been trained, if they were having a poor experience, because then they would find out that they would have been trained and then they should have been trained. Does that make sense? I don't know if I'm saying the right thing, but I almost feel like, if you're having a great experience with everyone that you're working with, then I haven't got any umbridge to raise, and I think people already think that they've been trained. It's a very strange question.

Participant B: Do they not have an induction?

David Pearson: It's not a universal requirement.

Participant B: That in itself is quite bizarre.

David Pearson: So I suppose many organisations do, but they might vary, and they might do different things. So certainly, when I was a senior manager in social care, we did, everybody did. But it's not a mandatory requirement and this is why Sir Gordon made this recommendation, that it should be consistently applied across NHS and social care.

Participant B: It absolutely should be consistently applied. Yes, of course there should be an induction in terms of values, but at the same time, what matters most is what is witnessed on the shop floor.

Participant A: That's what I was trying to say.

Participant B: So it doesn't matter if you put a video out saying we're compassionate, caring people, if then 5 minutes later you see someone has treated someone like crap, and you're susceptible and you're going to learn to do it like that. So yes, but also by itself, what's the point?

Participant A: That's what I was trying to get at. It was almost like if you're being treated really well, you would just assume that they have had that induction, but it's really bizarre, the question you actually read out, it was worded very strangely.

David Pearson: Yes, sorry, I do apologise. It was picked up from the wording of the recommendation by Sir Gordon and I suppose, building on what you're saying, I think the implication of what you're saying is, yes there should be this training, but then there must be a way of checking other than complaints and

things that go badly wrong, that it's actually being deployed. In other words, you need to have a systematic way of checking that it's being done and what the impact is. OK. Thank you for that. I'm going to move on then to Area 3, which is culture of safety and whistleblowing, and I'll just read out the two recommendations that apply here, and I think [the moderator] is going to stick them in the chat because he's been doing that quite frequently, if you want to refer to them.

Participant A: Oh, I didn't see that.

Participant B: Sorry, it's helpful.

David Pearson: That's alright, we haven't drawn your attention to it, but I just thought because these are wordy, no disrespect to the authors. So, recommendation one: culture of safety. 'Every organisation involved in providing NHS healthcare should actively foster a culture of safety and learning in which all staff feel safe to raise concerns. The board should ensure that progress in creating and maintaining a safe learning culture is measured, monitored, and published on a regular basis.' So, this plays to the point we've just made actually about how you follow up to make sure that the cultures that you aspire to are being adhered to and are being carried out on a day-to-day basis. Secondly: 'system regulators should regard departure from good practice, as identified in this report, as relevant to whether an organisation is safe and well-led.' So, in the context of the England then, this is, as you rightly pointed out, the CQC who have had got criteria about safe and well-led services as you know. The second recommendation is primary care. 'All principles in this report should apply with necessary adaptations in primary care. NHS England should include in its contractual terms for general primary medical services, standards for empowering and protecting staff, to enable them to raise concerns freely with these principles. NHS England and all commissioned primary care services should ensure that each has policy and procedures consistent with these principles, which identify appropriate external points of referral which are easily accessible for all primary care staff for support, and to register a concern in accordance with this report.' And then finally on this section: 'in regulating registered primary care services, CQC should have regard to these principles and the extent to which services comply with them.' So, in here are some contractual requirements on those services, for example, primary care. Policies and procedure consistent with the principles of people being able to identify and raise concerns and also mechanisms which enable that to be done as safely as possible. But that's what in summary, I think this section's about. So the question is, have you or someone you've cared for or represent, had any experiences within the NHS, including in general practice that gave you insights into the culture of safety within that organisation and culture of safety, going back to the previous thing is about having the right procedures, having the culture and having ways in which people appear to be able to challenge and raise things. If so, can you tell us your experiences with this, including what went well or could have been improved. It's quite chunky piece this, but it's our last section, so any initial thoughts on that?

Participant B: Well, I can only speak from my own experience ,which is that after my child died, everyone started saying, "well, of course the [medical specialty] team have done the things their own way for too long, and this ward has been a mess for too long", and everyone started saying "this team has been doing their own thing for too long", but they wait until someone has died before anyone says that. And subsequently, I've had people from [hospital] contact me anonymously. I've met one of them in the pub saying, "this is the problem with that ward, or this is the problem with Paediatrics, but please don't use my name". And I've even had an anonymous letter sent here from somebody at [hospital] saying, "look at this, follow the money and you'll find this out". But that meeting with someone in the pub, they would say, "the time I went to somebody at [hospital] and I said this is a problem, I had disciplinary thing turned on me". So, I know these Freedom to Speak Up things exist, and I know [the Patient Safety Commissioner], who I've worked with, has been instrumental in putting that through, but

even she would say that a couple of hospitals said to her, “well, we're very proud that nobody has used our Freedom to Speak Up policy”. And she's like, that's not the thing to be proud of. That's not the point. You should be proud if people do use it, not if they don't. They're scared, nobody wants to lose their job, nobody wants to be seen as a troublemaker. Until somebody dies, again, I always say it's when somebody dies, when there's a preventable death like my child’s and it's a shock, everyone suddenly starts saying, “I always thought it was this, that and the other”, but there is no easy way. The culture does not encourage that, and maybe that's the case not just in the NHS, but lots of private organisations as well. Maybe that's just human nature, but it's not easy and it's clear to me that there were things really badly wrong at [hospital], and that people thought it, but they waited until [my child] died to say it. And why was that? And this was very recent at a major hospital in [region] where you would think that this…

David Pearson: Thank you. Alright, Participant A.

Participant A: Well, we had a whistleblower in my child’s case, and it was a whistleblower based upon the out-of-hours care that we didn't receive but should have received. It was the ambulance trust actually, but there was an audit of the telephone call and the telephone triage, and they audited this phone call with a compliance of about, I don't know, 76% - it should have been about 90 or something - and we had a whistleblower to say, “it wasn't, I audited that phone call, and it was 28%”. When that happens it creates a cascade of all these other people that come out of the network to say, “I'd been on shift for 13 hours, and the week before someone hanged themselves in the toilet”, and then it all comes out of the woodwork and you think, how can an organisation continue to operate when its toxicity is at the heart of everything it's doing. I think the issue with primary care, is that they are businesses. First and foremost, they are businesses, and they are run by people who want to make money and need to make money. And that therein lies the problem, because they are not there to service their patients. They are there to make money from the patients they are servicing, and if they don't, then they go under and we see that, and certainly down here in rural [region], we have single handed GP practices. He's 76, he's going to retire soon, and we can't get someone to replace him because it's so far out that way. So I think GP practices are almost outliers in terms of culture, because they’re run as businesses; you can't really tell them what to do. You can guide them as to what they can and can't do. You can tell them they've got to have this policy and they've got to have X policy, and everyone's got to have an induction, and everyone should be X, Y and Z, but actually that doesn't happen. They'll get the policy out when the CQC turn up, but actually what they're doing is very different. And I've seen that from the inside, that's the problem with GP practices, unfortunately.

David Pearson: Sure. So, in following this up then, the next question was do you think staff feel secure raising concerns about potential or actual patient safety issues, is the answer no?

Participant B: Straightforward no. I don't know if that is unique to the NHS, but it's quite clear that that's the case in the NHS, and that some moves have been made towards it, and Freedom to Speak Up is a good introduction. It is a positive thing, but I would love to see some examples where someone has gone and made a complaint and something good has happened out of it rather than them being frozen out. Maybe they exist, but if they do exist, I think we need to, or the NHS needs to shout about them louder, because you only ever hear the stories of people going to…

Participant A: Well, [name of whistleblower].

Participant B: Yes, it's like people who go and speak up and then get told “oh, you're a troublemaker and you're difficult”.

Participant A: And then they get managed out.

Participant B: So, if there are good examples of things that have been found out, let's hear about them. Let's publicise them more clearly, because at the moment, if I were a doctor and I thought something was going wrong, there's no way I'd say it because it just sounds awful. Your life gets made a misery.

David Pearson: So, actually it is almost like you can read the next question because you've probably answered it. So it says: what do you think would help make the staff feel secure to raise a concern about a potential or actual patient safety issue? So, the point you raised was we hear about situations where people haven't spoken out.

Participant B: Or where they have spoken out and got into trouble.

David Pearson: What we haven't heard enough, which is your point, which is situations where people have raised things, things have changed as a result, and they have been adequately supported in their quest.

Participant B: Unfortunately, you can't prove about life saved, so that's why you don't hear about them. Although having said that, you could probably over time, look at statistics and things.

David Pearson: Yes, sure. And there are standards aren't there around NICE standards, or practice standards, where you could see where something that was clearly not adequate, objectively, was changed to something else as a result of that. You'd have to do some forward evaluation to establish what difference it actually made, so there are ways probably around that. The next question then is, are there any other things that you think would be helpful in making staff feel secure to raise their concern over a potential or actual patient safety issue, as well as the point that Participant B made?

Participant A: I think it's almost impossible, but I know that there's a hospital in America, I think it might be Chicago, where they got a new chief exec and he sort of turned around the whole culture of the hospital and put in place a team of people that would just investigate if anyone rang up and said, "oh, there's a puddle on the floor in ward Y". And they just deploy someone to go and mop it up and then if someone rang them up and said, "I've amputated the wrong leg" or whatever it might be, they would just investigate it and deal with it. And it was almost anonymous, and it turned around the culture of the hospital and - I can't remember for the life of me what the hospital is - I just don't think we have that in the NHS. I think it's taken, well, how old is the NHS, 75 years or so? It's taken 75 years to get here, to build this culture. It's going to take that long to undo it, unfortunately, and I think we've still got so many people that are stuck in their ways of thinking. They don't like change, and they don't want to be told what they should and shouldn't do. Doctors don't like to be told that they're wrong. I genuinely can't see how we're going to change the culture within the NHS of speaking up.

Participant B: Organisations, not just the NHS, are naturally defensive. That that is a fact. And you could see it in other private organisations in the US, possibly here, where people have complained about something, and you have to fight an organisation's natural defensiveness by possibly having somebody outside. To give you an example here, we've gone through something here at [my company] where people complained about someone, it went to the manager and now they're going to a legal company or an outside company. Where if you make a complaint, it goes to somebody outside the system or the normal hierarchy, but a respected system, like a lawyer or someone that carries weight. And I think there's something to be said for that because, like I said, organisations are naturally defensive and they won't always take things seriously. So having a third party would help.

David Pearson: Yes, thank you. I understand that, that's helpful. The next question is, have you in your experience noticed any difference between the attitude towards patient safety in hospitals, compared to in general practice, or do you think it's the same?

Participant A: I think my last question probably answered that. I think it's pretty much the same. I answered that at the very beginning, didn't I?

David Pearson: Yes, you did.

Participant A: I think when I said 10 years ago when my child died, and then what I'm doing now, I'm doing more and more and more of it, and helping people to understand how their actions have consequences on the people that they're treating, and their loved ones and their families, I think it's just considerably worse.

Participant B: I don't really have enough experience in general practice safety to answer that, I just don't know.

David Pearson: Yes OK. And actually, I think the final question, we've covered it, but I'll read it just for completeness. Do you have confidence that staff in hospitals would raise the concern if they're worried about patient safety? And I think the answer is no, from what you've said, and I don't want to put words into your mouth or misquote you at all.

Participant A: No, I'm nodding, but I mean no, sorry.

David Pearson: Yes, OK.

Participant B: Like I said, with Freedom to Speak Up, I'm pleased that it happens and that's a first step. But I think it's going to be a problem if the same people, like the board that should be held accountable for it, are also the ones who are…

Participant A: Marking your own homework, so to speak.

Participant B: Marking your own homework, yes.

David Pearson: OK, so that's the end of my questions. We've got 10 minutes before we would go back into the group as a whole and Jane would say some things at the end and thank you. So, I could talk to you two, for hours actually, fairly easily.

Participant A: I feel like we've come here and been very glum.

Participant B: Well that thing, the point is that you are glum. Because what happens is somebody you love, in our case, the worst possible thing, your kid died in a preventable way, and then you try and make the system better because you can't believe it could happen and you think the only good thing that could come out of it is if I'm driven to change it. And then you're met with this extraordinary system where they say, "oh, actually, we can't do that across hospitals because we don't actually have any control of hospitals, because even though we're NHS England, if we tell them what to do, they get [annoyed] with us, so we have to be quite careful."

Participant A: That's true.

Participant B: I mean, this is essentially what the NHS says to us, "we can't tell them what to do. We sort of have to gently encourage them. If we say the wrong thing, if we're too dictatorial". So, there's a weird sort of baby stepping around it, and in some ways I understand that because that is human nature, but it blows your mind that that is how the whole thing is run. It is extraordinary when you look under the bonnet and you think, "God, no wonder my kid died, because there's nobody checking this, or marking the homework, and you know it's going to happen again and then exactly the same thing will happen to someone else, probably in about 3 years' time, if not before". The only reason people know about what

happened to [my child], is because I'm a journalist. Otherwise, this horrific story of what happened to this kid would just never have been told, nobody knows about it, and nobody learns anything from it. Literally what would have happened is that there would have been a sticking plaster in that one ward that said, “OK, we've solved this problem in this one ward because this happened”. But there would be no wider learnings from it, either across the hospital or across the system because it's not built like that. It's just built to go, “oh, we made a mistake here, we'll do that here”. But there's no way of saying, “by the way, if you're all acting like this, you should all change it”.

Participant A: What I find really bizarre from when I sort of moonlighted in commissioning is, if you commission a service, or if you commissioned on a really mundane level; I commission a company to come here and put a new roof on my house and they mess it up, I then sack said company and get another company in to do the work properly. In NHS health and social care, that doesn't happen. Mistake after mistake after mistake, millions of pounds spent on litigation where things have gone wrong, people have died. But yet, we don't really do anything about it, do we? We continue to commission the service from the same commissioners and I'm not suggesting that we can't have that hospital so we’ll have a new one, it doesn't work like that. I can remember having a phone call with the chief executive of Southwest Ambulance Trust, and he said to me about this report that fed into [my child’s] NHS England report, because it was wrong and there were omissions and things, he said, “you know someone in such and such a team dealt with that”, and I said, “no, they didn't”. I said, “you sit at the very top of that organisation. It is your responsibility. They are working for you, and you are accountable. Don't try and deflect this question that I have on to someone else that is more junior, because if they've got it wrong, you're responsible for them. You're responsible for signing it off”. He didn't like me, and that's fine, I don't really care. But in the end, we worked all right together, they just don't want to take accountability. They just don't take accountability and, I received a letter with my name spelt wrong, saying sorry for the omissions and redactions and the things that they had purposely put wrong in the report. And I rang him up and I said, “come and sit on my sofa and say sorry to my face”, and I just made him feel uncomfortable because I could, and because he should be. But people don't have, like Participant B, like myself, a lot of people don't have - I suppose the word is tenacity - to stand up and say, “no, this is not OK. I am not going to be treated like this”, and people do need to listen, and people do need to learn. What about the millions of other - or thousands of other people? The other Participant Bs out there, and the other Participant As out there who've lost children or loved ones who don't speak up, who don't speak English as their first language. You know the PHSO is just about to change their threshold for cases that they look for because of funding issues, which will mean the equality is not there, they’re not for everyone basically. And then we have the Supreme Court ruling over here where people, like the average Joe, are not going to have the money to fight these massive machines. Where does that leave the little person? Where's their voice?

David Pearson: So, going back to where you started, Participant A, you talked about being glum. I don't think you've been glum at all. I think you've told it how it is from your perspective, both as somebody who's lost her child, but also somebody who's continued to work to try and make a difference to future generations of people who gets sick, and you want them to have the right attitude and the right approach. So, I don't think you've been glum at all. Quite frankly, I think it's been very balanced, if I may offer that personal opinion. So, I don't think that at all. So, the other groups are going on for another 8 minutes.

Participant B: I actually have to go, I'm afraid.

David Pearson: Sorry, OK, you've got to go. So Participant B - sorry you did tell me that, I just forgot it temporarily - so, if I could just tell you what's going to happen next. What's going to happen is that we

will produce our report in the spring sometime. We're slightly hesitant about time scales because of things like general elections and fitting in with other work, but that work will also feed into some work that the Health and Social Care Select Committee are doing, which is on a similar theme, so those insights will inform their work, which will also be subsequently published. As far as this conversation is concerned, there will be a transcript which will be sent to you, so that you can have a look at it and make sure you're comfortable with it before we use it, so that will be made available to you. I'm pleased we've got a transcript actually, because I think you've both said some very valuable and important things that I'm glad we've got a record of. I've heard it, that not only have you had the pain of your personal experiences, but the tenacity, I think as you described it, I can't remember whether it was Participant A, to keep going and try to make a difference for the sake of others. And I think two things about that. First of all, I have no doubt that you'll help, you're helping us with our work, and we do this because we hope it will make a difference. So, we can't be certain, but we hope, and we expect that it will, and in that regard, you've been extraordinarily helpful. So as far as I'm concerned, all power to your elbow and keep doing what you're doing, if I may be so bold.

Participant B: Thank you.

David Pearson: No, thank you. Now, you've got to go, Participant B. Bye Participant B. It's been very nice to meet you. Thank you.

So do you work full time then Participant A?

Participant A: I work full time and I lead on the clinical and the educational stuff, but being nonclinical, because we've always felt that that has a better inroad to helping organisations to be a better version of themselves. I mean, obviously this is very sepsis specific. Obviously front and foremost what Participant B and I have been saying about listening to parents, listening to loved ones because we know when something's not right. And then making sure that processes and protocols are followed and helping organisations to understand that and implement that. And also helping them when things do go wrong. And I do other stuff with patient safety. I work alongside Rod Bearings, at PHSO, the CQC, NHS resolution, because it's the whole flow of sepsis. Most sepsis cases arise in the community, so it's getting it right in the community. It's getting public messaging right. Then it's following the patient right through to the other side, and then even when things do go wrong and when people do die, its working with medical examiners to make sure that the right coding is on death certificates because that's variable and we don't really understand the incidents. Then it's working with DHS to make sure data is right, because there isn't a data registry around sepsis like there is with cardiac and things. So, it's all encompassing. And when I lost one child, I lost the ability to be able to parent my other child in the same way that I now parent my other child. So this is my way, I suppose, of being a mum somehow, I have to do something, because I'm still a mum. I still want to do something for my child. So I suppose this is probably the only way I've found to do that.

David Pearson: Yes, yes. And, clearly without having your experience, I get that, I get that entirely, why that would be important, and that's how it feels. And of course, vicariously, it helps other potential [children], doesn't it?

Participant A: Yes. I always get asked whenever I go out and give talks - and I do talks all the time - the one thing I'm always asked is, "what happened to the doctors that were involved?" And I always deflect from that, because it isn't about the person, it's about the organisation. I'm not angry, and I don't blame those that were involved in my child's death. I don't even blame the doctor that sent my child home. Forgiveness is something slightly different, but I don't blame him. I'm not angry with him. He didn't do it on purpose, and if he could go back and change it, he absolutely would. And I had the ability to be able

to talk to him without prejudice, and for him to be able to say, “[your child] is the first thing I think of when I wake up and the last thing I think of when I go to bed”. And I was able to say, “good, I hope that is the case”, because it's going to inform his practice forevermore. And so, to go about things with anger, and blame, and finger pointing is not going to create a learning environment for people to harness.

David Pearson: Yes, you've turned your pain into a positive energy.

Participant A: Yes, I guess so.

David Pearson: I think it's what you've done.

Participant A: Yes, I suppose so.

David Pearson: And before we get whisked away, it's been a real privilege to meet.

Participant A: No, thank you, David. That's really kind. Yes, I'm sure our paths will cross again at some point.

David Pearson: Yes, I hope so.

End of transcript

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