HOUSE OF LORDS

Preterm Birth Committee

Corrected oral evidence: Preterm birth

Monday 22 April 2024

4.15 pm

Watch the meeting

Members present: Lord Patel (The Chair); Baroness Blackstone; Viscount Colville of Culross; Baroness Cumberlege; Lord Hampton; Baroness Hughes of Stretford; Baroness Owen of Alderley Edge; Baroness Seccombe; Lord Winston; Baroness Wyld.

Evidence Session No. 15 Heard in Public Questions 206 – 213

Witnesses

I: Nadia Leake, Author of *Surviving Prematurity*; Francesca Segal, Author of *Mother Ship*.

Examination of witnesses

Nadia Leake and Francesca Segal.

Q206 **The Chair:** I welcome you both. Can you please introduce yourselves?

Nadia Leake: I am the author of *Surviving Prematurity*. I had twins born in 2012. They were 17 weeks premature. I am also a PhD candidate at Newcastle University, researching the barriers and facilitators to implementing family integrated care in UK neonatal units.

Francesca Segal: I am a novelist and the mother of twins born after a placental abruption at exactly 30 weeks.

Q207 **The Chair:** You are both authors and mothers of twins born preterm, at 23 and 30 weeks. You have both written about your experiences. Your book, Francesca, is *Mother Ship*, and Nadia, yours is *Surviving Prematurity*. It is your experiences as mothers of preterm babies that we want to hear, particularly how things could be better for parents and premature babies. I read both books, as have some other members of the committee, and I learned a lot. I experienced your ups and downs, and in your case, Francesca, sometimes those of the characters you wrote about, particularly Deepak.

Thank you for coming. What do you think could be done to help parents and their babies?

Francesca Segal: We need an understanding of what the experience is like. In 2015, I was pregnant with twins. I was calm, relaxed and naive. The novel that I was writing was due in November and my babies were due in December. In late September, 29-weeks pregnant and without warning I began to bleed. At exactly 30 weeks my twins were delivered by emergency caesarean. One night I was at Pilates and the next I was in hospital and supposedly a mother of two.

My children spent the next 56 days in NICU and special care. As in almost all neonatal units in this country, parents were not permitted to stay. It is impossible to emphasise how much leaving felt like a daily amputation. Each night, I went home to a silent house where I would express, cry in the shower and fall into bed for a sleep that was broken not by the cries of my children but by my alarm going off to tell me that I had to pump. With every accumulated day of their incarceration, I had to work ever harder to shut down the grief of that separation, just to survive day after day the fundamentally unnatural separation of a post-partum mother from her babies.

What does it mean to be a mother who needs not only help but supervision and permission to change a nappy? My only relief was to be touching my babies, if only with a fingertip, but I had no responsibility for them. My relationship with my daughters felt provisional and conditional upon my good behaviour. Who did these babies belong to? I did not know how to handle them or nourish them. I did not know how to keep them living from hour to hour. When I sat in silence between these two incubators, I would wonder, "Am I a mother now? Am I a mother when I play almost no part in the care of my children?" Sometimes I would ask myself, "If I am a mother now, will I still be a mother if they die?"

These infants ought to be still in utero, and if they cannot be, then each adaptation that heals the wound of that separation will mitigate future damage, empowering parents to feel connected, to understand their babies, to step into their caregiving roles as soon and as fully as possible.

It hardly needs saying that the NHS is the most remarkable, extraordinary institution. I experienced staff who were committed, indefatigable and generous. But it is important to remember always that an optimal neonatal unit never separates mothers and babies and can even care for mothers as patients alongside babies as patients.

On many units, the Covid-19 pandemic has reversed hard-won progress towards family-integrated care. Now more than ever, hospitals need to understand that parents are not visitors. They are not optional. Hospital inpatients would be exposed to fewer infections if we sent the doctors home too, but some risks are worth taking. NICUs and SCBUs are not orphanages to care for the physical well-being of babies until they are well enough to be discharged and re-adopted by the women who gestated them. It will be to the detriment of a generation of premature babies if we do not ensure unrestricted parental access where that has been revoked.

Language matters too. Kangaroo care, for example, the placing of an infant skin to skin with a parent, is known on the ward as “cuddles”—"Let’s have cuddles”. Cuddles may be a lovely, soft word for parents, but for the staff it is essential not to forget that kangaroo care has proven benefits in relation to thermoregulation and thus weight gain, to infection susceptibility and to lactation success and, ultimately, is proven to reduce the length of an infant’s stay. If you call it “cuddles”, it is light, it is optional. If you call it a cost-saving medical intervention, it starts to look a bit more like what it is—essential and worthy of prioritising on a long, hard shift.

A parent of a child who is in an incubator cannot simply pick up that child. It is the language, again: you need permission, and that needs facilitation. So parents must be empowered early, beginning what in many cases will be a lifelong need for advocacy. Delayed school places should not be a lottery and dependent upon the feelings of a local head. There is this age-old wisdom that “they’ll catch up by two” but research increasingly shows that prematurity has lifelong consequences for hypertension, for cardiac health, for neurology, for mental health, for executive and cognitive function and so many other areas.

Advances in medical care mean that an increasing minority of adults have been born premature. Healthcare providers need to be educated to ask about prematurity, just as they might ask about smoke exposure or a family cardiac history, and then to understand that the disease progression of an adult born early can look different from that of a full-term peer.

To conclude, I offer three points that to me are vital. First, kangaroo care needs to become a priority and be taken seriously. According to the WHO, in infants born early, immediate kangaroo care reduces deaths by 40%, hypothermia by 70% and severe infections by 65%. It is free. It costs the NHS nothing and it must be part of a true recommitment to family integrated care, which acknowledges my second point—that parents are not visitors. Unrestricted access to their babies in a family integrated care model is essential to promote an active early involvement that improves outcomes for parents and children alike.

My third point is that prematurity is for life, so in early childhood, as a minimum, school deferral needs to be an automatic availability for children born at, I do not know, 32 or 34 weeks. There are some children who would be in a different school year who are compromised and fighting battles that not all parents are equipped bureaucratically to handle.

Nadia Leake: I agree with everything that Francesca has said. We parents, as we continue to speak to each other and to anyone who will listen, are finding that this story is common across the board. It does not matter whether your baby has been in hospital for 20 weeks, as ours were, 10 weeks, 15 weeks, it continues to impact throughout life. We need a society that understands what prematurity means to a family and to that baby growing up, so I completely agree.

To our story, I became pregnant through the fifth attempt at IVF. We were desperate for a family. I went into labour having visited family in London. I came down from Newcastle 22 weeks pregnant. What could possibly go wrong? However, on the way back, we got to the start of the M1 and I asked my husband to pull into the services—and there I was, bleeding. Luckily, we were not too far from Barnet Hospital, which saw us extremely quickly. However, when I was examined, within minutes of arriving at the hospital, I was told, "You are fully dilated with bulging membranes. There's nothing we can do". I was transferred to the maternity unit, where the plan was, "Nadia, you and Martin can stay here, and you can have all the pain relief that you want. We will deliver your boys here with us and you can hold them until they take their last breaths with you".

Needless to say, I did not like the plan. It was the longest night of my life. Our babies were healthy inside my body. This had been the fifth attempt at IVF after several years of marriage. We were told that whenever they were born they would not last for long. Throughout that night, they were moving. We could feel them. We tried to take some joy from that, but of course we wept.

The next day, the amazing midwife, who had been with us on the first day and told us the plan, said, "Nadia, we've had a discussion and there's something that we can do". On day two, they decided to bring their top sonographer in to estimate the weights of the boys. He said that if they are over 500 grams, we will try to intubate them, get some oxygen into them, resuscitate them, keep them alive. There was a very long 20 minutes while this man scanned our children and decided whether they were big enough to save. He estimated their weights as 513 grams and 570 grams. Later that day, at around 6 pm, they were born at 510 grams and 540 grams.

Not everyone knows what a 500-gram baby looks like, and certainly my toys at home were bigger than my children. This tub of butter, which I brought from home this morning, is 500 grams. My boys were 510 grams and 540 grams at 23 weeks gestational age.

I am of course extraordinarily grateful to the NHS. The boys were stabilised, but just imagine this little baby, immediately after birth being taken from mum and dad, hands on them, which had to happen to save their lives but in went the needles, in went the tubes. That was their first experience of life, way before they were ready for the world. Later that day the boys were transferred to Queen Charlotte's hospital in Hammersmith, and I was discharged the following day. That was the first act of separation. Queen Charlotte's was outstanding. It did everything that it could for our boys, but unfortunately Raif died at three weeks old.

I will weave in my recommendations as I go and this is my first, because education is key. At that time, Queen Charlotte’s was quite forward thinking, with family integrated care. From day one, parents were equal members of that care team, so we were able to have these conversations about what we felt needed to happen next. This was not about any medical knowledge; we were mum and dad and we knew our babies, because we stared at them for as long as we could every single day.

Raif died at Queen Charlotte’s. Harrison, the surviving twin, began to go downhill. We had six or seven weeks of not knowing whether he would survive. He was blue-lighted over to Great Ormond Street for life-saving heart surgery. Here comes another thought about who we are protecting with some of the decisions are made, because we were told as he was being transferred that he might not survive the journey and we were not allowed in the ambulance. So we got the Tube, not knowing whether we would get from Hammersmith to Great Ormond Street with a surviving child or as bereaved parents.

Harrison survived. We had a week at Great Ormond Street and then went back to Queen Charlotte’s, where, as I say, family integrated care was fairly embedded at the time—this was 11 years ago. Once Harrison was well enough to transfer back up north, we went to our local hospital, where family integrated care was emerging. I say that because, one day, standing by his incubator as bereaved parents trying to keep the surviving twin alive and doing what we could to be parents, my husband said, “What’s wrong with us?” Our mental health took an extraordinary dip. It was not bereavement. It is so hard to explain that the death of one child is one thing. Not being able to parent and mother your baby is akin.

We were in a very bad state. The worst had happened, because nothing bad was going to happen to Harrison now. He was doing okay and his job now was to put weight on and learn to breathe. When my husband said that, I had a bit of an epiphany and said, “It’s here”. It was the environment. This is where I come to another of my recommendations—I will lay them out clearly more later: my recommendation on policy and family integrated care, because it makes that much difference.

A difference to myself is lovely, but family integrated care provides a difference to the baby. There are tangible outcomes from clinical studies which will show an improvement in weight gain, a reduction in nosocomial infection, a reduction in retinopathy of prematurity—the oxygen can cause damage to the eyes and lead to blindness in these babies. It also improves maternal mental health and can reduce length of stay in hospital. So there is the fluffy “Let’s have cuddles”, and there are real outcomes for babies and parents when family integrated care is implemented.

We talk about mental health, but the term PTSD needs to come into play. I believe the committee has heard about this in the past, but let me put some colour around that for you. Even while on the neonatal unit, the insomnia kicked in and it was more than worry. It was a fear every day of what happens now, when does the next baby die. There were hallucinations. After Raif's death, I would see Raif's dead face when I was looking down at Harrison as I held him. There were nightmares.

Into my second pregnancy, that PTSD came back. We had another baby, with a lot of support, at 36 weeks, but it does not go away. This experience has stayed with us for life and Harrison is now experiencing the consequences of preterm birth. He has autistic spectrum disorder and ADHD. He is a wonderfully strong, fun, amazing boy, but he is not the child that he would have been if he had born term.

Being a mother on the neonatal unit is wholly dependent on the people around you, because we only have the choices that are given to us on a daily basis. Again, this is a long time ago now and strides have been made, but where family integrated care is implemented fully you have more opportunities to do the things that you do as a family. Family integrated care is the bridge between going home with your baby normally, feeling that joy, love and autonomy, and trying to be a family in a hospital where there is no space for intimacy.

So another recommendation I will spell out in more detail is on accommodation and being able to spend time with your baby overnight. It is not a day job. I was there from 8 till 8; I wanted to be there 24/7. If your child is admitted to a paediatric intensive care unit, you can probably stay, whether it is on a cot that folds out or a room you are in. For some reason, neonatal babies do not seem to need their mums overnight, because you generally cannot stay. There is a disparity there.

We need much stronger policy on family integrated care. In 2021, the British Association of Perinatal Medicine published the framework for practice for family integrated care, and although units across England and the UK are working towards it, there is no particular accountability, no benchmarking. It is down to Bliss, potentially, which is working on an accreditation scheme for family integrated care, but this needs to be put into policy with the funding that follows.

By itself, however, a policy will not do. As part of my PhD, I have completed a systematic review into the barriers and facilitators of family integrated care from the viewpoint of healthcare professionals, and a few other recommendations have come from that. I believe that we need a long-term plan to modernise neonatal units. Many units were designed with space for a baby in a cot and with room for one nurse standing by it. With family integrated care, we are trying to achieve an expectation that families will be much more involved with their babies while they are in the neonatal unit. That means that the neonatal space is no longer fit for purpose. It is too small. There is no room to swing the proverbial cat. Some of you will have been on a trip to Chelsea and Westminster Hospital. Most hospitals do not look like that. It is a nice, shiny new hospital and we need more like it.

My third recommendation is on education specifically to do with family integrated care, because it is the buy-in of healthcare professionals on the unit that will make a daily difference to families. Without them really understanding why, they will not go that extra length. It is not easy, without a huge amount of worry, to take that 500-gram baby with tubes out of the incubator to place in the kangaroo mother position. Francesca has explained the life-saving value of that. That takes space, education and training. The systematic review identified the barriers to staff, who are saying that they want to do this, but it takes time, it takes more people than are available, and if staff go off and do training, who looks after the baby?

The one benefit of our experience is that with nearly 10 weeks in one hospital and nearly 10 weeks in another, it was like a mini-experiment, and from experience I can tell you that family integrated care makes the world of difference, but now we have the clinical data backing it up.

Those are my three recommendations: policy, new neonatal units, and education for neonatal staff.

Q208 **The Chair:** Thank you for those very powerful messages. As I said before we started, we will learn a lot from you. I would like you to expand on this a bit more. Both of you, as you said just now, have experience of having your babies moved from one place to another—in your case, Francesca, I think at one time you had babies in two different hospitals—and it must be difficult for parents when that happens. Can you expand on that?

Francesca Segal: I suppose I was lucky in the sense that they were both in London and a Tube line ran from one to the other. But there was a period of several days when I was post-surgery myself and had a twin in UCLH and a twin in the Whittington. Both needed as much of my time as I could give them and, more practically, both needed breastmilk. There are other mothers who would have been noisy enough that that separation would not have happened.

As Nadia said, you realise how random some of these decisions are. When my first twin was moved, I was refused a space in the ambulance with her, but when the second was moved the crew invited my husband to go. I realised then that there had not been a policy in place to prevent me from going; it had just been the decision of that particular ambulance crew.

I understand that issues with beds come up. We were in a level 3 unit and UCLH needed to make room for the 24-weekers that were coming in and my 1-kilo babies were comparatively large, but it was extremely difficult to be split and it emphasised that we were not considered to be essential, that we were expected to be simultaneously in two places at once.

Q209 **The Chair:** Nadia, you mentioned that Harrison, your son, now requires a lot of help in different areas. We have heard in our evidence about the importance of longer-term follow-up of babies born preterm. From your experience, Nadia, and yours, Francesca, where can improvements be made?

Nadia Leake: About 50% of babies discharged from neonatal units go into the community, solely into the care of a health visitor. The Institute of Health Visiting is working on a programme called the neonatal families ambassadors. This has been running for three or four years now and I have been involved in that work. But, again, we need to invest in education for health visiting teams, because they are the only constant for many babies who have gone through a neonatal unit.

If a baby is discharged without any major medical needs, the only people bridging that gap are the health visitors. The health visiting teams will look after babies from birth through to school, and this is where we can bridge that gap and inform the school that this child may well be at risk and can start looking as early as possible to the interventions that can support them to optimise their school attainment and life down the line.

We were extraordinarily fortunate. We live in Whitley Bay. There are plenty of services and Harrison had them all. This is where you can see the difference. I am one of those mums who will shout. We might be fortunate with where we live and who we are. Every time I look at that, I think, "That's wonderful for us, but what about the others?"

The health visiting teams are national and can continue to bridge that gap between neonatology and schools, because those first five years for a child are everything. I believe there needs to be some support with health visiting. Harrison was able to go to a specialist school for just eight weeks so they could assess him and start to put in place what he would need when he started school. I do not think there are many of those units available in England anymore, so what you do for babies without early intervention will make the difference.

Francesca Segal: It is really interesting what Nadia says about being one of those parents who shouts. In an ideal world, there should never be situations where it is required. Leading up to those early years, delayed school entry is one of those things. My daughters were lucky enough that the time of year when they were born did not alter their school cohort, but we were in hospital with a lot of babies who had been longer-term inpatients and had been born in August but were due after Christmas. I stayed very close to a small group of women who were there when I was in hospital, and I watched agonising school battles. There were those who were lucky enough to encounter comprehension when they met with local authorities or schoolteachers who understood, and people who really struggled or who were told, "Okay, they don't need to start school now, but we'll parachute them straight into year one".

There needs to be something in place to protect the parents who are not able to fight those bureaucratic battles. The four of us have a WhatsApp group and I was the only one who did not need to fight that battle for my children. What I watched went on for six months; it ought not to have gone on for more than five minutes.

Nadia Leake: Harrison was one of those children who was born in August. He came home in December. To go back to accommodation, I spent two nights with Harrison just before discharge. He had four months in hospital and I spent two nights with him.

To the point about school and that year group, it was his autism that saved him from that trouble, because somehow he could read and write at the age of three. We did not teach him. Again, it was luck. If we think about the corrected age of a baby born four months early, when he is four years-old and supposed to be going into reception, cognitively, in his brain development, he is three years and eight months. He cannot catch up.

As Francesca says, there is real trouble now with babies who are crossing over that school year. I believe you are aware of the Prem Aware Award scheme. That needs a huge amount of support to be rolled out across England so that more schools and local authorities are aware of the risks of prematurity and that children who may need to go into a different school year can be identified early.

The Chair: Were you personally able to do that for Harrison?

Nadia Leake: Harrison is an anomaly in that he started school early. It is very strange, but he really does not fit the mould for most premature children. He was able, through the autism, to read and write very early, so they took him out of nursery and put him into reception. That is not the case for most children. Looking across the board, there needs to be a huge amount of flexibility in education because of the risks for these children.

Q210 **Baroness Blackstone:** I declare an interest, because I am the chairman of the trustees of the Royal College of Obstetricians and Gynaecologists. Also, I can empathise very strongly with everything you said, because I am the grandmother of very premature twins. I have observed much of what you have described. It is not the same being a grandmother as being a mother or father. Even so, you are able to pick up on a lot of the experiences and the difficulties.

What would have made the biggest difference to you both when your very premature babies were in hospital? What hospital policies would really have improved your experience? I can say from my own experience that in some ways my son and daughter-in-law’s problems were greatest when they got home, because they were not really prepared for how difficult it would be to look after two tiny babies when they already had a two and a half year-old. The answers to those questions would help us to think about what sort of policies we should be recommending.

Nadia Leake: I knew that when I was with my children I was okay, and when I was not with them I was not okay. We absolutely need to move to zero separation, but to do that the infrastructure needs to be in place. We know what we need, but it is not really possible right now. Many units across the country are doing everything they can to ensure that parents have complete access, but there is that time away overnight.

Even food provision is a problem. As a parent on a neonatal unit you are not head-counted in that hospital for food. I know there are a couple of initiatives in the north-east looking at how to provide food, but otherwise you are at the mercy of whatever provision there is in that hospital. Some of it costs a lot, which especially affects parents who do not have a lot of spare money.

They are certainly ways to mitigate parents needing to leave the hospital, but this goes back to the fact that many of these units are trying to do more with the same space. They need lockers so that parents can put their things away. They need a fridge. They need a small kitchen. There is no more room, so how do they go about that?

As for the second part of your question about when you get home, that was certainly where the rubber hit the road. There is an overwhelming fear, and a lack of understanding from community healthcare professionals about what it feels like to have a baby come home. They have not been on that 20-week journey with us, and they just see a baby who requires a little bit of oxygen requirement. The first time that Harrison went back into hospital was just two months after discharge. He had bronchiolitis and nearly died again. He spent another two weeks in hospital, but this time we were in PICU, so we could stay.

For me, everything comes down to education—the more we know, the more we can do. In the community, it comes down to the health visiting teams and the mental health services for parents. When I sought some support for my mental health, everything was conflated with bereavement. Actually, I am coping with the fact that Raif is dead. I am not coping with the fact that I am now trying to keep Harrison alive. There is also the guilt that comes with, "What on earth have I done to these children?" There was no understanding of that.

Francesca Segal: The degree and the depth of my trauma throughout this experience only really became clear to me when my third daughter was born full term and I suddenly had an understanding of all the things that had been denied to my elder daughters through this essential but unnatural birth experience.

My youngest daughter also had bronchiolitis. She was a full-term baby. It was just one of those things. We went into hospital overnight with her when she was seven weeks old, at which point my elder daughters had still been in hospital, and I stayed. Seeing that folding bed in the corner of the room was a sucker punch, because I suddenly understood that I had left my daughters. It was the first time that I had allowed myself to believe that had happened.

Throughout that NICU experience, I was made to feel, by the climate of the ward—and we had exceptional care—that I was somehow on trial as a parent; that I was being judged and watched and might not pass certain tests and be allowed to take them home. Nurses are busy, stressed and overstretched. In the morning, when you went in, you would not know whether you were going to have a nurse who was going to push you forward and enable you and say, "These are your babies. Touch them, hold them, sing to them". It never occurred to me that I could sing to them until I heard another mother singing.

I do not think I kissed them until they were seven or eight weeks old in hospital when a nurse said, "Oh, give them a kiss for the photo". I thought, "Infection, infection. I mustn't". She was my child. I was feeding her. Nothing is too small to teach when a mother is traumatised, particularly one who became a mother through that process. If it had happened the other way round and I already had another daughter and had come in, I might have been braver.

When I was there eight and a half years ago, parents were excluded from other parents' ward rounds. Now, most hospitals will give you noise-cancelling headphones so you are not hearing private information. We were asked to leave for a long period over a ward round and, more crucially, we were excluded from nursing handover every day. It was made clear to us that, even though we were the only consistent care day after day, our input was not welcome at nursing handover. There was a clear hierarchy of responsibility. We were a "nice to have", but the nurses were essential.

By the time your baby has been in hospital even for a couple of weeks, you know your onions, you have stuff to say, you have observed them, you understand colour changes, and you can make a meaningful contribution—if you want to; not all parents would.

I was told to leave for nursing handover when my increasingly aware and increasingly—as they approached full term—distressed babies understood that I was leaving. I was basically pushed out of the door at 10 to 8 every evening, leaving them wailing. There should be inclusion as a full member of the team for the parents who are able to. Not every parent is able to, that is also an understanding. There are parents with five children at home and single parents who cannot do it, and there must be provision for them too. However, for the parents who feel emotionally and practically able to participate fully in their children's care, it would make all the difference, a lifelong difference.

Baroness Blackstone: That is very moving and clear from both of you. Thank you.

Q211 **Lord Hampton:** Thank you for the extraordinary stories that we have heard. You have both talked a lot about education and how nothing is too small to teach. I just did a quick list of people you need to teach at the moment—neonatal staff, ambulance drivers, head teachers, health visiting teams, doctors and parents themselves. How do you do this? Could you get ambassadors who could go through the journey and teach all the way through? Is it internal? Is it a mixture? How do you see that going? If you could wave a magic wand, how would you do it?

Nadia Leake: There is a lot in place already. We need to think about the care co-ordinators, who were put in place by NHS England in 2021 or

2022. Part of their role is to improve the experience of parents on neonatal units. Generally, they will push forward family integrated care and run a lot of the training. The staff on the wards also run the training, but this is where release time comes in: who does it, when and where, how does the staffing work? There are consultants running their family integrated care programmes out of goodwill on their days off. That is not sustainable, and it does not give the intervention the value it should have if it is not job-planned.

On the point about the other people you mentioned outside of schools, this is where the health visiting teams come in. The Institute of Health Visiting has already started with its ambassador programme, but this must be wider-reaching.

Q212 **Viscount Colville of Culross:** This happened to you several years ago. Nadia, you have been studying the response and how the health service has improved its support for parents. You have just talked about the ambassador scheme, the integrated care boards that are now being introduced. They are there as a concept. Do you feel that they are not being rolled out fast enough or extensively enough to be able to support most parents who have premature babies and who therefore go through the psychological trauma that you have both just described?

Nadia Leake: To clarify, it is the family integrated care framework for practice—FICare, we call it—from the British Association of Perinatal Medicine, which has been rolled out and the care co-ordinators are doing that. There is certainly a speed issue. We know that on average it takes 17 years for new interventions to become embedded in any practice in healthcare. That is part of implementation science.

My research looks at the barriers and facilitators regarding implementational practice of family integrated care from the viewpoint of healthcare professionals. This is where we see, "We want to do this, but these are the areas we need". An ecosystem is required.

It is not a lack of will, for the most part, to do more for and with parents. It is the physical structure, the job planning, the lack of staff numbers, potentially. My illustration of taking a baby out of the incubator, the skin-to-skin care, works if you can get the baby out safely.

We also need to think about the healthcare professionals caring for increasingly immature, very fragile babies. Their stress levels go up, and in the systematic review we are hearing a qualitative piece. In the words of the doctors, nurses and other healthcare professionals in neonatology: "Actually, it might be easier just to leave the baby in there. Because I've got four babies in incubators in this tiny room, and all the parents and cousins and sisters are coming in now because we're trying to do family integrated care".

When you are trying to do more with babies and to some extent relinquish control, it ramps up the level of stress and perception of risk that the healthcare professionals encounter. The controlled environment is a safe environment. You have mums and dads wanting to pick their own baby up, and you start to skew the balance in where that control sits, not from a personal perspective but from a safety perspective.

Francesca Segal: That control issue and that sense of security is really important. I was nodding violently as Nadia was talking. Even if you know academically that it is better for the course of a baby's stay in hospital for them to have skin to skin with their mother in your shift today, it is much easier not to rock the boat and for that baby, who is sleeping and whose stats are stable, whose oxygen and heart rate are stable, to stay where they are. It is a lot. You are moving Chihuly glass. It is frightening. You do not always get a yes when you ask to hold your baby.

Nadia Leake: The work that I have done so far and what we are going to be looking at for the UK, which I can break down by region after the analysis is done, will give us a deeper understanding of how it feels for the healthcare professional trying to do this. I want to make it extraordinarily clear that these are amazing people doing amazing work. They just need more support to do more of it.

Viscount Colville of Culross: Is that all that is needed to shift that balance when it comes to control? Do they just need a bit more support or do they need educating? What do they need to shift that balance more towards integrating the parents and family into that care?

Nadia Leake: Give me another 18 months and I will have finished the research. It is complicated. It is not straightforward and it is not the same for every person. I hope I am not speaking out of turn when I say that my work will be the first wide work on "How does this feel to you? What does it look like? What do you need?" I would love to send you that when I am finished, but right now I would not want to say whether it is A, B or C, because I do not have an answer.

Francesca Segal: What you did say, if I may—I am not speaking for you—and what I thought was really interesting was that you illustrated that each unit has its own culture. There is an ingrained culture, and shifting things can be very painful. If you are a devoted, committed NICU nurse late in your career, to be told that some choices that you made early on with the best of intentions might not have been optimal is really painful. Sometimes the route is to resist that new path, because it hurts to be told that you may have done unwitting harm.

There are climates of openness and very slow change. I totally understand why that would be the case.

Q213 **The Chair:** You both wrote and have now talked at length about the importance of integrated care and family and parental involvement. You always describe in your books the relationship that parents develop with the professionals and how they react to you, recognising that, unlike in any other branch of medicine, the professionals who work in neonatal intensive care have to work with very fragile young babies who require intensive care, not like adult intensive care where it is for a few days, a week or so, but for months at a time. Therefore they themselves also form relationships with these individual tiny babies and sometimes are affected by their ups and downs.

What kind of training and so on might be appropriate for the professionals who look after these babies, and how did you find them and the communications et cetera? This is your chance to talk about Deepak.

Francesca Segal: Deepak, lovely Deepak. There is no other area of medicine I can think of where the nurse you leave behind you is in loco parentis. You are leaving a nurse to change a nappy, to feed your baby, to comfort them. Very premature babies do not cry. They are too small and weak and not neurologically capable. That does not mean that they do not feel the distress. When they are older, they cry, they tell you when they are not happy.

So you are leaving behind you a nurse who is fulfilling that role. I cannot imagine the emotional strength it must take to stay open and empathetic towards those tiny beings as the people they are, who suffer what they must suffer in order to live. The best nurses will always be the ones who maintain that very vulnerable, open channel to the humanity of the people they care for. The people who do that job are extraordinary, but the trust that a parent must put in the person they leave at the cot-side of their child is unlike anything else.

Nadia Leake: When we left Queen Charlotte’s, we had already begun to call many of the doctors and nurses “auntie” and “uncle” for the children. There was a wonderful young registrar who was trying to resuscitate Raif, and his act was just to say, “I’m sorry”. He and I are still in contact. He now has young children. We send each other pictures of each other’s children and new year and Christmas wishes. Those relationships, as with everything to do with prematurity, are lifelong. But that goes both ways, because when the hurt happens that also hangs on. It is about that communication and deep understanding.

On education, you asked what we could do to help them. Here I want to reference the butterfly project, run from Newcastle University and the RVI. It looked at loss of a twin or higher-ordinance multiple pregnancy. The teaching that has gone on about how to care for a family when they still have the surviving baby has changed the culture around bereavement in that case. Education can make a difference. That was a qualitative programme. Videos were created. It is around the world now. When a baby dies, a purple butterfly is put by the surviving baby’s cot so that anyone going up to that cot knows that they have lost a child but they are still in neonatal care. Small, practical things can be done that make a world of difference to everybody.

This is where we keep our minds open and the ideas flowing. The changes come, they have come, but of course we need more.

The Chair: We could go on, because we have learned so much from you. Your stories and your recommendations could become the report. We do not need any more evidence. Thank you both for coming to talk to us today. It has helped us a lot and will be the basis of our report: the importance of parent involvement in integrated care. Nadia, I wore a butterfly tie today to remember Raif.

Nadia Leake: Thank you.

The Chair: Francesca, in a lighter mode, why did it take you so long to name your daughters?

Francesca Segal: I know. Everybody asks that question. We kept the ward entertained with suggestions. They are called Raffaella and Celeste. We got the right ones eventually.

The Chair: Thank you.