HOUSE OF LORDS

Preterm Birth Committee

Corrected oral evidence: Preterm Birth

Thursday 5 September 2024

9.55 am

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; Baroness Watkins of Tavistock; Lord Winston; Baroness Wyld.

Evidence Session No. 19 Heard in Public Questions 244 - 253

Witnesses

I: Kate Brintworth, Chief Midwifery Officer for England, NHS England; Professor Donald Peebles, National Clinical Director for Maternity, NHS England.

Examination of witnesses

Kate Brintworth and Professor Donald Peebles.

Q244 **The Chair:** Welcome to our witnesses. It would be very helpful if you would introduce yourselves, for the purpose of the record, with your name, your designation and your organisation before we move to the official business.

Kate Brintworth: Good morning, Chair. I am the Chief Midwifery Officer for England for the organisation NHS England.

Professor Donald Peebles: I am an obstetrician. I work at University College London and I am the National Clinical Director for Maternity Services.

The Chair: I think we know each other, Donald. Thank you very much indeed. Before I start the evidence session, could I brief you? We have had all the evidence sessions except for NHS England. Later on, we will hear from the Minister. We have heard some quite harrowing stories from the parents of babies born preterm about the lack of care, the lack of follow-ups, the lack of long-term follow-ups, and assistance for parents while their tiny babies are in the neonatal nursery.

We have heard from professionals about the lack of funding for research and evidence-based practices, about variation in care and about staffing issues. Unless all of this is addressed, things are not going to change much for babies born preterm and their parents. Our questions are based on the evidence we have heard, and your response will therefore be extremely important. We will start with Viscount Colville.

Q245 **Viscount Colville of Culross:** Good morning. Thank you very much indeed for coming. I will start with a big question, but could you try to give relatively short answers because there will be lots of subsidiary questions? The committee has heard that the current target to reduce the preterm birth rate to 6% by 2025 is unlikely to be achieved. Do you agree and, if so, why?

Kate Brintworth: Would you like me to start?

Professor Donald Peebles: It is an easy answer; we agree.

Viscount Colville of Culross: Just give a few reasons why.

Professor Donald Peebles: The preterm birth rate covers a very wide range of gestations. The causes of prematurity, say at 26 weeks, are very different from the causes of prematurity at 37. The data is a very big catch-all. You could make improvements in one bit and not in another bit. We would far prefer to look at this in a gestation-related way.

Having said that, the preterm birth rate for all gestations was going down. It was not as fast as we would have wanted but it was going down, until about 2020. It has clearly gone up, and our best evidence would be

that it has gone up again this year by a little bit. There is no way that we would meet that ambition of going from 8% to 6%.

Kate Brintworth: It is important to look at the context. One of the things we are acutely aware of is that we are looking at a population who come to us in poorer health. Women tend to be older when they have their babies. They tend to weigh more. They have more hypertension, diabetes and a range of co-morbidities. Many women have babies now who, even when I started training, would have been told, "Don't have a baby", and that has a significant impact on the health of the pregnancy and the baby.

Sometimes we have to acknowledge that it is better for a baby, in some circumstances, to be born early, if the balance of risk suggests that it is better to intervene. As Donald said, it is a very complicated picture. You cannot just apply one crude measure or intervention to make it improve.

Q246 **Viscount Colville of Culross:** We have heard various suggestions for how improvements could come about, one of which has been the uniform implementation of the Saving Babies' Lives care bundle. That could help bring down the birth rate. We have heard that that is not being done uniformly. There are various elements of it that we have particularly heard about, like the Tommy's app that has a risk score involved and allows machine learning to anticipate the mother experiencing any kind of complication. That is not particularly being rolled out. Are you concerned that the bundle is not being implemented?

Professor Donald Peebles: Yes. The bundle is all evidence-based. If there are evidence-based interventions that will improve outcomes for babies born prematurely, we want every woman who needs them to have them. Any variation in that is unwelcome. We want to bring everyone up to the highest standards of practice.

In terms of the implementation of the Saving Babies' Lives care bundle, while there is certainly variation, there is also evidence of real improvement. The most recent compliance data with all elements of the care bundle was 87%. It has improved quite significantly over the last two or three years. That is because of the enormous efforts of midwives and obstetricians across the country who take it really seriously and do their utmost to make sure that women and babies get the interventions that they need.

Obviously, under that headline figure I am sure we will talk about the perinatal optimisation interventions, which are more mixed. The variation there is greater. The question is: do we have the right mechanisms in place to tackle that variation? I know, because they are close colleagues and we talk about it all the time, that at BAPM—Sarah Bates from the south-west—they have done some fantastic stuff with PERIPrem down in the south-west. I know you are fully—

Viscount Colville of Culross: We will come on to that. As you said, we have done very well with the bundle and getting it up to 87%. What more

needs to be done to make it an even higher figure than that?

Professor Donald Peebles: At the moment it is an upward trajectory. I am not saying that that is the ceiling of where we would get to. Over the last few years the compliance rate has gone up year on year. There are always going to be situations in which interventions cannot be given for various reasons. One has to be realistic about exactly where one can get.

The other thing is that we are very aware that, in saying something is implemented, there are different ways of implementing. The implementation might have different effects in different places, depending on the people who are implementing and the energy. There is a difference between putting a tick in the box and saying, "Yes, we do this", and the degree to which it is done. Again, I suspect we will come on to this, but I think we are much better with the mechanisms that we now have in place at creating that enthusiasm, energy and sharing of best practice that front-line staff need to feel to really do this stuff well.

The operating framework for the NHS, with the focus on ICBs—I know you have heard from some impressive-sounding ICBs—and their ability to work with providers on their patch, seeking to provide local solutions to local problems, is another way of generating that energy and enthusiasm.

Viscount Colville of Culross: Kate Brintworth, do you think more could be done to increase uniformity in this area?

Kate Brintworth: The point Donald makes about local solutions is really important. There is constant tension when you have national and sometimes even regional guidance, in that you get people complaining, "That won't work here because", and the risk of stifling innovation. There is something about creating principles and the right conditions for change, and acknowledging that the care bundle is a very complex package with multiple interventions across all parts of a maternity service. Implementation will be a process and not an event. You have to take a quality improvement process, where you start to implement at parts. You review, assess and move on. It is always going to be a journey that organisations have to go on.

We have issued ICSs with a toolkit to help them monitor their own progress, so they can see which elements are challenged. As well as Donald's description of the ICS support, if ICSs are struggling, bearing in mind that they are relatively new entities, we have very experienced and knowledgeable regional maternity teams who know their services inside out and can help to join them up. Everyone is focused on it. When we did a round of visits in every maternity service in 2022, every region used the Saving Babies' Lives care bundle. It was part of the question. It is also in the maternity incentive scheme that is run by NHS Resolution. There is a financial incentive to make sure that the board is fully appraised of the importance of the care bundle.

Viscount Colville of Culross: It is interesting that you talk about local solutions. One of the areas we have heard a lot about is socioeconomic

and ethnic inequalities leading to disparities in preterm birth, particularly socioeconomically. However, in 2021-22 the LMNSs received ring-fenced funding to produce equality action plans, but since then NHS England has decided not to ring-fence that money because its new operating framework places greater responsibility on integrated care systems. Are you taking enough action to reduce those inequalities? Is dealing with it at a local level one of the ways that you can get to that?

Kate Brintworth: It is fair to say that inequalities are probably one of the highest priorities in our programme. It certainly is personally for both Donald and me, and for Ngozi Edi-Osagie, who is the National Clinical Director for Neonatal Care. It is really important that you have local solutions. What you need in rural Torbay is not the same as in urban Birmingham. You have different populations. People have to be able to have responsiveness to what they see in their population.

Q247 **Baroness Owen of Alderley Edge:** Are current staffing levels sufficient to provide high-quality and safe care for mothers at risk of preterm birth and their babies?

Kate Brintworth: We would always say that we would like more staffing in maternity. It is our job to advocate that. We probably had our low point just after the pandemic, when we were very challenged with staffing. Investment has paid off. We have more midwives in post now than we have ever had before. There are probably around 27,000 funded establishment posts, but all those posts are not filled. We still have a gap remaining of around 1,900. We are continuing to fill it with various initiatives.

We are on a journey of improvement. Investment has paid off because we have been able to increase the establishment. I would say the same for obstetricians. We have more obstetricians than before, but we know that we still have gaps. It is the same for neonatal nursing. We have 550 more neonatal nurses, but we would still like that to increase. The short answer is that we are on a journey of improvement with that.

Professor Donald Peebles: I completely agree. We have been modelling for the future and thinking about what is needed over the years to come, rather than just looking back. As with many things in the NHS, what is expected has changed completely, beyond recognition. Kate started off by alluding to the big increase. Every risk factor for preterm birth has gone up in the population. It is the same for all pregnancy outcome risk factors.

Sadly, intervention rates have gone up. Caesarean section rates are going through the roof and intervention rates have gone up, partly because of the Saving Babies' Lives care bundle to intervene to save lives. All of those things add up to real demand on the workforce.

Then there are the more subtle things. We have already talked about quality improvement. Our staff need room. They need brain space to do quality improvement and to implement the Saving Babies' Lives care

bundle and things like that. We are quite confident in the long-term workforce plan, for instance, and its expectations when it is reviewed. We will be making the case very clearly that the status quo and the target that Kate is aiming for will not be sufficient, going forward.

Baroness Owen of Alderley Edge: Are staffing commitments in the long-term workforce plan sufficient to deliver this? How will you ensure that they are achieved?

Kate Brintworth: One of the things about pregnancy is that you only have nine months' warning of what your birth rate is going to be. It is important that we continue to review, as Donald described, not only birth numbers but the complexity in the population. There is also something about reviewing the care offer. The complexity of what we offer has changed radically. I believe that some of you are healthcare professionals and might remember something called a "Co-op card". A woman's notes were recorded on a card that was about this big for her entire pregnancy. There was not very much more, apart from slightly more detailed records in labour.

Midwives are now expected to record, and may record, up to 1,500 data items across a woman's pregnancy. That is a lot of time in front of computers. We are not saying that it is not the right thing to do, but it is important that that is part of the context and constant review of what we actually expect people to do. When you look at the average booking, which is the first appointment when a woman comes in in her pregnancy, there are probably around 35 to 40 things that a midwife needs to explore and unpack with the woman, and make a risk assessment and judge further referrals on. It is a very complex package. It is not just someone turning up saying, "I'm pregnant"; "Congratulations. We'll see you again in another month". It is evolving into a very technical care package. For now, we have made our best guess looking at birth rates and complexity, but we need to keep it under constant review.

Q248 **Baroness Watkins of Tavistock:** I declare my interest as a non-executive director of NHS England.

You have talked about the complexity of the cohort of people now having babies, and I can really tune into that. We do not have very many opportunities for people who are already registered nurses to go on and do midwifery since we adopted the three-year programme as the core component. Some people think that having a more mixed economy of doubly trained people might actually assist. Could you tell me what you think about that? It could be very relevant for the workforce plan.

Kate Brintworth: I should probably declare an interest in that that is how I became a midwife. I trained as a nurse first. I think your phrase "mixed economy" is a good one. We need undergraduates who come through that route, but we also need people to come in who have been nurse trained, to bring in that experience to meet the needs of our population. We should be growing our population of maternity support workers into apprentice midwives and qualifying that way. That is a really

important route. We have seen great success in some pilot projects. Yes, I am a big fan.

The Chair: What is NHS England's role in promoting that?

Kate Brintworth: Obviously it is contingent on funding. I met the lead midwives for education on Tuesday, which was very pressing considering that they are just starting to see their courses fill up for the new academic year. One of the things they talked about across all their courses is the financial pressure that students feel. Many people have accepted courses and then deferred them because they need to earn money and they want to go and work for a year, but they are concerned about getting on and starting their courses. While the courses might be filling up ostensibly, there is a delay in them coming through. We see that on both the nurse entry and the undergraduate course.

We hear from organisations for the apprenticeship that it is quite difficult to backfill staff who might be undertaking further training. The organisations want to do it. They support them because they recognise that they have a population who will be absolutely committed to their role once they have qualified, but they have jobs to do that need backfilling. There is a financial pressure that this creates.

The Chair: What is the role of NHS England?

Kate Brintworth: To ask for money. Obviously, we are encouraging organisations to do this. We have supported apprenticeship funding, but we are always interested in ways that will make it easier to get our workforce through because we see declining numbers applying.

Q249 **Baroness Owen of Alderley Edge:** When do you expect to achieve the ambition of midwife continuity in care?

Kate Brintworth: Continuity of care interests me a great deal. I spent the first five years of my career practising continuity of care as a midwife, and I then went on to manage a service that had a vast number of models of continuity of care. One of the things that everyone would agree is that continuity as a basic principle is important across all elements of healthcare. People want to see the same GP when they go there.

The basic principle that it is really important to put up front first is that it is about being held through your pregnancy and that someone knows who you are and understands your needs. They are someone you can go to if problems arise. You create trust, and in creating trust you create the opportunity to explore what might be more difficult elements in someone's care, be those physical, social or psychological, but you need the workforce in place to do it. As I have already outlined, we have significant challenges in our workforce.

It takes significant organisational development. It is not as easy as saying, "Right, let's get seven or eight of you together and off you go, you can look after that cohort". You are asking people who have often specialised in perhaps one area, such as the postnatal ward or the

antenatal ward, to work right across the service and into the community and liaise across all areas. You need to make sure that workforce is prepared to do that and is adequately supported.

It is quite difficult to say. It is going to be contingent on when we can get the right workforce in place, but we are very cognisant of the evaluation that City of London undertook about the implementation of continuity. We are also cognisant of the latest evidence from Cochrane, which is that continuity does not appear to have the effect on preterm birth that was previously thought. We are looking again at continuity and what we can do to support it.

In the meantime, what we have said, talking about the principles of holding, supporting and creating trust, is that we are focusing on women from ethnic-minority backgrounds and the most deprived areas. They really need that support, extra guidance and intense focus on their needs to help them through their pregnancy.

The Chair: By the way, although the Cochrane report suggested that, when we took evidence from parents they do want continuity of care.

Kate Brintworth: Yes.

The Chair: That is not something that the Cochrane report said. If you focus your policies based on scientific evidence, which is what one should do, and ignore the evidence from parents or patients, that would be wrong.

Kate Brintworth: I completely agree with you. I did not say that. I was just making the point in the context of this committee that it has been seen as an important tool in preterm birth. Every evaluation of continuity says that it improves women's and families' experience. That was also my own experience.

Q250 **Baroness Hughes of Stretford:** I want to return to the issue we touched on earlier, which is about the variation in the implementation of the national guidelines, the Saving Babies' Lives care bundle, across the country. First, what does NHS England intend to do, or what has it already been doing, to reduce that degree of variation in implementation?

Professor Donald Peebles: As I mentioned previously, the PERIPrem project was a very good example of how to do quality improvement. To a degree, what we are doing is looking at projects like that—there are many others—seeing what the features of good-quality improvement are and trying to replicate them in a sustainable way that does not depend on a one-off injection of cash. We will not just need to do that this year. We will need to be doing it in 10 years' time, so we want to create the mechanism within maternity services, and the capacity, to do quality improvement not just around preterm birth but lots of other things as an ongoing thing.

The Chair: Professor Peebles, you are not answering the question. The question was quite clear. We have heard in evidence from Baroness

Hughes of a great deal of variation in practice—unwarranted variation of evidence-based practice. What is NHS England doing to reduce that or absolutely remove it?

Professor Donald Peebles: I said that we had learned from the PERIPrem project. We have a whole package of things around interventions. The Saving Babies' Lives care bundle itself is a supporter of reducing variation. It sets out a very clear plan. There are incentives to it. Data is collected and shared at system provider and regional level.

Baroness Hughes of Stretford: Perhaps I could intervene. The problem is that there is a plan in that bundle, but it is not being followed sufficiently. You mentioned the maternity incentive scheme. I think you said earlier that on the latest data, in April, about 87% of local areas were compliant with the bundle.

The information we have been given suggests that 104 of the 120 participating areas declared themselves to be compliant, but that incentive scheme allows ICBs to declare themselves compliant if they feel that they have made their best endeavours, and are making progress. In the 104, and in the 87% that you quoted, there will be an unknown number of ICBs that are not actually compliant, but the incentive scheme allows them to declare themselves to be so, and to be financially rewarded. Do you think that is a strong enough mechanism for you to know absolutely which areas are compliant and which are not?

Professor Donald Peebles: It is a very good question. We debated this endlessly with the maternity incentive scheme. The reason for doing it this way is because we introduced those interventions as a block in 2023 and the idea that you would achieve all those things within a year seemed to be unreasonable. On the flip side, is it reasonable to say, "You will do all this stuff within a year, and if you don't there will be a financial penalty"? That is the alternative. It seemed to us that this way of setting a trajectory but being absolutely clear that that trajectory has to be met is the right way of bringing about quality improvement. Next year the levels that we expect people to achieve will be higher.

Baroness Hughes of Stretford: But if under the scheme an ICB can declare itself to be compliant without being compliant, how does NHS England have independent assurance and robust data about the actual level of compliance through participating areas? How do you know?

Professor Donald Peebles: ICBs and providers have access to good-quality data about the degree of compliance with each of the 70 interventions in element 5. I think we have the data. Kate mentioned the implementation tool, and I think that has been discussed here previously. It allows providers to track themselves against the ambitions, and for that data to be shared with the systems, which are ultimately responsible for what happens on their patch. The data is there. Each year we will make that trajectory closer and closer to 100% until we get there. I do not know the exact speed of that, but we are impatient and want to make it happen.

Baroness Hughes of Stretford: Correct me if I am wrong, because this is an important point to absolutely nail here one way or the other, but the data that you describe is the performance results, the latest edition of which was published in April this year. As I said, according to the MIS guidance, "where full implementation is not in place, compliance can be achieved if the ICB confirms it is assured that all the best endeavours—and sufficient progress—have been made towards full implementation". The data the ICB can give you by collating your performance results can declare that it is compliant when, in fact, it is not.

Kate Brintworth: We should probably talk about the operating framework as well in this context. Another thing about how the maternity incentive scheme was constructed a number of years ago was that it was never constructed so that there was submission of anything other than the position of the organisations. It does not have systematic, independent variation, which is why it was asked that the ICSs, when they were stood up, stepped into that place to do that variation.

The other thing is that it is the role of the ICSs to oversee their organisations. If they run into difficulties, there is regional involvement. As a national team, we do not collect that level of data. The operating framework suggests that you need to focus your efforts locally and, if there is a problem, it is escalated through ICS, region and then up to the national team. That is how we are currently working, allowing organisations to work through their local issues. That is the nub of what you are describing.

Baroness Hughes of Stretford: I am sorry to labour this point, and I will move on in a minute.

The Chair: It is an important point that has not been answered.

Kate Brintworth: It is an important point.

Baroness Hughes of Stretford: In producing the performance data that I understand NHS England publishes, what you are saying is that you do not have, and therefore cannot give the public, any assurance as to the veracity of the level of compliance that you are reporting because an ICB can declare itself to be compliant, and you say that it is its job to do so if it is not compliant. The 104 out of 120 or the 87% does not actually mean very much, does it?

Professor Donald Peebles: Behind the scenes, before those compliance data are declared nationally, at NHSR they have an incredibly rigorous process where they scrutinise the data. They go back to trusts. They question what has been submitted to them. One of the signs of success is that when that has happened in the past there have been a number of trusts where the data was not as good as trusts said it was, and those trusts then became non-compliant. The number of trusts that are declared non-compliant has actually decreased because they are getting better and better at doing this stuff. Behind that, there is a serious challenge to the data that you do not see.

The Chair: Why do we not see it?

Professor Donald Peebles: I suppose no one has asked. We declare it. You can look on the trusts' websites and they say, "We are now non-compliant". Trusts have had to hand back vast amounts of money because the process said, "No, the data isn't what we would expect it to be". Trusts have handed back money, and that is available on trust websites. It is out there.

The Chair: Would you accept that what we have heard described in the last 10 minutes is a set-up of long strings of bureaucratic rubbish? It does not benefit the patients at all. The patients see no benefits if ICBs and trusts say they are compliant when they are not. Nobody seems to hold them to account except the bureaucratic procedures that are established.

Professor Donald Peebles: I suppose Kate and I spend our lives going round maternity services talking to front-line staff. That absolutely would not be how it feels to them. They spend their lives, as I think I said earlier, implementing these interventions. Far more women have access to the interventions and get them now than they did before. That has led to real improvements in things like neonatal mortality.

I can see where the challenge of bureaucracy comes from, but when you are in a maternity service and talking to a fetal monitoring midwife or an obstetrician, their passion would be overwhelming.

Q251 **Baroness Cumberlege:** I welcome our witnesses. Thank you for coming. I want to ask you about the impact of prematurity on development and learning support for parents. I think parents sometimes get rather missed out. I am sure they do not in some places, but in others I think they are thought just to be an adjunct to the whole issue. There is the question of schools. Schools recognise the specific learning needs of children who are born prematurely. Is that something that has come across your desk?

Kate Brintworth: The involvement of families in the care of their child is absolutely critical. A family that has gone through a premature birth has gone through an incredibly shocking process. I think the word "harrowing" was used earlier. Everything that they were expecting has been turned on its head; their needs, psychological support for them, engagement in what is happening and trying to get them to come to terms with it. They might have a very fragile, small baby who appears to be in a box in front of them, and not the dreams they will have had for that pregnancy. I think you make a really important point about the care of families.

One of the things that we have been trying to do in maternity is to work increasingly closely with our service users, both from maternity and neonatal, who have experienced neonatal care. We have a fantastic national level service user voice. That is not the answer to the question, but it is about bringing that voice into everything we do and think about.

It speaks to what the Chair mentioned about the difference between bureaucratic process and the family's lived reality.

We are bringing our regional colleagues much closer together. We have become a maternity and neonatal programme. One of the reasons why that is important is that in maternity we have a very long history, as you know, of involving women in their own care, making them the leads in their own care and moving from a sense of it happening to them to their directing what happens. By coming closer with our neonatal colleagues, we can share that learning across to neonatology.

I understand that our neonatal colleagues are implementing family integrated care. We have transitional care where babies who previously would have been separated from their parents are being cared for on the postnatal ward, sometimes very vulnerable babies. The last time I was working clinically, there was a baby who had been born at 34 weeks and was having double phototherapy. She had feeding difficulties, but was not taken away from her mother, who absolutely was leading the charge on getting things right for her baby. We encouraged services to work with the Bliss charter and we funded 10 care co-ordinators to really up that level of involvement for families.

On the longer-term educational response, we would have to come back to you. I must confess that that is not my area of expertise.

The Chair: We look forward to getting that.

Q252 **Lord Winston:** Can I come back to a point? You mentioned the premature babies who are severely premature, and small babies who we all recognise have massive needs for care. There is definite evidence that babies who are slightly smaller, or just mildly premature, have long-term difficulties. We also heard from patients who have given evidence that the amount of follow-up that they have had has not been very good. In fact, they have often not been expected to make an appointment to have the proper follow-up, and so on. I wonder whether you feel that is a real issue or just something we have heard that is anecdotal.

Kate Brintworth: One of the things that I have learned from service user colleagues and from listening to women who have had experience of neonatal care is how often there is a time lag or delay in the shock of what has happened to them and their needs. Often what everyone does is focus on the baby and then forget that, actually, you need to look after the family with an equal level of vigour. If the family support is there, the baby will be all right. I agree with you that it is really important that that support is there. I have myself heard women talk about it being lacking.

Professor Donald Peebles: I completely agree with that. Kate and I are aware of the impact of all sorts of birth trauma and the longevity of that impact. It is much more than the current maternity pathway, which actually finishes quite soon after pregnancy. It has raised serious issues around how we look after mothers and their babies after any form of trauma. Being delivered at 34 weeks is a traumatic thing. It may not be

the headlines of the 26-week premature baby, but we completely accept what you are saying.

Lord Winston: Are we doing anything about that?

Professor Donald Peebles: We are interested in the pathways of care beyond the maternity pathway—for instance, how that links in much better with primary care. What are the roles of women's health hubs, for instance, to be a focus? They are being set up throughout the community and are where mums and their babies will be going for all sorts of reasons. What can we do in those hubs to bring together some of this care? It is at its early stages, but it is absolutely on our radar.

Kate Brintworth: We have been setting up perinatal mental health in each ICS, so that they have a defined offer for people who have experienced trauma. We need to make absolutely sure that that includes those who have had a preterm birth and recognition of how shocking it is. I think we could probably come back to you again with more detail on that from a neonatal perspective about where they are.

The Chair: We have heard lots of evidence. We would be grateful to have more evidence from you. You mentioned that you engage with parents and families, and mothers particularly who have had a preterm baby. The reality is that we took evidence from two mothers of very preterm babies who have written books about them. They are pretty articulate about the issues that they faced. Are you aware of that?

Kate Brintworth: I was aware of the evidence, yes. I have read the account.

The Chair: Have you read their books?

Kate Brintworth: I have not read their books, no.

The Chair: You might benefit from meeting them and hearing at first hand. They have a detailed chronicle of the issues that need to change to make it better for parents—for instance, accommodation, not just accommodation for parents of preterm babies who are there for a long time, but even accommodation to express milk for breast-feeding, and other things. There are units that do not have any accommodation. Is it not the role of NHS England to know about that and to do something about it?

Kate Brintworth: Yes, I absolutely agree. We have just completed an estates survey of maternity and neonatal care because we are very concerned about the variation. We have touched on variation across a number of issues. Parental accommodation and separating a mother from her newborn baby are the most traumatic things a mother can face. When my own son was born, he was not very well initially. I vividly remember sitting and looking across and saying, "Are you going to take him away?" I remember that feeling very powerfully. It is why there are things like transitional care and outreach care. It is not just about the estates, although I will come back to that.

We increasingly see outreach models where babies can go home sooner and have care in the home, so that we do not go through the trauma of separation. We have literally just completed the estates survey because parental accommodation is so important. Every time we visit a unit, they want to show us their parental accommodation, either to show us something that they are proud of and the thought that has gone into creating space for families to try to make sure that they can do it, or to say to us, "We need more space".

It is important to recognise the huge variation in estates that exists. Some of the buildings that we have are approaching 100 years old or, in some cases, older. The footprint that is allocated to maternity and neonatal services is often very limited by the trust. Staff recognise that having parents there is not just beneficial to the baby's health but absolutely fundamental to that baby going home well, but at times they are constrained by capital and estates. It is why we want to be able to describe that picture and say, "This is what needs to change".

Professor Donald Peebles: That will happen quickest when it is driven by the voices of the women you talked about, Chair. It is a really big step forward, and we really welcome it, that on our senior leadership groups and in all the main meetings we now have neonatal service users with lived experience, who actually talk to this sort of stuff all the time. They are driving the agenda with us, and we are really grateful to them.

The Chair: Ms Brintworth, in your voice I hear the passion that you clearly feel for making things better for mothers of preterm babies. I appreciate that. I hope you get the necessary authority and responsibility to do what you say you intend to do. I recognise the passion in your voice. Thank you.

Q253 **Lord Hampton:** I am slightly building on what Baroness Cumberlege and Lord Winston have asked. We have heard all about the health issues and developmental issues of severely preterm children through their lives. How can the co-ordination of care post discharge be improved for preterm babies and their families, including through GPs, health visitors and enhanced monitoring? We have heard about hubs. We have also heard that only 6.7% of neonatal units were doing the four-year assessment for extremely preterm babies. Why is the enhanced development, support and surveillance in NICE guidelines for extremely preterm babies at age four so rarely delivered in practice?

Professor Donald Peebles: For the detailed answer we would need to seek advice from our colleague, the National Clinical Director for Neonatology, Ngozi Edi-Osagie. This is not a prime bit that we are experts in. What I do know is that what happens in most places is that follow-up until two is adhered to, but it is the nature of the follow-up thereafter. If you had a normal Bayley's assessment—

Lord Hampton: I am sorry to interrupt. We have had a figure of 74.4%, which I would say is quite low.

Professor Donald Peebles: What Ngozi says is that when you have a developmental assessment that is normal, in some places people do not see the need for longer-term follow-up. It is if there is any question mark around that sort of normality trajectory. It is just not treating that cohort as homogeneous.

Lord Hampton: Do you feel that we should be not looking at normal and continuing? The research seems to be that it may seem normal now developmentally, but normal might change to abnormal.

Professor Donald Peebles: When I talked to Ngozi about this, her feeling was fairly strongly that, if a Bayley's is completely normal at two, it is unlikely to become abnormal thereafter.

Lord Hampton: I am not a medical person. Who should be responsible for ensuring that enhanced follow-up assessments happen?

Kate Brintworth: It will depend on who is the primary lead. If a child has continuing health needs, one would imagine that it is the person who is co-ordinating. If that child is having regular follow-ups with their local hospital through the paediatric team, or if the child is being managed in the community with the GP, it is contingent on whoever is in touch with the family to make sure that the person is signposted or referred correctly to the services that they need. We will include that in the response to you. Obviously, paediatric services are outside our remit.

Lord Hampton: This is a slightly innocent question. Is there somebody who is responsible for following NICE guidelines, or is that just general?

Kate Brintworth: All organisations are commissioned with the expectation—

Lord Hampton: But within the organisation do you have specific people or is it just everybody?

Professor Donald Peebles: I am sure it is routine practice for pretty much everything in a NICE guidance that you are expected to follow it at trust level, unless you declare an exception because you actually do things better, for instance, than in a NICE guidance. There is a set process for declaring compliance with NICE.

The Chair: It was suggested to us that it would be of great benefit, and the guidance says it should happen, that all children born preterm were assessed at age four, not only for their health needs but for their educational needs. Are you aware of that, and is something being done? Do you agree with that or not?

Professor Donald Peebles: Chair, I think we have already declared that this is not our area of expertise. We can provide evidence afterwards to answer your question.

Baroness Watkins of Tavistock: I fully accept that it is not your area of expertise, but what is worrying to many of us on this committee is how

the baton is passed and how we alert to try to ensure that follow-up occurs. We are permanently looking at the way we record information. Is there something that could be done on the transfer from your services to neonatal that would flag to a GP, or to whoever is decided, that they should look at age four?

We are looking right across the health service. How do we plan for the future to ensure that we minimise costs? There is a feeling among many of us on the committee that, if we get this right, children might have help earlier, particularly at four, that would in the long term not only benefit the children but have a cost benefit.

Professor Donald Peebles: We absolutely recognise that ambition. Closer to my area of expertise, I find it frustrating that we know that a mum who develops gestational diabetes during pregnancy, and then gets better afterwards, has a massively increased risk of then developing diabetes further down the line. There is a real opportunity to do exactly what you are talking about with babies and get in early to prevent problems. We do not have a smooth mechanism for joining that up and I think we recognise that.

We would love to see integrated care systems. One of the reasons why they were set up was to enable a much better connected population approach, where you can realise the benefits that you are talking about, of early intervention and changing the life trajectory of healthcare needs thereafter. There is huge opportunity. I am sorry to sound so vague, but we talk about this opportunity a lot and how we are going to realise it.

Kate Brintworth: We are talking about the linkage of maternity and neonatal datasets. That is something we are trying to explore, because we recognise exactly what you are saying. It is the need to flag various issues across a range of areas. I can understand why the committee is exercised about it.

Baroness Wyld: Very briefly on that point, I do not really understand—forgive me—why it has to be your area of expertise in order for you to comment on why it looks like a pretty fundamental failing and a drop-off from 74.4% at two years' check to 6.7% at four years' check. You have made the point that some people think that if you are "normally" developing at two, there will be no change by four. Forgive me, but it just feels to me that you are not looking at these babies in terms of their whole trajectory, but are thinking of them in isolation, and that is a problem.

Professor Donald Peebles: What we have just discussed is how we see the link of maternity and neonatal, out into primary care, as a really important pathway that does not work at the moment. In terms of discussing the benefits of a two-year assessment and a four-year assessment, that really is not our area of expertise.

Baroness Wyld: But do you accept that it looks like a potential systemic failure?

Kate Brintworth: It looks like there is something happening; or not happening—to understate the case. For us to speculate without the expertise about what has happened, and why, would end up leading you down a garden path that is not helpful. That is why we need to get our paediatric colleagues who are responsible for this to respond to you.

When a woman has a baby, we write to a GP with a raft of information about what has happened in the pregnancy, both from the maternal and the baby's perspective, about any continuing health needs. We have recently funded and put guidance in place around the six to eight-week check so that there is that moment to pause and say, "Where are we up to? What needs to happen next?" It should include triggers for the longer-term care that you have referenced.

The Chair: With all due respect, we talk a lot as clinicians about pathways of care, et cetera. You have mentioned it several times. This inquiry is about preterm births. It starts from day one of the risk of preterm birth, both primary and secondary, right up to the birth of a baby that is preterm and the consequences for the baby of that preterm birth, depending upon the gestation. Does NHS England, in its policy development, think or work in silos, or do you work together and say, "What's the problem?" As in clinical care, with multidisciplinary teams, do you evolve your policies as a team, addressing the issue that is the problem, which, in this case, is preterm birth?

Professor Donald Peebles: Absolutely, we think as a team.

The Chair: Then why are you telling me that it is not within your expertise?

Professor Donald Peebles: Because there is a critical member of the team not here, who would be answering your questions—the national clinical director. Last year, we created a new post in England, the National Clinical Director for Neonatology, in recognition of all these challenges and to reflect what happens on the shop floor, which is midwives, obstetricians and neonatologists working together every day of the week. When I am in a hospital not a day goes by when I am not visiting the neonatal unit. We work absolutely as a team. I am sorry, but your questions have just exposed the fact that there is a vacant seat on my left. I am sorry about that. In terms of teamwork, it is what we do.

Lord Winston: We put out a call for evidence on this subject some time ago.

Kate Brintworth: I am sorry, we were not made aware of the questions until a few days ago. My apologies.

The Chair: Are there any other questions from the committee members? I know it has been a bit tough for our witnesses. We have been rather strong in our evidence session, but that is only to help us get the best evidence possible. There is nothing personal about it. We are enormously thankful to both of you for coming today to help us with this inquiry.

Obviously, in our report we will do what we can in promoting what might be best practice and we hope that will help you. Anything else you might wish to submit will be gratefully received and taken into evidence. I thank you enormously, and I am sorry that the session has been a bit challenging for you. It was only to get the best evidence, which we have done. Thank you.