HOUSE OF LORDS

Preterm Birth Committee

Corrected oral evidence: Preterm Birth

Monday 26 February 2024

4.10 pm

Watch the meeting

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

Evidence Session No. 6 Heard in Public Questions 68 - 75

Witnesses

I: Dr Sarah Bates, Consultant Paediatrician and Neonatologist, Great Western Hospitals NHS Trust; Professor David Edwards, Professor of Paediatrics and Neonatal Medicine, King's College London; Professor Chris Gale, Professor of Neonatal Medicine, Imperial College London.

Examination of witnesses

Dr Sarah Bates, Professor David Edwards, Professor Chris Gale.

Q68 **The Chair:** Good afternoon. Welcome to all three of you and thank you for coming today. You come with a big reputation, to help us with the inquiry on issues related to preterm babies, how their outcomes could be improved and what needs to be done to help their outcomes improve. Please help us with that.

Before we start, could we get you on record, with Dr Bates first and then Professor Edwards and Professor Gale? Can you please say who you are?

Dr Sarah Bates: I am a neonatologist in Swindon in Wiltshire. I also hold regional roles as the operational lead for PERIPrem in the south-west of England, as the advisory lead for PERIPrem Cymru for the Welsh Government, and as the national quality lead for perinatal medicine for the UK for the British Association of Perinatal Medicine. Thank you so much for inviting me to speak today.

The Chair: I gather that you may have to leave a little early. Please feel free to do so whenever you wish. I hope you can stay for as long as you

need.

Professor David Edwards: I am a professor of paediatrics and neonatal medicine at King's College London and a neonatologist at St Thomas' across the river. I have been looking after preterm babies and researching into the problems of preterm babies for 40 years.

Professor Chris Gale: I am a professor of neonatal medicine at Imperial College and a consultant neonatologist at Chelsea and Westminster Hospital, just down the road in the other direction. I am president elect of the Neonatal Society.

The Chair: Thank you very much.

Q69 **Lord Hampton:** Having three experts here, as a lay person can I simply ask what complications can arise for babies born preterm? How can neonatal care reduce their impact?

Dr Sarah Bates: Preterm babies, sadly, are at a much higher risk of dying and experiencing brain injury than babies born at term. The newborn mortality rate in England is rising and does not compare favourably with those of some of our western European colleagues. Over two-thirds of the infant mortality rate is related to prematurity. Similarly, through the first decade of life, the impact is enormous in terms of death and brain injury. That is why we really need to take action to address some of the concerns. I defer to my two colleagues to see whether they have anything they would like to add.

Professor David Edwards: It is absolutely right to start with death and brain injury as the two major problems, but the problems go way beyond that. It is worth remembering that the problem of being a premature baby is not just that you have lost your mother; you have also lost your placenta, which is a huge endocrine organ and controls an awful lot of development and growth.

The rates of other problems are very large. Cerebral palsy is 6% across the board. Psychiatric problems are doubled. Cardiovascular problems and high blood pressure are probably doubled. Gastrointestinal problems have a 10% increase. There is a 10% increase in diabetes. There is a significant increase in asthma and, very worryingly, an increase in chronic obstructive airways disease. I think the increase in high blood pressure and chronic obstructive airways disease in adolescence, which is very clear, augurs very badly for the future. It implies that premature ageing is a possibility. Certainly, there is some evidence that premature babies age prematurely, as well as being born prematurely. There is a very wide spectrum of problems. In fact, across the board it is quite difficult to find things that are not increased in preterm babies.

The Chair: Professor Gale, in answering you might put some numbers on it, if you can, and stratify according to the gestational age. That would help the record.

Professor Chris Gale: Absolutely. I will reiterate and add some data to colour the points that have been made by my colleagues. Death is clearly the most important headline: 41% of all child deaths occur in the neonatal period. Of all the deaths in children below the age of 10, 46% are attributable to preterm birth. Brain injury is a major problem. Preterm brain injuries are the most common cause of perinatal brain injuries. They affect about 1,000 babies annually in the UK. They are associated with a far higher risk of cerebral palsy. There is a nine times increased risk of cerebral palsy, for example, following intraventricular bleeds in the brain.

As David says, preterm birth casts a very long shadow, and it is not limited to those factors. Behavioural disorders such as autistic spectrum disorders are increased four times following extremely preterm birth. ADHD—attention deficit hyperactivity disorder—in childhood is increased two to three times following extremely preterm birth. Retinopathy of prematurity, which is blindness caused by prematurity, is the most common cause of childhood blindness. As David said, up to half of extremely preterm children will be discharged requiring home oxygen at the point that they go home from the neonatal unit, as well as a far higher number being affected across later childhood and, we increasingly recognise, into adult life.

There was a second aspect to your question, which is: how can neonatal care reduce those factors? We have focused very much on the problems rather than how we can ameliorate them through good-quality neonatal care. It is important to recognise that the treatments that we have often affect multiple outcomes. I heard the end of the last session, where we were talking about delayed cord clamping, for example. We know that that reduces death, but it also reduces intraventricular haemorrhage and other adverse outcomes. Antenatal steroids, which we discussed previously and I am sure we will pick up on today, are very effective at reducing death and respiratory disorders in preterm babies, as well as intraventricular haemorrhage and other brain injury.

The effects are quite significant. Antenatal steroids reduce perinatal death by about 15%, and there are other, simpler factors such as babies being born in the right place, in centres with tertiary neonatal care. This is for the most extremely preterm babies. That reduces death by about 5%. We see this across all the interventions that are evidence-based in terms of reducing adverse outcomes following preterm birth: they affect multiple conditions, reducing death, brain injury, lung disorders and a whole range of other adverse outcomes.

I will let other people talk so I will stop.

The Chair: Take your time and carry on.

Professor Chris Gale: You talked about the severity and gradient of preterm birth. It is worth recognising, as I think you were alluding to, that the more extremely preterm you are—the earlier you are—the higher the risk. It is a very clear relationship, with the highest risk for almost all

of these conditions, ranging from death through to later life effects, being seen in the most preterm babies, those born at 23, 24, 25 and 26 gestational weeks of birth.

Professor David Edwards: If the committee would like figures, a very good publication has just come out from Scandinavia that defines the risks and outcomes in about a million births. It gives very precise figures. That is what I was quoting, but, if you wish, I can certainly send it to the committee.

The Chair: It would be a great help if you would not mind sending it. We will circulate it for the committee members.

Lord Hampton: Dr Bates, could you say something on the treatment?

Dr Sarah Bates: Professor Gale has outlined some of the core interventions that we know completely alter the long-term trajectory of babies born early. When you put those together in an optimisation care pathway—place of birth, well-timed antenatal steroids, magnesium to reduce the risk of cerebral palsy, delayed cord clamping, keeping a baby warm and offering them early maternal breast milk, with some other interventions after that—that is a really powerful way of not just altering survival significantly but, as Professor Gale and Professor Edwards mentioned, altering the long-term trajectory. That is a very cost-saving endeavour for a country. Neonatal illness is by far the leading cause of life years burdened by disability. If we can put in those often very simple and low-cost interventions at the time of a preterm birth, we will make an enormous difference.

Lord Hampton: Things such as cord clamping seem to have such an effect, but it is not done everywhere. Having aspirin seems so obvious to the lay person. How do you get such things to be done universally?

Dr Sarah Bates: That is a very important question. It is something that BAPM has been focusing on, along with other organisations, including NHS England. You are absolutely correct that that very simple intervention, which has the potential to reduce mortality by a third, is not reliably delivered. We still have around a third of babies nationally being born preterm who do not get that intervention. It is, essentially, free, but we have huge interregional variability.

In the most recent National Neonatal Audit Programme data from 2022, in one region of London the rates are 42% and in the south-west 76% of babies receive that intervention. You asked how we make it universal. That needs investment to close the lost-in-translation gap and to ensure quality improvement at every unit level, and to make sure that every baby receives that intervention and the rest of the interventions in the care pathway every single time.

The Chair: Professor Edwards, did you want to come in?

Professor David Edwards: I think most of it has been said. The point is that changing practice is not simple. It is not an easy thing to do. You

cannot just do some research, write a paper and expect things to change. It needs sustained effort.

If you look at the national neonatal database, it is quite clear that well-evidenced procedures that have been around for a long time are quite well adhered to and quite well established across the country. New things are where the variation is, and cord clamping is, surprisingly, relatively new. I think that tells you that it takes time to implement these things in different places. A sustained effort is needed. The will is there. It just takes time and effort and, to some extent, resources.

Professor Chris Gale: I agree with everything that has been said. An additional point is that understanding what works best in improving implementation in regions and nationally is an important area of research in its own right. The concept of implementation science, learning how best to ensure that findings are translated from research into practice, requires focus, research and all the same kinds of support—funding, infrastructure, as well as people—as discovery science and randomised trials and effectiveness research. That is absolutely critical. We need to improve how we deliver those interventions. We also need to be very careful at measuring the work that we do to try to improve delivery, whether it works and it is effective, and then to carry it out and spread it more widely if it is, but not to focus on it if it is not. There has been underinvestment in testing to understand which approaches to implementation really work and which do not work.

The Chair: That is a good point. Thank you for that. You have concentrated on things that are not done universally in obstetric practice. In the next question we will come on to neonatal practices, where, presumably, there are things not done either. You have just built yourself a good research project on implementation science, both on the obstetric side and possibly on the neonatal side, in delivering better outcomes for the babies. You might expand on that when we come to the question that relates to research.

Q70 **Baroness Seccombe:** What challenges these parents must face. I hope that they know about all this, and that there is counselling and help provided to them. What guidance is currently available for neonatal care, and is it sufficient to achieve the best outcomes for preterm babies?

Professor David Edwards: There is a lot of guidance. There are something like 18 national documents that it is obligatory for units to follow, and something like another 32 that are produced by learned bodies such as the British Association of Perinatal Medicine and the Royal College of Paediatrics and Child Health. There is a lot of information out there.

It is put together by expert groups. In general, it is very good. It is done by committed and careful people who work hard at putting these things together. When guidelines come from that kind of evidence base, they are well respected, and people try to follow them. There is quite a lot of information on how you should do things. We are no longer in the heroic

phase of neonatology that I started in when I was young, when you did what you could and did your best. It is now much more codified. Where there is an evidence gap, it is less easy to write guidelines and the guidelines are not so well respected, but where there is evidence I think the guidelines are well respected across the country.

The Chair: Are the guidelines universally followed?

Professor Chris Gale: The answer, unfortunately, is no. I think that relates to the delayed cord clamping, which I would argue is a joint intervention.

The Chair: Okay but let us go to other things—for instance, surfactant.

Professor Chris Gale: Surfactant administration is an area where we do not have national data in the same way that we do for many of the items in the National Neonatal Audit Programme. I cannot give you data on the proportion of babies that receive surfactant nationally in the same way as I can tell you the rates of delayed cord clamping or birth in a tertiary centre.

The Chair: By the way, for the rest of the committee, surfactant is a treatment. Professor Gale might tell us the details. What is it, how is it administered and what does it do?

Professor Chris Gale: It is a treatment. I think it is relatively unique in neonatology, being a medication, a therapy, that was developed specifically for preterm babies, rather than being developed for another group and then translated into preterm. It is a fantastic example of research from fundamental science right the way through to translation into a treatment that is widely used and has changed the lives of thousands of babies. It is a fantastic example in both those fields.

It helps with lung development. I think that is what you are moving to ask me. It is a protein that is deficient. It is not produced in very preterm babies, and it can be replaced by putting a tube into the top of the baby's lungs and squirting it into the baby's lungs, helping to support the baby to breathe while it spreads around the lungs. It tends to be produced in preterm babies after a couple of days, so you are supporting them through that initial period.

Patrick Bouvier Kennedy—one of John F Kennedy's children—died of surfactant deficient lung disease, even though he was born relatively mature. I think he was 34 gestational weeks. That very much triggered a great interest in the condition and research into preterm birth, certainly in the US. That was many decades ago.

The Chair: So it is a good treatment.

Professor Chris Gale: It is a good treatment.

The Chair: Is it used in every neonatal unit, or is it the same problem as cord clamping?

Professor Chris Gale: It is used in every neonatal unit. The guidelines about exactly which babies should receive it are less clear because there has been a great deal of development in how it is delivered. We are much better at giving it less invasively, with lower side-effects, in more targeted groups of babies who will benefit. We have also got much better at supporting babies from a respiratory point of view without surfactant. We are able to avoid putting babies on a ventilator, or to give them surfactant without putting them on a ventilator, whereas previously we would generally have to put babies who received surfactant on a ventilator.

The landscape has changed slightly, and the group of babies we have identified as those who would benefit the most has changed over time. There remain important uncertainties. There is currently a trial for moderate to late preterm babies to determine which of those babies will benefit most from surfactant. There remain uncertainties in that particular area, and the guidance is less clear-cut compared with something like delayed cord clamping, which we know babies should receive in every situation where it is possible, although I think there are still uncertainties in relation to delayed cord clamping. For example, if babies need active resuscitation at birth, it is quite difficult to provide that and delayed cord clamping. There needs to be additional research to see whether those babies would benefit from them both being delivered together or not. Even within something as relatively straightforward, from the sound of it, as delayed cord clamping, there remain uncertainties.

The Chair: To go back to Baroness Seccombe's question about neonatal care and what will improve the outcomes, do any of you have anything else to add?

Dr Sarah Bates: I think we have lots of guidance. I strongly support Professor Gale's comment that we are very much moving away from viewing these interventions as obstetric or neonatal. We should be one perinatal team around the mother and the baby, taking shared responsibility for delivery of all those core interventions. We have those interventions in lots of guidance nationally. Version 3 of the Saving Babies' Lives Care Bundle was published in July last year. The guidelines, as Professor Edwards said, are good, but we need to support implementation in all centres, of all sizes, all round the country to make a real difference.

If you look, for example, at a neonatal intervention, maternal breast milk, although I would argue that it remains perinatal, that is a bespoke and specialised medicine that changes the trajectory for babies for a really long time—

The Chair: Dr Bates, hold on for one minute because we are drifting into the next question. At this point it would be helpful to combine the questions and for all three of you to answer. I will let Baroness Hughes in now, and then all three of you can respond to both questions. I note that Lord Winston wants to ask a question, and I will come to him.

Q71 **Baroness Hughes of Stretford:** Thank you, Chair, and thank you all for coming today. We have strayed into the territory of a line of inquiry that I want to open up—not only today; I did so previously with other witnesses—and you have all mentioned it. It is about the consistency of guidelines, implementation, good practice, recommended treatments and all the issues around that in terms of timing, place of delivery and so on—everything we might know and recommend—actually being implemented. Every intervention at every opportunity every single time—I think you said something like that, Dr Bates. The starting point is that you have all said that there is inconsistency. It would probably be astonishing if there was not.

How can we improve the consistency with which everything we know and would be issuing guidance on is applied at every opportunity, where it ought to be? Professor Gale, I think you said that that was a science in itself that needs a lot of thought about how to achieve it. Do you have any pointers for us to things that might be done to improve that consistency right across the piece? Dr Bates, you are nodding.

The Chair: I think, Dr Bates, you started mentioning your PERIPrem care bundle.

Dr Sarah Bates: The care bundle—the concept of these interventions as a care pathway—is recognised nationally. There are many teams around the country working on trying to implement it. We can see that areas that have had an enhanced support model, with real focus at unit level for midwives and nurses, with project management support and data support, have had an accelerated rate of consistent implementation.

If you look across the country at who gets this care bundle—again, I refer to National Neonatal Audit Programme data—only 15% of our preterm babies in England and Wales are getting all the interventions that they should. This is a very small core group of interventions: place of birth, steroids, magnesium, cord clamping and breast milk. Only 15% of babies are getting that. There are some areas of the country where that is only 10%, and other areas, notably the south-west and Wales, where it is 25%. There is still work to do in those areas, but those areas are showing a greater rate of implementation and change.

Baroness Hughes of Stretford: What is the factor that increases the level of consistency in the places where it is higher?

Professor David Edwards: Dr Bates knows far more about this than I do—

Dr Sarah Bates: I think it is additional investment.

Professor David Edwards: —so if you do not mind, I will pass it on to her.

Baroness Hughes of Stretford: Dr Bates, you are being invited to respond.

Dr Sarah Bates: I am so sorry. It is hard not to interrupt. I think it is additional investment at unit level. That has come with some small financial investment, which I am sure we will come on to in the next question, and has ensured that at every unit there is a preterm birth lead team with responsibility for focusing on and implementing the interventions with every baby, every time. Those preterm birth lead teams are then co-ordinated at regional level with programme management and support to look at real-time data to drive the improvement process constantly. I think that is what has made a real difference.

Professor Chris Gale: The reason we know about this variation across the country, and the reason we are able to do the work that Sarah is talking about, and are able to evaluate how effective we are at delivering all these interventions—which we know are beneficial and where we know there are differences in the relatively low proportion of babies that receive all of them—is that we have very robust national data describing neonatal processes and outcomes. That is relatively unique in the developed world. If we were having this conversation in the US, for example, there would be no such data at national level that would enable us to evaluate that, or in other similar high-income countries in Europe such as France or Germany.

We are very lucky to have that data to inform all this work and help us to evaluate it, but it needs to continue. We need to continue to create high-quality data to describe the care that babies are receiving and, of course, the outcomes of that care, in particular the longer-term outcomes that we started this session talking about—outcomes through into childhood and later life. Linking all that together is absolutely critical to understand where the benefit is and how the treatments and processes that we put in place to try to improve uptake really work and improve outcomes for babies and their families.

Lord Winston: The first multicentre trial on surfactant, to come back to that for a second, was in 1986 in the *New England Journal of Medicine*. That is almost 40 years ago. Why has it taken so long to decide when and how we use it?

Professor David Edwards: That is not quite what happened. As you know, that trial was a very small number of very mature babies. It became fairly clear within a few years that those mature babies would benefit from surfactant.

What has happened since then is a combination of things. First, the population at risk has become very different. Instead of infants being born at 34 weeks, 33 weeks or 28 weeks, they are now born at 22 weeks or 23 weeks. It is a very different population. There are very few of those babies in the trials. We know very little—in fact, we know nothing—about how to look after 22-weekers. There are no 22-weekers in those trials.

The second thing is that the way of administering surfactant has become advanced, in the sense that we can do it less invasively now. It has

become clear that any kind of respiratory support is bad for the lungs. It is much better if the babies can breathe by themselves. We do as little as we possibly can now, including giving as little surfactant as we can. It is still life-saving, but if you can get away without it, you reduce the long-term problems. It is a different population, and there are advances in development and a better understanding of the biology, but your point is a very good one.

Baroness Watkins of Tavistock: Do you think there is sufficient protected time for continual professional development for staff so that they can keep on top of these new pieces of knowledge and implement them?

Professor David Edwards: You have put your finger on a crucial problem. That is not only a concept that needs to be understood, but the staffing levels need to be thought about to allow it. You have put your finger on an absolutely crucial problem.

The Chair: Thank you; that is a good point. Could I be more challenging to you? You have given us data that is horrible, terrible, about the number of babies who get several vascular problems that subsequently lead to long-term problems. You also talked about the number of children, preterm babies, who end up being blind. Presumably, that is related to oxygen levels. What can you do in the neonatal period to reduce both those conditions?

Professor David Edwards: That is a very challenging question. The brain injury problems are multifactorial. One thing I would like to say is that they begin before birth. I do not think we should be separating the individual just by the birth period. It is very clear that many of the problems that we are dealing with begin before the children are born. I think that was a point that your previous witnesses brought out. We need to think about the continuum of life, not just after birth.

The second thing is that it is not just a question of oxygen—ischemia—and damage. The whole problem about prematurity is maldevelopment—wrong development. The factors that cause maldevelopment of the brain and other organs are poorly understood. We know quite a lot about how cells die if they are starved of oxygen. Most of these babies do not have that problem. They have a problem where the brain is not growing or developing properly. The same is true of the lungs. The potential worry that many of us have about long-term lung disease in these children as they become elderly adults is the same problem. It is a development problem. It is not as simple as a shortage of oxygen. It is a more complicated piece of biology that we do not understand very well.

Professor Chris Gale: To add to that very eloquently made point, if we take a wider view, the majority of preterm babies do very well. We are focusing on the very adverse outcomes, and those absolutely cast a long shadow, especially for the most preterm babies. Preterm birth becomes less common the lower down the gestation you go, fortunately. The majority of babies looked after on neonatal units up and down the

country are relatively more mature and have excellent outcomes. Those outcomes have improved dramatically over the last decades as neonatal care has established itself as a specialty.

You talked specifically about oxygen and blindness. Clearly, excess levels of oxygen have been linked with the development of retinopathy and prematurity. It is an important example of how oxygen, as a drug and a therapy, was widely introduced in the 1950s as a treatment in neonatal care. It was never fully evaluated in a randomised trial at the time of introduction. It led to a huge increase in, initially, blindness and then, as the oxygen was removed, an increase in death and neurodevelopmental problems such as cerebral palsy. It has been in only the last 10 or 15 years that we have undertaken the trials that should have been undertaken in the 1950s—the really large definitive randomised trials, the effectiveness research—to demonstrate the optimal targeting of how much oxygen we should be giving to these babies. They were led in the UK and internationally as part of collaborative work to understand that and to balance the risk of death and adverse neurodevelopmental outcomes and gut conditions such as necrotising enterocolitis with preventing blindness and retinopathy of prematurity.

This is an example of the value of effectiveness research. We have implementation science to evaluate how to do things better and effectiveness research to understand how things work in clinical practice. At the other end of the spectrum, you have discovery science to bring new treatments through into clinical practice and to be evaluated in trials. We need to focus on all three areas if we are to try to solve things and improve outcomes for preterm babies.

The Chair: Thank you very much. It is good to have that information from you. We will now move on to an extremely important area of the questions that we would like information about. Last week, we heard harrowing stories from parents of preterm babies, and their experiences. They made several points to us. Our next two questions focus on that.

Q72 **Baroness Cumberlege:** Thank you very much for coming today. I have just been reading about Professor Edwards. One of the things that interested me in the information we have been given is about very preterm infants. I think we are talking about the most vulnerable infants, fragile, et cetera. It talks about an MRI scanner, which I understand, in the neonatal intensive care unit is "to allow the sickest and most vulnerable infants to be engaged in research programmes". Do we know absolutely that the involvement we have—the disruption that we cause—does not do any harm to these very preterm infants?

Professor David Edwards: You mean by involving them in research?

Baroness Cumberlege: Yes.

Professor David Edwards: That is a very good question. The honest answer is that it is very difficult to show because you are not doing a trial of doing research. There is no large trial of doing research.

What it is possible to say, however, is that it is very clear from multiple studies that units and hospitals involved in research have better outcomes than those that are not. That is true not just in neonatology but across the medical spectrum. The chance of doing harm, if research is carried out properly, ethically and correctly with due care and attention, is very unlikely. Although there is no large randomised controlled trial that says that research does no harm, there are plenty of observational studies that show that children, adults and babies who are involved in research do better.

Professor Chris Gale: I reiterate that. In neonatal care, in particular, there is very compelling observational evidence that babies enrolled in large trials tend to have better outcomes than similar babies who are not enrolled in trials. It is unclear why that is. It may be to do with the additional focus of being in a research study, or the fact that some treatments are beneficial for babies. I think the evidence is the other way from the concern that you have expressed. The evidence suggests that it is actually beneficial for babies to be in trials.

Baroness Cumberlege: Thank you very much. It is so good to have experts here giving us information. It is much appreciated.

The Chair: Professor Gale or Dr Bates, do you have any comments? Does the PERIPrem bundle include any guidance regarding this?

Dr Sarah Bates: The PERIPrem bundle was introduced in the south-west of England in 2020. As you know, we have a population of around 5 million. We invested £250,000 in the implementation of those simple perinatal interventions. Through that, we have seen a significant reduction in mortality and brain injury. During the same period, as I said, the mortality across the UK has either remained static or risen. Brain injury rates have stayed static. This has led to the south-west being one of the only regions where newborn mortality is falling. We now have the lowest rates of one of the severe forms of brain injury, periventricular leukomalacia. That was not just about those interventions. It was the investment in the preterm birth lead team in every single unit and the support for quality improvement.

As Professor Gale referred to, that methodology needed to be validated, and has been validated, in both an evaluation of the programme itself and by comparing it with lots of other different improvement programmes in England over the time. I think that has made a big difference. I would be delighted to take any other questions that you have about PERIPrem.

The Chair: Professor Gale, do you have any further comments about that bundle?

Professor Chris Gale: No. Sarah has covered PERIPrem very well.

Q73 **The Chair:** I will move on to what I said about the evidence that we heard from parents of preterm births. The key thing was about the importance of integrated care that involved families. We would like it on

record, first, for one of you to define what integrated care is, and its importance in improving outcomes for preterm babies. What would the appropriate services that are integrated and involve the families look like? Where are they available now, including the wider issue of the contribution to integrated care of other health professionals, such as specialist nurses and clinical psychologists?

Professor David Edwards: There are different definitions of family integrated care across the world. It is worth saying that, since the very dawn of neonatology, it has been the aspiration of neonatologists and neonatal nurses to integrate families into the care of the baby. It is not a new concept. What I think is new is the emphasis put on it, on two things in particular: shared decision-making, which of course is a complex and difficult issue that needs careful discussion; and shared access and resources, which means making it easy for parents to be with their child.

In our country we do not tend to have units with separate rooms where the mother can live with the baby. They are relatively common in the United States. Those approaches have complications. In the UK we still tend to do it on the open unit-type model, but we try very hard to give the parents permanent access to their child, permanent engagement with their child and shared decision-making in what goes on, where that is rational, and in particular to engage them in the care of the baby. The obvious examples of that are providing breast milk, kangaroo care and being with the baby as the baby grows up. It is not a new idea. It is a very old idea, but it has come to prominence for the reasons that you mentioned.

The Chair: Does it help to improve outcomes?

Professor David Edwards: That is difficult to tell. There are certainly studies that say that it does, and there are certainly studies that say that it reduces the time spent by a baby in intensive care. I think that is very rational and likely to be the case. The more confident the mother is with her baby, the easier it is for her to go home. There are other ways of dealing with that. Many units have homecare teams, where nurses go back home with the babies. That also works very well.

It is difficult to be certain. It is one of those things that, as Professor Gale would say very clearly, needs careful implementation and research. I think that is absolutely right. It is clearly the way forward. I am slightly worried about it in some ways. If it were to be applied in a rather thoughtless way, it has problems. It is well known that lack of resources at home, poverty and difficult lives for mothers make it difficult for them to come to the neonatal unit to look after their baby. You can imagine that if a large amount of resource was spent on family integrated care in a careless way, all it would do would be to increase the disparities in health between the poor and the rich. The rich mothers would be able to come, but the poor would be at home or having to go to work.

The Chair: Are mothers from poorer backgrounds helped now?

Professor David Edwards: We try to. It is not always easy. Sometimes they have to go to work because they have no money. Sometimes they have other children they have to look after. It is difficult. If you were to come to a neonatal unit, you would see an awful lot of emphasis put by the staff—the doctors, nurses and psychologists—on helping mothers to be there with their baby as much as they possibly can. Family integrated care is quite a difficult thing to do in a way that is sensitive, rational and reasonable, but it is an aspiration that has been there since the dawn of the speciality.

The Chair: Should it be an aspiration?

Professor David Edwards: Yes, it should.

Professor Chris Gale: I do not have an enormous amount to add. Professor Edwards has covered it very nicely. Trials have evaluated it and have demonstrated tangible benefits in relation to breastfeeding, bonding and the mental health of parents, as well as timeliness of discharge. In certain models, largely in other countries, there is evidence that it is beneficial. I reiterate that it is variable; it is very driven by local circumstances and environment. It is challenging. There are groups in society, for example, families with other children and deprivation in particular, where it is much harder for families to engage in family integrated care. The key point is that, if we want to deliver it equitably, we need to provide support for families so that they can really undertake it, particularly for the most deprived groups in society.

The Chair: I will let Baroness Wyld come in to champion the cause of support in a minute, but would you like to comment first, Dr Bates?

Dr Sarah Bates: No. I think Professor Gale and Professor Edwards have answered that really well. I do not have any more to add.

The Chair: How important is the role of clinical psychologists, both for helping the team in neonatology and for integrated care?

Professor Chris Gale: There is a huge team involved in neonatal care. It is not just neonatologists, neonatal nurses and clinical psychologists. There is a range of allied health professionals, such as breastfeeding support workers, as well as charity through third sector organisations such as Bliss. There is a huge range of people supporting families in providing the best care for their babies. Staffing is a huge problem in neonatal care.

The Chair: Can you enlarge on that? What kind of staffing? Which discipline are you talking about, and do you have any numbers?

Professor Chris Gale: Nursing makes up the biggest proportion of neonatal staffing. There is good evidence. We look at nursing staffing every year as part of the neonatal audit programme. We know that currently about 70% of nursing shifts have the required or recommended number of nurses, and about 30% have lower than the recommended number of nurses. That is particularly problematic in some regions. In

north-west London, where I work, about 58% of shifts have the recommended proportion of nurses. It is an additional problem in tertiary units, where we look after more babies and require more nurses. The babies require more intensive care.

We talked about special activities in terms of consultant numbers. There is recognition with regard to the clinical academic workforce, which has also been the subject of review within House of Lords, that there is a shortage of clinicians to focus on research as well. It cuts across. We also have challenges across the allied health specialities, which were recognised as part of the *Getting It Right First Time* report that Dr Adams discussed when we were here previously. That is being rectified. There is an increase in allied health professional support. Physiotherapists, occupational therapists, speech and language therapists and dieticians are all required as part of a comprehensive multidisciplinary team to look after these babies.

Q74 **Baroness Wyld:** Last week, we heard a lot of examples of disconnected care, as you know. There were some very basic things about mothers saying, "I wasn't able to eat because I was caught between the maternity ward and the neonatal ward". Do you think those are structural issues or cultural issues within hospitals? Presumably, it is not like that everywhere. To make the mother's experience better, and presumably the outcome for the baby better, what are the barriers that we should look to get rid of? Dr Bates, you are nodding, so I might be vaguely on the right track.

Dr Sarah Bates: I think you are absolutely right; there are some structural problems in providing parents the required amount of support. I think you are also correct that it is disparate across the country. I refer back to Professor Gale's comment about Bliss. Bliss is doing a huge amount of work to ensure that it is equitable and that there are some clear standards for units to meet for the parents' requirements. Bliss's work in that area is fantastic, and that is probably the best route to address some of the issues that you very eloquently raised.

Baroness Wyld: Thank you. We took evidence from Bliss, as you know. Do you want to come in, Professor Gale?

Professor Chris Gale: Some of the work about recognising parental leave, with the additional requirements that come with having a preterm baby, is really important. I think there is an element involving resources to ensure that families are able to make the financial sacrifices that are required to have a baby on a neonatal unit.

We have what is called a networked model of care in the UK for neonatal care, whereby within a particular network or a region—networks can be large; for example Scotland is one network—the idea is that babies will ideally receive care close to where the family lives, but if more intensive care is provided it will be done at regional centres. A lot of the most premature babies will, by their very nature, receive care quite a long way from where the family lives. There are enormous travel times, with other

children affected. Of course, you also have to take into account the need for parents to work. These babies will be on the neonatal unit for weeks or months. The most preterm babies may be in hospital for three, six, nine months or longer, at a tertiary centre a long way from home. There is a requirement to support families with the tangible financial aspects of that.

Baroness Wyld: I sponsored that Bill in the House of Lords. I think it is due to come in next April. You have to know that the benefits are there. You have to be equipped to go and ask for them. How much awareness do you think there will be among the workforce? Is there anything else that the Department of Health should do to raise awareness in the workforce, so that they can equip the parents?

Professor Chris Gale: This comes back to a point I made earlier about implementation science. How do we get the information out there so that it applies to research findings and is taken up in the clinical context, as well as publicising it and ensuring that families make the most of the benefit that is there? I am sure there are people much more practised than I am in how you get that message out to the people who need it the most. Again, we should evaluate it and measure it. We should take a scientific approach. That would be my aspiration.

Baroness Wyld: Thank you very much.

The Chair: Professor Edwards, do you have any comments on Baroness Wyld's question?

Professor David Edwards: Only to add very briefly that the team extends beyond the neonatal unit. The obstetricians are crucial in all this. Once the children go home, that is equally important. The team extends beyond the neonatal unit.

Baroness Wyld: Apologies for not bringing you in. I was too aware of the clock.

The Chair: Another point made to us was about the importance of long-term follow-up of babies born preterm. How effectively is that done? What is the value of it? Who should do it?

Professor David Edwards: It is crucial. It is absolutely fundamental to doing the job properly. Again, it is something that has been going on in neonatology since the beginning of the speciality, but it is very difficult to do properly. It is very difficult to get the children to come back. It is well known that the children who have the most problems tend not to come back to follow-up. It is expensive. It is complicated. Currently, it tends to focus on a few small areas.

What needs to happen is a much more expansive view of what is needed to become apparent. Educationalists are hardly involved in the follow-up at the moment. It is at school where these things are really starting to happen. We need to rethink the follow-up programme and have a much more catholic view of how it should be put together.

Professor Chris Gale: I completely agree with everything that has been said. Of course, there are equity issues around follow-up. We need to focus in the same way that we focus on delivery of interventions in ensuring that follow-up is undertaken robustly and equally across the board.

I would also make the case that, in order for us to understand the long-term effects and the long-term benefits of the treatments that we are putting in place, we need to think about neonatal research from the angle of later life impacts. That requires funding studies for much longer and into adult life, for example.

The Chair: Are there no cohort studies done for follow-up?

Professor Chris Gale: There are cohort studies. There have been a lot of very effective cohort studies that have looked at and documented the impact of preterm birth. That is where a lot of the information comes from. What we want to do, moving beyond that, is to understand the long-term benefits of the treatments that we are developing. That involves doing, for example, randomised trials where we do not follow up babies at just two years, but into childhood to understand how that treatment, how that drug that we have developed and that we are giving to those babies in the neonatal period, affects them across all aspects of their learning, behaviour and development, across all the components of care into later life.

Baroness Watkins of Tavistock: I am particularly interested in the education pathway for children born very preterm. It occurs to everybody now, I think, that investment of the public pound early might actually have very good beneficial results for the long-term costs of some children in particular. How many years would you want to follow up—until they were 18, or even longer?

Professor Chris Gale: In an ideal world we would want to know what happens right the way across into adult life. Increasingly, we are able to link to education. Of course, education is funded to do exactly this and to determine how children do across multiple domains of development. That, to me, is the priority. As David says, it is linking more closely with education and educationalists. We need to think more about how we can improve outcomes, not just in the neonatal units but after the children have gone home and when they are at school, by targeting interventions on children born preterm at later stages, and robustly evaluating those to see if they work.

Q75 **The Chair:** The last, short question is this. You keep making the point about further research being done. You also made a point that gave me the impression that there is a silo between the obstetric side and the neonatal side in the necessity to focus on research, the genesis of which is that the problems in neonates occur antenatally on the obstetric side. Therefore, there needs to be a better understanding of the causes and the development of the fetus and that that has implications for the neonate. There is a silo. There is one case for breaking down the silo,

particularly in research. That is one part of the question. The second part of the question is: what research can you identify in three areas that will make a difference to the outcome for preterm babies, which currently is not done, and which needs to be done?

Professor Chris Gale: That is a key point. I will take your second question first on the three areas of research. They need to be broad. We need to recognise that neonatal care is a broad condition. Preterm birth is a broad condition. It affects babies in multiple ways.

As I said before, we need to think about discovery science and bringing new treatments through. We need to think about the effectiveness of research and testing those treatments in the NHS to make sure that they improve outcomes. Then there is implementation science to make sure that they are delivered effectively and equitably across the country. That is absolutely key and critical. I do not think we can say that one particular treatment or one particular sub-area is more important than the other. Most of the things that we deliver in preterm babies affect multiple parts of that baby, and affect them in multiple different ways, as we have talked about, at multiple stages.

Can you remind me of your first question?

The Chair: The silo.

Professor Chris Gale: I do not think that neonatal care is siloed away from maternity care and the care of the woman. Antenatal steroids, magnesium sulphate and delayed cord clamping are all good examples of cohesive working between maternity and neonatal services, with perinatal research following up through into later childhood. I disagree with your point that we are siloed. I think we need to work better.

The Chair: I will challenge you. Professor Edwards, you suggested that some of the causes of cerebral effects in the neonate may have a genesis in the antenatal period, but there is less understanding of it. Is that correct?

Professor David Edwards: There is less understanding of most things, but, yes, that is true.

The Chair: Are there more areas of research?

Professor David Edwards: If it was up to me, I would put a lot of emphasis on the period before birth for preterm babies. I think that is poorly understood and it could be understood a lot better. If I was going to identify one area where we could make a big difference, it would be understanding brain plasticity better. That will determine how a child responds to a brain injury. If the theories are correct, it should be malleable. It should be changeable. It should be possible to manipulate. You should be able to improve outcomes if you understood it a bit better. I would focus on brain plasticity as an important area.

If you want another area, I would study inflammation. I think inflammation is at the root of a great many of the things that we are talking about.

The Chair: Dr Bates, do you have anything further to add?

Dr Sarah Bates: As the national quality lead, my concern lies with discrepant implementation. I really think that is where we need to be focusing as a country at the moment, implementing what we know works.

The Chair: Thank you very much. That is a good point. I thank all three of you very much for coming today. It has been most helpful. I say that most sincerely. We have benefited a lot from your information, which we will use. Thank you.