HOUSE OF LORDS

Preterm Birth Committee

Corrected oral evidence: Preterm birth

Monday 11 March 2024

4 pm

Watch the meeting

Members present: Lord Patel (The Chair); Baroness Blackstone; 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. 9 Heard in Public Questions 122 - 134

Witnesses

I: Hilary Cruickshank, Clinical Specialist Neonatal Physiotherapist, NHS Lothian, and Chair, British Association for Neonatal Neurodevelopmental Follow-up; Professor Samantha Johnson, Professor of Child Development, University of Leicester; Professor Neil Marlow, Emeritus Professor of Neonatology, University College London.

Examination of witnesses

Hilary Cruickshank, Professor Samantha Johnson and Professor Neil Marlow.

Q122 **The Chair:** Thank you for coming today. We appreciate enormously your taking time out of your busy schedules to help us with our inquiry, which we consider very important to helping children who are born preterm. First, could you introduce yourselves and your positions so that we get them on record, and then we will start the questions?

Hilary Cruickshank: I am a clinical specialist neonatal physiotherapist from Edinburgh with over 20 years' experience. I am chair of the British Association for Neonatal Neurodevelopmental Follow-up, and I am the lead physiotherapist for the neonatal workforce review happening in Scotland just now.

Professor Samantha Johnson: I am a developmental psychologist and professor of child development at the University of Leicester, where I have been carrying out research into the long-term outcomes of premature birth for 20 or so years. I am a member of the executive committee of the British Association for Neonatal Neurodevelopmental

Follow-up. I was also a member of the NICE guideline committee, which produced the recommendations for the clinical guideline for the developmental follow-up of children and young people born preterm.

Professor Neil Marlow: I am emeritus professor of neonatal medicine at UCL in London. I have been studying outcomes after very preterm birth for many years now. My first study was done in the early 1990s in Bristol. Before that, I worked with Malcolm Chiswick following up a group of babies in Manchester. Over the years we have done a whole range of studies, trials and various interventions, most with the intention of having a good look at long-term outcomes. I have been president of various societies, including the British Association of Perinatal Medicine and the European Society for Paediatric Research and, for my sins, which I suspect were serious, I was chair of the neonatal intensive care national review for England that reported about five years ago.

Q123 **Lord Winston:** It is nice to meet you all, albeit in a rather formal arrangement. We have already heard some slightly disconcerting evidence from various witnesses that the obstetric follow-up of women who have given birth prematurely is not currently formalised in the way we think it might be, and that it has been somewhat erratic. Because of your expertise, can we now turn to what is rather more important in some respects: the neonate?

Professor Neil Marlow: We have known for many years that the occurrence of severely disabling conditions among babies who are born very preterm is much higher than we see in the general population. To that end, most neonatal services in the country have sought to develop some follow-up programme to identify early the babies who appear to be developing the severe disabling conditions that we are aware of. We know that those are much more frequent at very low gestations, so most of us will arrange for follow-up services to be targeted at the most immature—those under 28 weeks and those under 32 weeks. In both those groups, we have close long-term follow-ups after they go home.

There are national guidelines. My colleague was on the NICE guidelines committee, but we had already set up such guidance from within the British Association of Perinatal Medicine, and on the national database we have two-year outcomes as a fixture. The challenge with those data, however, is that they are not completed very well at the moment, and that is a source of some anxiety, because we wish them to be completed so we know what is going on.

We have carried out two large population studies—you have probably heard them referred to as EPICure studies—which we ran from 1995 to 2006. We did that because there was no centralised system for collecting data to find out how this group of babies was developing. When we started in 1995, we had no idea how well they were doing other than that we were seeing many more of them in our clinical practice. So we collected data on this group, and it was quite challenging, I have to say, because we found a high proportion of children with serious conditions

such as cerebral palsy, serious developmental delay, and hearing and vision loss.

Over time, as we have got better doing neonatal intensive care—our neonatal intensive care practice has modified significantly over the years—we have seen those rates come down a bit. They are still significant, and it is still true that at the lower end of the gestational range we see very high rates of serious impairment. If you look at the general population, the rates of neuro-impairment are increased at higher gestations, but only marginally if you look at the absolute increase in disability rather than the relative one.

Lord Winston: Can I clarify that? When you talk about higher gestations, are you talking about babies who are born much more prematurely, or the reverse?

Professor Neil Marlow: I am talking about higher gestations. At 34 to 36 weeks of gestation, where the absolute rates of impairment are higher but they start from a very low base rate, the relationship between gestational age and serious impairment is almost exponential. The NICE committee, which considered follow-up very carefully, took notice of this. As the absolute risk became a lot higher at around 28 weeks, it felt that that was the group that it should put resources into picking up and identifying. It put a rider on that saying that any baby who had neurological complications as part of their neonatal period should also be followed up alongside them.

Q124 **Lord Winston:** I am awfully sorry. We have such a short time to ask the questions that we feel we need to ask, and I do not want to interrupt you because this is important and interesting stuff, but perhaps I could ask Professor Johnson a question. Is it perhaps the case that the more premature babies do not slip through the net so much as the ones who are less immature when they are born?

Professor Samantha Johnson: The NICE guideline, for example, recommends that babies who are born at less than 30 weeks gestation should receive enhanced developmental surveillance and support—we know that the risk of developmental problems and disorders is much higher among that group than among children born at term—with a view to these problems being picked up early and the children being referred as early as possible for support.

Children who are born at less than 30 weeks of gestation have an assessment once in the first year at between three and five months, once at 12 months and once at two years of age. It is recommended that those who are born at less than 28 weeks of gestation have a developmental assessment at four years of age, which was really intended to be a preschool assessment for these children so that we could identify some of the most common difficulties that they might have, such as cognitive problems, socioemotional problems and early signs of learning difficulties, which can have a long-term impact.

Lord Winston: How well are we doing? Given that you are giving quite a broad spectrum over quite a few years, what is actually happening out there in the community?

Professor Samantha Johnson: There is quite some variation. I know that Hilary has some data and can give you some figures on that.

Hilary Cruickshank: I can. The British Association for Neonatal Neurodevelopmental Follow-up did a survey of all neonatal units in the UK in 2022. We had a response rate of 79%, which is pretty good. Some 85% of them were doing some form of neonatal follow-up until the age of two—that is good, but we do not know about its quality—but only 6.7% of them were doing the four-year assessment.

Lord Winston: Who is doing the follow-up assessments?

Hilary Cruickshank: Up to the age of two, it will be run by the neonatal unit or a community paediatrician, depending on where you are. I do not have the data on that, but some have AHP input and additional kinds of therapies and some do not. It is really variable as to who does the four-year assessment.

Q125 **Lord Winston:** Briefly, coming back to the NICE guidelines again, what do we have on what we are expected to do as doctors?

Professor Samantha Johnson: The recommendation is that, at four years of age, children born at less than 28 weeks of gestation should have a face-to-face developmental assessment that looks at their health and growth. In particular, it names a couple of instruments that should be used to identify behavioural, social or emotional problems and developmental delay, and recommends the use of a standardised IQ test, which was meant to be used for educational planning. It says that it is important to provide that information to parents, education practitioners and other healthcare professionals, so it can be useful in thinking about the provision of support.

Lord Winston: How many parents default?

Professor Samantha Johnson: I do not have those data, unfortunately.

Lord Winston: Does anybody?

Professor Samantha Johnson: At the moment, we know from a recent publication by the National Neonatal Research Database that 71% have a neurodevelopmental assessment record at two years of age. Whether that is through a number of parents defaulting I do not know, but the issue with the four-year assessments is that they just are not being offered widely.

Q126 **Lord Winston:** How do the three of you think we could improve the follow-up, or do we not need to?

Professor Neil Marlow: There is a desperate need for the smallest babies to have some form of cognitive assessment before they go to

school. The challenges of going to school when you have a low IQ, which is often unrecognised, mean that it can take two or three years for your issues to be identified, and those two or three years are critical to laying down patterns for development. One reason why the NICE group recommended it was that it offered the first follow-up point for doing real intervention and for changing the trajectory of what was going on.

Hilary Cruickshank: To do the four-year follow-up, money is needed. We need to engage neonatal teams and look at which team does it. At four, it should definitely have neonatology, educational psychology, an occupational therapist and a speech therapist. If you want intervention to promote better outcomes, you need a full MDT around it and you need to motivate the teams to do it. We would all desperately love to do it, but everyone is looking for money. We need more funding. I wonder whether the NNAP collecting the four-year data would motivate it more, but I do not know.

Q127 **Lord Winston:** What about a more chemical assessment of kids, given that in the literature there is a lot of evidence that epigenetic factors may be affecting what is happening to these children? Should we be checking their status and their methylation patterns, for example?

Professor Neil Marlow: We know too little about that at the moment to be able to look at the pattern in the individual child in a way that helps us. We know that epigenetic changes occur during neonatal intensive care. That is not surprising. If you have ever been on a neonatal unit, you will know that it is a harsh environment for a child to grow up in. Even though we have taken many steps to try to soften that, it is still a harsh environment. It is very clear that epigenetic changes will happen; we just do not know which individual markers will predict what is going on. It would be lovely if we did.

Baroness Watkins of Tavistock: I do not understand who is accountable for making sure that these four-year visits take place. Is it the ICB or the neonatal unit that alerts? I am very shocked that it is only 6.7%, I have to tell you.

Professor Samantha Johnson: I am not a clinical psychologist, so I am not the best person to answer this question. Neil probably is.

The Chair: Briefly, Neil, who should be responsible?

Professor Neil Marlow: The responsibility for organising it has been placed very firmly by NICE with the neonatal unit, so it is part of that neonatal funding.

Q128 **Baroness Cumberlege:** I want to ask you about the assessments before school admission and whether they really work well. I have represented a rural area for decades, although I no longer do so because I am now in the Lords.

Some of the systems that we are talking about come across to me as very clever, succinct and comprehensive, but in some parts of this

country—I am thinking of rural areas in particular, because that is where I am deeply seeded; my husband is a farmer, and all the rest of it—they are not like that at all. In fact, I started a preschool playgroup, because I was so worried about these children. It was haphazard and not professional. It was just what I thought would be better than nothing. It was done in the village hall and was not pukka.

I think we have to be very careful not always to think about urban areas, where you have a lot of resource, a lot of people, a supply of professional information and all the rest of it. Other areas are not like that. We have to be careful not to go right across the country thinking that this is how it is, because the country is very patchy. In some areas, it is really difficult to get anything to happen, even to recruit people to provide help in the playgroups that you set up and everything else. We need a bit of judgment.

The Chair: I do not suppose you disagree with that. On Baroness Cumberlege's point about people in rural areas, I presume that the same follow-up services should be available to rural preterm babies as there would be in any urban areas.

Professor Samantha Johnson: That is what we are saying. The four-year assessment is really important, and all children who fall into that category should have it. Over the years, my interest in the educational outcomes of these children has grown. The four-year assessment is really important because of the kinds of difficulties that they face.

The Chair: That is a good point.

Q129 **Baroness Blackstone:** I want to ask a question about the research that is done when these assessments are followed through. Is data collected on the outliers—small children who are extremely well, have no obvious disabilities of any kind, are achieving highly in the level of their language, social and motor skills, and so on? If that work has been done, what can we learn from it? What characterises these children that we might hope to follow up on in looking at other children who are not doing nearly as well?

Professor Neil Marlow: We have looked at outcomes in several populations now, and there is always a slender majority of children who do not have the problems that you have heard a lot about at school age. My impression is that they have generally done very well. When we have done longitudinal studies following children through to 19 years, we see that those groups breed true over adolescence, if you like, and by and large they continue to perform well. So our system for educating that group of children is working; at least, it is not leading to a detriment in their outcomes. The problem that we are beset with is identifying the children who do not have such good outcomes.

Baroness Blackstone: My question is slightly different.

Professor Neil Marlow: I know.

Baroness Blackstone: I am asking what we learn about those who do

have good outcomes. What qualities and characteristics make them different and lead them to be less damaged by their very early immature gestations, compared with those who are badly damaged?

Professor Samantha Johnson: We know a lot about the risk factors that lead to poor outcomes, but we know less about resilience and the factors that lead to better outcomes in this group. That is probably where we need to do research and look at what predicts children having better outcomes. You need a much richer set of data about a lot of different environmental exposures that sometimes are not collected in routine data or large cohort studies. The resilience factor is a research priority, because we need to better target interventions as well.

Baroness Blackstone: So that research has not really been done yet.

Professor Samantha Johnson: Not to a great extent that I am aware of, no.

The Chair: That is an important point. We have heard evidence for weeks now about the problems, but not necessarily about possible solutions based on evidence. If we are to make any helpful suggestions, we need that kind of evidence to show the research that is required. In the follow-up studies that you mentioned, Ms Cruikshank, is the kind of evidence collected that Baroness Blackstone referred to?

Hilary Cruickshank: Which work was that?

The Chair: The Scottish work.

Hilary Cruickshank: We are really just looking at the workforce review and looking at equity of service. We know that early intervention promotes better long-term outcomes. If you have a full multidisciplinary team where babies and their families are supported by physiotherapists, speech therapists, occupational therapists and dietitians, they have better outcomes, but that is just not equitable across the UK, and it is certainly inequitable in Scotland. It does not necessarily depend on your geography, either; there is some fantastic remote rural work going on in Scotland that is thinking outside the box, which is lovely.

Early intervention, supporting the family and anticipating care and guidance definitely mean that we have better outcomes, without a shadow of a doubt, but access to that is just not equitable, and that is a huge issue.

Professor Samantha Johnson: For me, it is about making sure that these children are in follow-up—that follow-up is offered and that they attend so that difficulties are identified early. The four-year assessment that I have talked about is important, because the kinds of difficulties that these children have are not always completely and directly observable. We know that some of the most common difficulties they have are cognitive problems such as low IQ and difficulties with working memory and with processing information mentally. Those are the most common difficulties, which can be quite subtle. We also know that these

children can have social and emotional problems that do not always present in the first year or two of life.

Often, children do not have difficulties in one particular area. They might have a range of difficulties that are subtle but, when combined, can have a significant impact on their everyday life and their learning. When they get to education, entering school is often a flashpoint. Suddenly they are in school and the cognitive demands of having to learn, sit and play in a structured way can compound these difficulties, or they become exacerbated or emerge at that age.

Education is an area where we can make the greatest change for these children. We know from our research with teachers and other education professionals that to date they have received very little training about prematurity. We know about it and what the outcomes are because we carry out the research, but education professionals generally have poor knowledge of the outcomes of prematurity and, therefore, of how to identify those difficulties and how to support them.

Because of the special constellation of difficulties that preterm children have—the social, emotional, attention and learning problems—they often tend not to be children who have behavioural problems, or externalising difficulties. They tend not to be aggressive, disruptive, delinquent or anti-social. They are not the children fighting in the playground. They are often the children who are quite compliant and seem to be quite happy in class and do not ask for help but are shy, anxious, and withdrawn. We are therefore worried that these children do not come to the teacher's attention as having difficulties. You often hear parents talking about their children slipping under the radar, because they are quite compliant children and therefore their difficulties may be missed.

The research is clear. When we did the research in 2015, only 13% of teachers had received any training about prematurity, and that was usually because they had had a premature child in the family. For that reason, we have developed completely free training for educational professionals about what preterm birth is and how it affects children's development. If we can raise awareness of prematurity in the education sector and have better information sharing between health and education, that would be a significant help.

Q130 **Lord Hampton:** My question is perfectly timed. I am a teacher and I have never had any training on premature birth.

Professor Neil Marlow: We will give you the website.

Lord Hampton: Thank you. That would be fascinating. In a way, we know the answer to this question if only 6.7% of children are getting a four-year review. The York study said that children born very preterm may require additional educational support throughout their compulsory schooling, and the Adult Preemie Advocacy Network said that "we may not catch up by two" and that birth history should be taken into account by clinicians. I think I know the answer to this question, so maybe you

could continue with how we could improve this. How effective is the follow-up monitoring between services, healthcare, community and schools?

Professor Samantha Johnson: At present, there is a lack of information sharing. We often talk about trying to bridge the gap between health and education. Parents frequently say that every time they see a new professional they have to retell their story and their child's journey, which can be very triggering. At the moment, there is a real lack of information sharing between health, what happens in neonatal follow-up, and education. That is crucial, because, as we say, these children might not come to the teacher's attention. If the parent does not mention prematurity, it can be overlooked.

One recommendation that it may be helpful to make is that schools ask about a child's birth history on admission. I add a caveat, though. It is okay to ask that question only if the staff know what to do with that information. If we are going to start asking about birth history, which is important in order to give parents the opportunity to talk about it and enable education professionals to provide appropriate support, we need to make sure that at the same time we are training education professionals about what prematurity means and how to support those children.

We want to avoid the potential negative effects of labelling. We want to keep aspirations high. As we have all talked about today, not every preterm child will have problems. So it is about careful training and asking about birth history. Also, schools adding at least very preterm-born children to their vulnerable children's list might be an important policy change or recommendation.

Prematurity is a risk factor, not a diagnosis. Not every preterm child will have difficulties later in life, but they are vulnerable children. It is about recognising that they may have difficulties and need some additional monitoring and support, but they may need nothing at all. Think of them as vulnerable, but ask about their birth history and put them on the vulnerable children's list.

Lord Hampton: Are we talking about primary and secondary school here?

Professor Samantha Johnson: Yes. We did our own studies published a few years ago which looked at Millennium Cohort Study data. Children born moderately preterm and very preterm have poorer academic attainment than term-born peers at the end of primary school, but by GCSEs it is only the very preterm children who have significantly poorer attainment than the term-born. Therefore those born at less than 32 weeks are the ones we would have the greatest concern about.

Lord Hampton: So keep an eye on everybody. Ms Cruickshank, do you have anything to add?

Hilary Cruickshank: It is important to highlight the four-year follow up. The majority of children should have some form of two-year follow up. Ideally, it would be a detailed one that at minimum meets the NICE guidelines—I do not think we can guarantee that for everyone—and that it has the appropriate expertise in the room when they see them, so that they get the earliest intervention. We start on the neonatal unit by providing support and advice to parents so that the children get the best possible start in life. We know that really simple things like reading make a massive impact on long-term development.

As Professor Johnson said, not everything is diagnosed or seen at two. Cerebral palsy is on the decline, and we are lucky to be able to use the Prechtl general movement assessment, which can diagnose that at the age of three months and make a massive impact on the outcome. But by two, we may or may not have picked up some of the more cognitive or sensory processing problems. So four is essential, and it is something that we really need to push for.

Lord Hampton: Should it roll out further?

Hilary Cruickshank: As we have heard from Professor Boyle, prematurity is a lifelong condition.

Professor Neil Marlow: My comment was going to be subtly different, because I am at heart a neonatologist. One of the problems in trying to get the four-year assessment rolled out and cemented in place is resource. You need a psychologist to assess the child. Clinical psychologists who you can get to do this work are thin on the ground. It is really important that we provide support.

As part of the neonatal review and our response to it, we funded a lot of AHP posts in physiotherapy, psychology and speech therapy within neonatal services to try to encourage them to take this out of the neonatal unit into infancy and childhood and to provide the springboard to make sure that these children got on to the right tracks. But it is still a major problem to encourage people to do these assessments when they do not have the resource to do it. So it is a challenge for all neonatal units to provide this, but that is why we did it. They need to be challenged, because this is important for the children and the parents.

Q131 **The Chair:** Can I ask about the role of physiotherapists? In previous evidence we have heard about the role of specialist nurses, which we understand, as well as clinical psychologists and physiotherapists. What is the critical role of physiotherapies for the parents because of all the different complications and disabilities that occur in preterm babies?

Hilary Cruickshank: One of the key things we provide is consistency on the unit and all the way through follow-up. On the unit, depending on the funding, we are there most days. We do not work 12-hour shifts, but we are the one constant that they see day after day. We have more time to spend with the families and we make a really strong connection with them. It is not about being hands-on or doing anything specific. We can

support posture and the environment, but it is about holding the family and helping them to be advocates for their child, as well as giving them a little power back—giving them ownership of their child, because this feels very distant. Obviously, nobody would choose to have a preterm baby. We know that this is a very abnormal experience and very traumatic. We know that our families tend to have PTSD.

So we hold them on the unit and can take them through follow-ups, so that when we have to have difficult conversations—when they come back to clinic—they do not have to tell their story again. We know their story and what they have been through. We know what their peaks and their real downs have been. Most of our families are very keen that we do not see their babies' outcomes as binary—as death or severe disability. If there is anything in-between for them and they have got their baby home, that is amazing. That is all they want, so we help to maximise what they can do.

Some families will take everything that you can give them. They will do everything for their babies and they have phenomenal outcomes. It is just incredible. Other parents will take dribs and drabs, you will support them, and they will need a little bit more. It is just about listening, holding the families and being part of their journey. As a physio I would definitely not need to be part of their four-year follow-up, but I would like to see it happen.

The Chair: How common is that physiotherapists and occupational therapists are embedded in a neonatal unit?

Hilary Cruickshank: In England, it is more likely as an in-patient. I do not think there is as much funding for out-patients, but massive funding was put in for in-patients in England, and the rest of us in the UK were very jealous. It is much more likely in England that you will have a full team of occupational therapy, speech therapy, physio and dietitians. Nutrition and growth are important for both in-patients and out-patients, and often the big stress for families is feeding.

Q132 **The Chair:** This question is to all of you. We have heard a lot about integrated care and the involvement therefore of parents around the clock. In your experience—in your case, Ms Cruikshank, that might be more in Scotland, and England might be jealous about that, although maybe I am wrong—how do parents have 24-hour access to knowing how their baby is doing?

Hilary Cruickshank: Obviously, they are allowed access to the unit whenever they like. We use video diaries, as they do in England. We use a system called vCreate, where nursing staff can take videos of the babies overnight and send them to the families, so the families get an alert on their phone that says there is a new video of the baby. There is a great one from Glasgow where the nurses did "The Lion Sleeps Tonight" for the baby. The parents absolutely love it. The feedback we have had from families is incredible. They say that when you get up in the middle of the night to express and do not know what is happening with your

baby, there is a lovely video of your baby and it just says, "Mummy, I'm sleeping really nicely today", "I had this done", "I'm in a new outfit", "I had to have a bath", or whatever, and the families love that. They can share them with any of their family if their family is not local and cannot visit. Once they have left the unit, they can download all the videos and photographs and keep them for themselves.

We use the same system for parents to send us videos for neurodevelopment. Once they are discharged home from us, the families can send us videos back. We use that to assess movement but also for reassurance. If parents are worried about their baby, they do not have to come to the clinic. They can take a short two-minute video and send it in, and we can contact them and let them know what we think about the video. We can either bring them sooner or just give them advice or reassurance.

Q133 **The Chair:** Good idea. You said that the four-year follow-up is important and should be the responsibility of the neonatal unit. Neonatologists work in the neonatal unit, not in the community, so are they the right people to take responsibility? How would they go about organising it?

Professor Samantha Johnson: Not being a neonatologist, I think it is for them to organise it, but it needs to be a multidisciplinary team, as Neil and Hilary have said.

The Chairman: So they are the organisers.

Professor Neil Marlow: Exactly right. When I was a chair in Nottingham, we organised our transfer so that we had joint clinics in the second year and then passed over to the community health team, who followed them up and gave us feedback on the outcomes they were getting as the children approached school. That is the sort of dynamic relationship that we need to have, but it needs to come from someone who thinks it is important to start with. Neonatal units should make sure it is important.

Q134 **Baroness Watkins of Tavistock:** I am sitting here thinking what the role of the health visitor is in all this. Should the health visitor not make sure that this happens at four? People will move across the country and so on, so should it be a requirement?

Professor Samantha Johnson: I do not think parents routinely see health visitors at their child's age of four. Obviously, there is the universal healthy child programme screening, and all children have an assessment at two to two and a half years as part of that. That is probably not sufficient for the preterm children, but I do not think they would routinely see children developmentally at the age of four.

Baroness Watkins of Tavistock: I do not disagree with you, but you could say that a health visitor who knows they have a preterm baby on their books should check, at four years, that they have been sent for. It would be really simple to do that.

Professor Neil Marlow: You would think so.

The Chair: Is it not a question of who is accountable? It does not matter who does it as long as they know what they are doing, but the person accountable is the one responsible for making sure that it happens. Thank you. We have overshot a bit, for which I apologise, but this has been a most useful session.