



Preterm Birth Committee

Corrected oral evidence: Preterm birth

Monday 4 March 2024

3.05 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. 7

Heard in Public

Questions 76 - 105

Witnesses

[I](#): Professor James Boardman, Professor of Neonatal Medicine, University of Edinburgh; Professor Jon Dorling, Academic Consultant Neonatologist, University Hospital Southampton NHS Trust; Professor Sam Oddie, Consultant Neonatologist, Bradford Teaching Hospitals NHS Foundation Trust, and National Clinical Lead, National Neonatal Audit Programme.

Examination of witnesses

Professor James Boardman, Professor Jon Dorling and Professor Sam Oddie.

Q76 **The Chair:** I welcome our witnesses to the session. May I ask you to introduce yourselves so that we have you on the record?

Professor James Boardman: Good afternoon. I am a professor of neonatology at the University of Edinburgh, a consultant neonatologist and the immediate past president of the Neonatal Society. I have also run active clinical research programmes for the past 15 years.

The Chair: You are a little softly spoken, Professor Boardman. Would you mind speaking up when you answer?

Professor James Boardman: Will do.

Professor Sam Oddie: Good afternoon. I am a consultant neonatologist at Bradford Teaching Hospitals in West Yorkshire, an honorary professor at Hull York Medical School, the clinical lead for the National Neonatal Audit Programme and the neonatal clinical lead for the National Maternity

and Perinatal Audit, as well as a data lead and executive committee member for the British Association of Perinatal Medicine. Not insignificantly, I am also the parent of a preterm baby.

Professor Jon Dorling: Hello. I am a neonatologist in Southampton and an honorary professor at the University of Southampton. I am also the BAPM research lead.

The Chair: Thank you. We will go straight into questions. My colleagues will ask a different question in turn, but other people may have supplementaries. Let us start with Baroness Wyld.

Q77 **Baroness Wyld:** Thank you. Good afternoon, witnesses. Can we start off by talking about the data? What data on neonatal care and outcomes is currently collected routinely, and how is it used to monitor and improve care and inform research?

Professor Sam Oddie: Thank you for the question. Data is collected and is available for describing care processes, neonatal outcomes and, to some extent, some measures of care structure in the United Kingdom. This data is published annually as data for assurance, describing what is going on, and it is more regularly available in a public form—what I call “data for improvement”, neonatal care dashboards. You can simply google that at the NNAP online. In the very near future, there will be a restricted access dashboard, which will give individual neonatal units still more granular data.

The data is used to stimulate quality improvement activity at unit level, local maternity and neonatal system level, regional level and national level, and it shows some striking variations in the quality and outcomes of care that are of great importance. I would point to a few things. The differences in mortality for very preterm infants—babies born between 24 and 31 weeks of gestation inclusive—vary almost twofold depending on where the babies are delivered. We think that is a strikingly important finding. Some measures of morbidity—for example, bronchopulmonary dysplasia, which is a breathing complication of being born preterm—also vary strikingly. Rates vary among neonatal intensive care units between just over a third to nearly 60%, so there are great differences in outcome.

I know that the committee had some interest in the use of surfactant in its recent meeting. There is a NICE—National Institute for Health and Care Excellence—recommendation on the use of surfactant in a non-invasive fashion, avoiding ventilating the patient. The proportion of babies in intensive care units who receive that approach to ventilation varies between a fifth and 70%. So there are strikingly different clinical styles of treatment for babies.

You also talked last week about the delivery of deferred cord clamping. I think the witness possibly understated slightly the variation in the delivery of that “new”—I am using air quotes—clinical technique. Neonatal intensive care units in the United Kingdom vary between eight

out of 10 and below three out of 10 babies receiving deferred cord clamping.

The rates of less common complications of very preterm birth vary significantly. I will not talk in great detail about that. The data maturity for some of those outcomes is really coming into being—with the exception particularly of preterm brain injury, where data incompleteness and poor data quality are certainly significant issues.

We can be clear that the data are showing the very pleasing adoption of new treatment strategies and new approaches. I draw the committee's attention to the revised guidance on how exactly we should screen babies for visual complications of preterm birth. You can see on the neonatal dashboard the adherence to that changing on a three-monthly basis in a way that is most pleasing.

However, there are real concerns about what we are seeing in the data. I mentioned that we collect data on the structure and delivery of care. I know that the committee has already heard about nurse staffing. There is a clear, demonstrated relationship between the extent to which neonatal units are adequately staffed and the outcome. We are able to measure the proportion of each shift for each neonatal unit that has the recommended number of nurses for the babies present on that particular day, so we have what we think is a good measure of staffing. Unfortunately, the annual proportion of neonatal intensive care units that have an adequate staff number of shifts varies from less than a third to more than 80%. So there is great variation between intensive care units in that instance.

So what do we do with the data apart from try to drive and inform quality improvement? We think that the data is informing research, for example in equity of access to neonatal care strategies, and there is clearly a wide variety of trials and observational projects. My colleagues are better placed than me to discuss those.

In general, the data is a great success for UK neonatology thus far. In gel, we collect the data once and then use it for multiple purposes. I think this data collection system is the envy of our maternity partners. We are very lucky to have ended up in this situation partly because of the way the software that we all use has evolved, as did the way we started to use it.

There are structural issues that we need to address in order for that data to flow in a still more transparent and equitable way, and the NHS needs to be able to make better use of its own data.

Q78 Baroness Wyld: You spoke about the importance of staff numbers and the variability in decision-making in care. Is it just about staff numbers, or do you have evidence that there is something else going on?

Professor Sam Oddie: Do we know why there are such differences in outcomes? No, we do not. It is one of the areas that we should prioritise in our research, based on this routine data. We need to understand why

the differences in mortality in particular are so striking, but one could also be minded to ask why patients from different ethnic groups have different care experiences and what the qualitative care experiences are.

Professor James Boardman: Professor Oddie has spoken to the National Neonatal Audit Programme, which is the systematic data collection on key outcomes. As he said, that fuels benchmarking and research.

At least two other data systems are routinely used by units in the United Kingdom. The first, which is proven to be a real driver of change, is the National Neonatal Research Database run by the Neonatal Data Analysis Unit at Imperial. This consists of real-world clinical data uploaded directly from the electronic patient record of every neonatal unit admission across the whole of the UK. At this point in time, it has real-world clinical data being uploaded regularly for tens of thousands of preterm babies. That data is available for the community to use. It has powered and answered research questions and has been important in benchmarking and driving policy. It is an important resource. It is an NHS-standard data asset and has been very important for driving research.

Many units across the UK are part of the Vermont Oxford Network, a benchmarking network that invites units to submit data on outcomes, including neurodevelopmental outcomes, to an international database. The network then places your unit against international comparators for looking after similar babies so that you can see how you are performing on a particular outcome. The goal is to drive quality improvement initiatives. That organisation also provides information to units about how they might deliver quality improvement. It is an extremely powerful resource, but not all units are signed up to it, although tens of them in the UK are.

There are regional routine data collection hubs that drive improvement. In Scotland, for example, there is a very good joined-up one with maternity services run by the Scottish Patient Safety Programme. It is slightly different in that it recommends an evidence-based care package and gives guidance to units on how to implement that package, and then modifies the package based on units reporting back their data.¹

A final way by which we can gather data and inform research questions is asking the community. As a neonatal community, we have recently done that. We have surveyed stakeholders, parents and colleagues and gone through a systematic, rigorous approach to prioritise the next trials that we should do next in the United Kingdom. We have gone through similar exercises with parents, answering their questions about their research priorities for the outcome for preterm infants.

Q79 Baroness Wyld: Going back to your first example, the lifetime Imperial

¹ Note by witness: The witness would like to clarify that the programme co-designs and co-produces guidance with clinical and quality improvement experts from NHS boards in Scotland, and provides advice for implementing practice change.

example, in order to help us to understand better how we use the data, can you give me an example of the sort of thing you might be monitoring and how you use it? You said that all this information about babies comes in in real time.

Professor James Boardman: Broadly speaking, the database contains around 400 variables for an individual baby. Those variables are medical, such as what treatments a baby has had, what they have been exposed to and what their course was during neonatal intensive care. It has demographic features about the family, such as socioeconomic information. It has the drugs that the baby has been given and his or her growth over the neonatal period. It also has their two-year neurodevelopmental outcome. I am a user of that database, and I am currently asking of it what, in order of importance, the weighted contributions are of all those factors for predicting important real-world outcomes.

Professor Jon Dorling: There is another system, the MBRRACE system, for reviewing deaths, including stillbirths and child deaths. Neonatal deaths go up to four weeks of age, so sadly a lot of preterm babies are part of that. They are probably the group of babies with the highest rate of not surviving. All the deaths are reviewed, and trends and reasons for deaths are pulled out of that. That is really important. We also use the data systems to run research, so we have a way of identifying babies whose parents we can approach to ask them to join studies. So the platform can be used to run research as well as for generating ideas and providing the outcome data. We are well stocked with systems for doing that, so there is lots of opportunity.

Q80 **Baroness Wyld:** In your view, of all the systems you have talked about, which has been the most useful so far? Which has developed the most impressive outcome so far?

Professor Jon Dorling: They are all useful in their own way, really.

Professor Sam Oddie: It is possibly worth pointing out to the committee that much of what we are talking about is the same when we describe an outcome of a patient having bronchopulmonary dysplasia, a breathing complication of preterm birth. With the exception of MBRRACE, the same data entry informs the systems of the different users, whether it is the NNRD or the NNAP. You put the data in once well and use it for multiple purposes.

Professor James Boardman: Each of those databases is set up for a slightly different purpose. The NNRD is set up more to fuel research. Others are set up more to drive quality improvement and audit.

Q81 **The Chair:** The different units send information to the national audit programmes. Do they get feedback on what they send?

Professor Sam Oddie: Yes, very much so.

The Chair: So every unit gets feedback.

Professor Sam Oddie: Absolutely. In the past, we did it through quarterly feedback to units only on their data and how it compared to the national average. In the past year, we have developed the NNAP dashboard, which members of the committee can google should they choose to do so and is publicly viewable. There will be a still more granular version of that available directly to hospitals, and those things will be in real time. Currently, they are refreshed quarterly. The expectation is that we may go to monthly refreshing of that data. In contrast to the NNRD, this is truly in real time rather than being refreshed intermittently. So yes, absolutely, the data is fed back, both in the improvement sense and in the annual data for assurance sense that I mentioned.

The Chair: Does that happen in Scotland too?

Professor Sam Oddie: Absolutely.

Q82 **Baroness Watkins of Tavistock:** I am particularly interested in the feedback loop for improvement. Does anybody monitor whether that improvement actually happens, or whether some centres get that information without changing? If I knew that I was two-thirds of the way down on one indicator, I would want to do something about it. We have heard from other witnesses that even though people get the information, nobody is necessarily holding them to account to use it to improve.

Professor Sam Oddie: The National Neonatal Audit Programme and the National Maternal and Perinatal Audit are not really in the business of holding people to account. The healthcare organisations—I know best about England—are of course accountable through the operational delivery networks and particularly to their local neonatal and maternity systems. However, there is a so-called outlier identification process in all national clinical audits, so where a unit, or indeed a region, is significantly different from the national average, that is overtly pointed out in a publicly available way. Indeed, any member of the public can see on NNAP Online the data for the assurance aspect of the work we do.

So yes, the data is fed back, but to be an outlier you have to be quite different from the national average. It is held more through the managerial accountability to LMNSs, as I said, and to ODNs. We are confident that the data have quite high levels of visibility within organisations, but we encounter different levels of engagement.

Q83 **The Chair:** I gather that the National Neonatal Audit Programme will report next year on ethnicity in data. Is that correct, and what have the challenges been, if any, of collecting the data?

Professor Sam Oddie: We are very concerned to understand whether care delivery differs by ethnicity or deprivation. We talked about deferred cord clamping. Our null hypothesis is that deferred cord clamping is delivered equally in every deprivation quintile and across ethnicities. In an earlier meeting, you also talked about antenatal steroids and other measures of the care process. We are optimistic that the null hypothesis will be proved, but I do not yet have the data available for you.

You asked about challenges, particularly around ethnicity. Ethnicity is a self-described concept, so clearly it is not meaningful to us for a baby to describe their own ethnicity. In its place we have used maternal ethnicity, partly for the philosophical reason and partly because baby ethnicity is incompletely described in routine datasets, so babies are often given the wrong ethnicity.

Finally, even maternal ethnicity is quite commonly incomplete in routine datasets, which is very disappointing.

- Q84 **The Chair:** We are rather keen to have that data to review it before your report comes out. In that case, we would welcome in writing any preliminary report or anything coming out in an earlier phase so that we can use it as evidence. I would be grateful if you would be able to do that.

My other question is: are there challenges to collect long-term follow-up data?

Professor Sam Oddie: Very much so.

The Chair: How can that be solved?

Professor Sam Oddie: The proportion of babies who have any clinical information recorded at two years across the United Kingdom is not much in excess of 70%. There is even enormous variation even between different parts of one city.

The Chair: We will follow that up in a later question.

- Q85 **Lord Winston:** Thank you for coming. We need to know what monitoring and further research would be appropriate in this area to understand the causes of mortality and morbidity. It is a very long question, but we need to get through it pretty quickly, so I have a few supplementary questions that I want to ask you after that.

Professor Jon Dorling: We have a good idea of what causes the death of babies. We know that it is often because the organs are simply too immature in this group of babies and they are unable to maintain life outside of the womb. So we know quite a bit about what causes it. It is more about identifying things that we can do about it. If the tissues are very weak, for example, can we do other things? Cord clamping is a very good example. We have identified that by delaying the time you clamp the cord, you give the baby more blood, and they probably stay warmer and have more oxygen. In research that we have been involved in, it has been shown to improve long-term survival and to help the brain. We would also like to know, but there is not enough evidence of, what it does to the brain in the longer term.

We have a good idea of quite a lot of what causes the problems. There are many antenatal factors. I think you saw obstetricians previous to this meeting, and clearly there are things that happen before the baby is born that are really important. Then there are things that happen around the

time of delivery, and the things that happen as the baby is being cared for and looked after in neonatal intensive care.

It is a very long course for a lot of these very small preterm babies. Lots of factors can be involved, but we need to identify more the things that we can do and what we can change to deliver something better to that baby throughout all the stages: antenatally, around the time of the birth, and after birth.

I do not have a simple answer, but there are lots of things. All the researchers involved are trying to find them and to find ways to improve things.

Professor James Boardman: There are five themes that can be probed to shift the dial. The first is to raise awareness in the research and clinical communities that preterm morbidities and mortalities start in the antenatal period. We know, for example, that some of the key morbidities that lead to disability, such as preterm brain injury, begin in some babies in utero, particularly those born to women with chorioamnionitis, for example. Once we have that understanding, the potential window for targeting interventions broadens out significantly. So looking at perinatal origins and antenatal experience is one thing.

The second is that we need to embrace preterm birth as a life-course disorder that leaves a legacy. It causes cerebral palsy in 5% to 10% of very low birthweight infants, while 30% to 50% have learning difficulties, and cardiometabolic and mental health problems are more common in this group. We need to study that and understand the programming effects of preterm birth on adult life course. We also need to advise patients and parents about it so that they can advocate for themselves as they move through the education and health systems.

We need to recognise increasingly that there are multiple drivers of risk and resilience, and how they interact. For example, whether a person lives in deprivation is probably very important, as well as the medical drivers. We do not know how much each of those things matters relative to one another at the moment, and we really need to understand that.

From the scientific perspective, there are common mechanisms that effect different diseases, and we as a scientific community need to recognise them and probe them more. For example, disorders of demyelination—brain ill-health in older age—have quite a lot of parallels in neurodevelopment, and yet scientific communities are not always at the same meetings or on the same page.

Finally, learning and neurodevelopmental problems are the most prevalent, so we need renewed attention on neuroprotective and neurorestorative interventions for preterm infants, developing new ones and taking those ready for trial to trial.

Lord Winston: That is very helpful. Thank you.

Professor Sam Oddie: I have little to add to what my colleagues have said. I am struck by the balance of resilience. That is a powerful phrase. Why is it that so many of these babies do so well? I am also very mindful of the impact of deprivation. I work in an area where deprivation is more prevalent than is typical for the United Kingdom. Understanding the interplays with that, particularly with respect to late and moderate preterm birth, with very numerous smaller effect sizes but still on a population level, is very important.

Q86 **Lord Winston:** May I ask the three of you this question? I grew up very much under the wing of Jonathan Wigglesworth, who was of course a brilliant neonatal pathologist. I watched post-mortems done by him and looked at tissues with him, and I did some research with him. I now wonder whether I am old fashioned, but is there still a place for better understanding of the tissues that we have? It seems to me that so often tissues are not stored or protected properly, and certainly are often discarded. That certainly applies also to people who have lost a baby, which of course may well be under 500 grams but may also be over 500 grams.

Will you comment on the pathology? It seems to me that, from the point of this committee, one of the big questions we know we will have is the question that that mother will ask us: "What caused the death of my baby?" To her, that explanation is of key importance, so it would be interesting to hear what your view of that is from a psychological but also from a scientific point of view.

Professor James Boardman: You have touched on an extremely important point, which is that the ability to examine tissues is fundamental. It has led to fundamental discoveries in the past and could still do, yet there is less ability to acquire tissues post-mortem from babies that do not survive. Rates of post-mortem have gone down. Exploring ways of restoring post-mortem rates would be potentially extremely informative.

Of course, we now have a whole range of new technologies. Cell-based systems are much better than ever before at modelling these pathologies, so we should take both approaches, using cell-based systems and bringing the state-of-the-art technologies to animal models where they are relevant, and using all strands of discovery science at the level of tissue.

Professor Jon Dorling: I agree; we need to identify more about what is happening, ways of working out what we could do about it, and moving it forward down the line, so we need to identify problems, do basic science and move things forward. We then need to identify interventions that we can give babies and their mothers before the baby is born, and once we have worked out what is best for improving things we probably need to do better implementation. We need to implement the changes and the best treatments. The fact that there is very varying data, as we talked about before, suggests that there are variations in practice that there probably should not be. All three strands are important, to be honest.

Professor Sam Oddie: I have little to add to what my colleagues say. I guess it may be worth repeating for other committee members that it is frequently cited that new information comes to light in between 30% and 40% of cases where a post-mortem occurs after a baby death.

Q87 **Lord Winston:** Do we have, therefore, enough pathologists and other people—cytogeneticists, for example—who have the capability in this country to look at some of these things, and is it worth thinking about that? Should that be one of our recommendations, or is it not necessary?

Professor Jon Dorling: We know that there is a limit to the number of post-mortems that can be done. We often have to wait some period of time. So there is definitely a staffing question there.

Professor Sam Oddie: There is no question that there is a shortage of perinatal pathologists and perinatal pathology expertise. There are deceased babies being moved from one part of the country to a very distant part of the country.

Lord Winston: It seems like a big gap.

Professor James Boardman: I think it is acknowledged as a gap by the royal colleges. Broaching the subject of obtaining consent for a post-mortem and then having to advise that that might involve the baby moving hospital is an extreme deterrent to parents agreeing to post-mortem examination.

Professor Sam Oddie: Let alone hundreds of miles away, which does occur.

Lord Winston: Of course.

Professor Jon Dorling: It is also more common for them to be done by people who do not have the backing of years and years of training, the non-specialists.

Lord Winston: Presumably there is also the education of nursing staff to make sure that we get the tissue properly and appropriately secured for histological examination.

Professor Sam Oddie: My understanding of perinatal pathology is limited, but it is probably less about nursing staff and more about maximising the quality of perinatal autopsy when it occurs, and, where families have invested in perinatal autopsy, to make that the best possible. I suspect that there is probably a future in including genomic approaches as well.

The Chair: To summarise, you are saying that there is a lack of perinatal pathology that will assist in improving care for preterm babies, and that primarily it hangs on the lack of expertise in perinatal pathologists.

Professor Sam Oddie: We would agree with that, for sure.

Q88 **The Chair:** What research is being done post discharge, and, when you

see all the equipment et cetera and different measurements that you have to do in neonates, is technological research being done to try to improve on this? Professor Boardman, you look anxious.

Professor James Boardman: Research is taking place, at three different levels, but there should be more. At one level, there are observational studies that are applying the very latest technologies to reveal new knowledge about preterm infants. That is crucial for phenotyping them, understanding them in the 2020s, quantifying the difficulties they have, and working out what makes them resilient or more likely to have a difficult outcome. We are applying very modern technologies to do that, such as fMRI, MRI, eye-tracking, and so on.

The Chair: Are you the only programme grant-holder in neonatology? You are too modest to say yes.

Professor James Boardman: I am from the Neurosciences and Mental Health Board of the MRC, but there are other programmes of research going on.

The Chair: So apart from yours there are no long-term neonatal research programmes.

Professor James Boardman: Not at the moment in terms of observation and applying this wide range of new technologies.

Lord Winston: You are not blocking the others, are you?

Professor James Boardman: I would say that the UK has punched above its weight, from previous cohort studies funded by public funds through the MRC. I am thinking specifically of the EPICure studies, where a population-level cohort was recruited and followed with very detailed information—this is 20 years ago now. They have now reported the 19 year-old outcomes. There has been an enormous wealth of information from that. However, we do not have one now, and care has changed so we need one now.

The Chair: That leads on very well to Viscount Colville's question.

Q89 **Viscount Colville of Culross:** Good afternoon. You have been telling us effectively about how little neonatal research is going on. I would like to divide my question into two halves. What are the main challenges to conducting that research? Perhaps you could leave funding aside, because that will be a subsequent question. We have heard, for instance, about the difficulty getting insurance for clinical trials. Is that a big issue, and are there others that we should be looking at?

Professor James Boardman: There are some challenges for research in this particular area. The first is that, at a very basic level, some of the pathophysiology of the diseases we are trying to treat is very poorly understood, and we need more discovery science to understand the pathophysiology. That needs a drive with funding, in my opinion. In the clinical arena, the fact is that to demonstrate the safety and efficacy of a

new intervention for an outcome in reality requires quite often thousands of babies. We need international collaborations and need the regulations on that to run more smoothly to enable them to happen so that we can really scale up patient numbers.

A useful exercise is to look at a condition where research was translated into practice very swiftly: therapeutic hypothermia for birth asphyxia. It entered into clinical practice extremely quickly. The reasons for that were these: there was an unequivocal result from a trial, so the community could get on board with it; there had been excellent PPI beforehand, so we knew that patients and staff would take it up, which is not always the case in perinatal interventions; there were no competing guidelines saying slightly different things but perhaps with a weaker evidence base, which often leave clinicians out of equipoise; and professional bodies such as the BAPM and NICE were very swift, after those results were published, to recommend the treatment. It was a major success of neonatal care, and we should be looking to emulate the ingredients of that success to overcome the challenges we have.

Lord Hampton: Sorry, I missed the start of that.

Lord Winston: It was on hypothermia—keeping the baby really cold and therefore preserving brain activity.

Professor James Boardman: I must also mention the workforce. We can come on to funding, but the clinical academic workforce has halved over the past 20 years. I know that a previous House of Lords committee led by Baroness Brown of Cambridge made recommendations to try to shift it back again. That is one sector of the academic workforce, but NHS employees are also major contributors.

The Chair: I think it was Lord Winston who promoted that inquiry.

Professor James Boardman: Great. More could be done to enable NHS staff to partner in these research endeavours, because they are crucial. There are actions for chief executives of NHS trusts, for VCs of universities, for funders to enable people employed by the NHS to contribute to research. The workforce is a major challenge in this area.

The Chair: Is it across the board or just in academia?

Professor James Boardman: It is particularly in academic perinatal medicine. Centres may want to participate in a national trial, for example, but many of them will not have a ready workforce to jump to and deliver that participation. That should change.

Q90 **Viscount Colville of Culross:** You talked about lack of international collaboration in order to be able to scale up some of these studies. What more needs to be done to increase that collaboration?

Professor James Boardman: More needs to be done with contracts offices at universities to ease the passage of data between institutions

and across national boundaries. Regulatory bodies between nations could also become more aligned to make the process swifter and more efficient.

Professor Sam Oddie: Professor Boardman made an excellent point. The likelihood is that many research trials—we have talked about the TOBY cooling trial, but many of us have been involved in other preterm baby trials—will depend on clinical staff, not primarily academic staff. There are real challenges there. The health service has changed enormously in the past 20 years. There are far more people delivering care, which basically means that there are far more people to train. You need to train people to a high level of sophisticated communication so that they can explain concepts that will seem straightforward to this committee, such as randomisation and equipoise, but are difficult to explain to the families I meet.

I know from my wider research team colleagues that explaining those concepts and facilitating this participation is difficult. We have been successful at it as a community, but there is a lot more to do. We need to run trials where participation becomes the norm and research is central to care rather than an add-on. A lot more can be done about that. That is about importance. I like the idea that leaders, such as hospital chief executives, would drive that and value it more. There is also something here about community discourse and everybody feeling that research is a positive, not an experimentation, because it is about improving and changing care.

Professor Jon Dorling: I would like to be positive about this. Trials are the area that the UK leads on. We are probably the strongest in the world at delivering randomised controlled clinical trials. You can see from the Recovery programme that it is possible to do amazing work at a good speed. We have the infrastructure and the ability. We run some of the biggest neonatal studies across the world. So there is obviously lots to improve, but there are also areas of significant strength. The UK has the unique ability to run some of these difficult clinical trials that have made, and I hope will continue to make, a difference to babies. We have to remember that as well.

Professor Sam Oddie: That is absolutely right. The strength that we have in collecting baby data is an enormous asset, and not just to the epidemiology; Jon touched on the trials nested in our clinical database and data collection. It is a major asset and part of our current success, but more can be done. As we look for smaller and smaller marginal gains in survival or morbidity, the number of participants you need for trials gets larger—hence the need for the international collaboration that Professor Boardman talked about.

Professor James Boardman: I have one further point to make on your original question. A significant challenge that remains is that there is sometimes an unjustified bias among ethics committees and regulatory bodies towards excluding neonates from studies. Although that is improving, it is not resolved. Sometimes there is a perception that studying preterm neonates is just too difficult, fraught and ethically

challenging. This could be addressed by improving the representation of perinatologists, clinical and scientists, on ethics committees, funding panels and wherever else they could exercise influence on the research process, including through regulatory bodies.

The Chair: We will try to cover that in the next question.

- Q91 **Viscount Colville of Culross:** We are also interested in making sure that, when you have research and find that something is efficacious, it is uniformly implemented across the health services. Professor Oddie, you talked about the accountability chain and getting leaders and participants involved. Is there some systematic way in which we can ensure that any new improvement we find in research can be rolled out uniformly so that we do not get variations in the application of research?

Professor Sam Oddie: To prevent there being any lag at all is quite a bold ask. It seems to me that there will always be leaders, and to some extent people will perhaps lead in directions that turn out not to be fruitful avenues. Some difference in clinical style or practice is not intrinsically a bad thing.

There is a difference between that and resistance or ill-informed failure to review the evidence. We see responses with a gentle challenge about why rates of deferred cord clamping are so low in such and such a place. They are a little hard to fully understand. There is great merit in the consensus that Professor Boardman touched on.

There is sometimes a need for balancing measures as we implement new treatments—you are nodding, so I assume that is familiar territory—but such measures are important in order that, as we introduce something positive, we do not inadvertently do harm. That is a real risk. As we widen the use of antenatal magnesium treatments to reduce the rate of cerebral palsy in preterm babies, that involves giving magnesium to women who turn out not to deliver preterm. That is fine—it is a little unpleasant, but not very, and most women see it as a major advantage—but if we had to give magnesium to every woman who is pregnant, it would be a problem. We want to be able to measure how many women are receiving magnesium, but we have no idea. There is no data collection system for that.

I could make equivalent points about other so-called perinatal optimisation strategies, such as transfer and antenatal steroids. We need a mechanism for measuring the cost—that is the wrong word—to the woman and the system of some of these perinatal treatments.

Professor Jon Dorling: I think we have got better at introducing change. We now have quality improvement teams. They have introduced a raft of interventions, such as PERIPrem, and they work with different providers to deliver them. Again, there are improvements to be made, and we have got better at this over the last few years, but there is undoubtedly more work to do, and improving the consistency of care is really important.

Q92 Baroness Watkins of Tavistock: I want to pick up this issue using magnesium as an example rather than the sole reason. Our report will land with the Government, which is why I am bringing this up. If we are overdelivering magnesium, which is not pleasant, we have questions about productivity and how much we could reduce cost through more targeted interventions. That seems to me to be very attractive. Is anybody talking about that in their research?

Professor Sam Oddie: In implementation, certainly people are talking about appropriate targeting. I am not so knowledgeable about the research. In the world of implantation science, as you could call it, there is the QUIPP app, which allows you to risk-stratify a woman who is threatening preterm birth to say how likely it is. Yet uptake and use of that app is by no means universal. That is a shame, and that has been fed into by a lack of appropriate products. There was a supply-chain issue which meant that one aspect of the app could not be delivered, and that surely can be sorted out.

The Chair: Is it true that the app is not evaluated in its benefits?

Professor Sam Oddie: My understanding is that it has been evaluated in its diagnostic accuracy and its ability to predict preterm birth effectively. But I defer to those who know better.

Q93 Baroness Thornhill: Thank you. This is fascinating. Can we talk money, gentlemen? We need to discuss funding and the different strands. What are the challenges to securing funding for neonatal research? How does that compare to other aspects of perinatal research and medical research in general? Can you paint a picture for us of how much funding you get, access to funding and what sits where?

Professor James Boardman: The Royal College of Paediatrics and Child Health estimates that just 5% of the public and charitable research spend in the UK goes towards child health. The playing field is not even. Within that, the proportion that goes to perinatal and neonatal problems will be a fraction. The funding environment is very challenging.

There should be an exploration of a way of increasing the cut of that spend going into early years research, including preterm birth. You may be aware that the Academy of Medical Sciences issued a very important report last month on prioritising child health at zero to five years. It talks about preterm birth and includes an extremely useful economic case for prioritising the early years. The economic return on preventing or treating some of the difficulties before the children reach adulthood is huge for productivity, innovation and the health of the nation. I commend that report to the committee. It is an excellent report in terms of the long-term outcomes. Specifically, that body is calling for research into the mechanisms that link different exposures to adverse outcomes so that we can get a better understanding of the basic science by which the preterm infant has been programmed to an adverse outcome—often, but not always.

The second part of my answer to this question relates to one that we have touched on before, which is developing a workforce that is competent to compete in a fierce funding environment. With the erosion of clinical academics, the number of those people has reduced, and we need to do more to boost the number of people with skills to compete alongside the other justifiable causes when applying for research grant money.

A very practical issue is that, with a couple of exceptions, most funding cycles offer three-to-five-year projects. This is fundamentally not suited to long-term outcome studies in preterm infants. There are exceptions; some funding bodies will stretch to eight years—Wellcome Trust is one notable example—but we need a long vision for funding longitudinal cohorts.

Q94 Baroness Thornhill: Do you believe that due to a lack of funding and financial insecurity, we are losing people as they move to more lucrative areas to do their research and data gathering, which is causing a bit of a brain drain? Is there any evidence that there are fewer people making bids for research at a level that will get accepted? I am trying to understand the process.

Professor James Boardman: There is a two-pronged answer to that. There is evidence that fewer people are choosing an academic career at the moment. That is not necessarily a brain drain; it is people choosing to go into clinical services rather than research. That needs to be tackled. I do not know of definite evidence that there is a brain drain of established academics in this area moving abroad to work in health systems that are more friendly towards academia. Anecdotally it happens, but I do not know that there are data to support that.

Professor Jon Dorling: I am aware that there are vacancy freezes within a number of universities because of the financial challenge they have following Covid and the reduction in international students and so on. So they are not appointing academics at the moment; they are waiting and trying to sort out their finances. They are also obviously under a lot of pressure with the tuition fees having been at the same level for a period of time. There is clearly a big challenge for universities as a part of this, I am afraid.

Q95 Baroness Thornhill: Who decides what gets funded? What is the process by which all this happens? There are different types of funding, what with perinatal and neonatal, so how does the system work?

Professor Jon Dorling: Most of the funding opportunities are grant calls that go out. They look for calls to do a clinical trial, for example, and people from across the country will come together and put a grant application in.

Baroness Thornhill: Who does the calling?

Professor Jon Dorling: The funders—the National Institute for Health Research, the Wellcome Trust—put out a call, and clinicians and

academics come together to build a team to put an application in. The important thing is that everybody is competing against everybody else. It is a competitive world. We as neonatologists are competing against the general medicine specialist, the orthopaedic surgeons, the whole community. That is probably one of the positives: you have to be good to compete.

There is less opportunity for us to go for calls that are just for our area. There are a few funders that do that, but it is not like Cancer Research, for example, which funds a lot of cancer research. There are a few small grant funders—Bliss, Action Medical Research, and others—that we can go to to do small projects, mostly.

Baroness Thornhill: What could we recommend that might change that?

Professor James Boardman: A specific focus on maternal and child health by funding bodies, such as the MRC and the Wellcome Trust, could change that—that is, funding calls that are specific to preterm birth.

Professor Sam Oddie: Your 5% statistic is shocking. Children are significantly more than 5% of the population, and the life course implications of early childhood experience are so dramatic.

Professor James Boardman: Almost 100% of them go through a hospital at birth, so it is a population that comes through our services.

The Chair: I was going to challenge you, but I have a feeling that Lord Winston is about to.

Lord Winston: No, I am not challenging anything. I just wondered whether you could give me some idea of the current role of UKRI.

Professor James Boardman: UKRI has priority areas and themes.

Lord Winston: We know what its role is; I meant its involvement with this sort of research.

Professor James Boardman: It has themes for which this research can be relevant; it has, for example, themes around multimorbidities. The onus would be on us as perinatal scientists to put a case around multimorbidity rather than a disease-focus that affects preterm infants, as it were. It also has themes that cut across medical disorders that we would need to place the preterm baby into.

Lord Winston: That is helpful. Thank you.

Q96 **The Chair:** As academics, you would all argue for more money for research, otherwise you would not be in academia. That is a given. But we also know that to win grants—you have won some, so you know this—you have to be competitive and clearly demonstrate the need for that piece of research. Am I misinformed when I am told that it is not an NIHR priority to give funds to paediatrics as a whole, particularly to

neonatology?

Professor Jon Dorling: It is not a clear priority focus area. It is just one of the areas that it will fund.

The Chair: It is not that it will not fund.

Professor Jon Dorling: It funds trials and other studies in our area, for sure.

Lord Winston: It has certainly funded various institutions for women and child health.

Professor James Boardman: Yes. To be absolutely clear, no one is asking to be less competitive, but there are subject areas such as stroke and cancer where a specific call may go out that is disease-focused—

The Chair: Even in cancer, the charities fund more cancer research than UKRI does. So the government funding for cancer research is far less than the charity funding. If we are going to help you to do this, it appears that there is plenty of need, in improving the care of babies in preterm labour and in preterm births, to make a point that better research is needed. You talked a bit about brain development and the perinatal rather than the neonatal period. Is there not a lack of action among neonatologists, as there is amongst perinatologists, and is there not an argument that they should get their act together to make a case? We can help by saying that there is a need, but at the end of the day you guys have to go out and get it.

Professor Jon Dorling: With respect, we do act. We have all put grants in. We recently put grants in and we are trying very hard to get more funding. So, with respect, we are trying, for sure.

Q97 **Lord Winston:** Turning the question round, can you tell us whether there have been any calls for focused research into maternal and fetal health that will be relevant to the sort of activities that you need?

Professor James Boardman: Not specifically, and not in recent years, no, and that is the problem.

Professor Jon Dorling: One very closely related area is platform trials. The idea of recovery has led to other areas where you might apply for platform funding. We put one in for perinatal trials, but it was not felt to be competitive; it was perhaps a bit expensive. That would have led to an approach a bit like they do with cancer, where they take one intervention, run that, and use the same infrastructure to run the next intervention. We are definitely trying, and we are very keen to establish things like that that would help and move things forward, for sure.

Q98 **Lord Hampton:** Professor Boardman, you said that fewer people are choosing research and that this needs to be tackled. That sounds like an enormous issue. How do you tackle it?

Lord Winston: Training.

Professor James Boardman: It is in training. There is a point in a medical graduate's training when they can make a choice, and the number of people making that choice has gone down. It is partly because the type of training that they have to do and what is asked of them has become less appealing. They might have to move all over the country at a stage in life when people are not wanting to do that, and they might have to work inflexibly compared to other pathways. So it has become a less appealing career option.

Lord Hampton: How do you make it appealing?

Professor James Boardman: One of the things that has happened is that a person's track record is not so visible on their application form anymore, so excellence is not building on excellence. We need to make it more competitive so that a person's track record in previous accomplishments can give them a boost up on to the next rung of the ladder. That is one thing. We should make academic training much more integrated with clinical training, such that NHS services and academic services value it equally.

The Chair: Basically, we have now lost what people like Lord Winston and me had in our era, which is that in teaching hospitals there was integrated care.

Q99 **Baroness Watkins of Tavistock:** I will ask my real question in a minute. In relation to the previous question, is it also that you can become a consultant so much more quickly than you could 20 years ago, without going through what Lord Patel has just described as a rigorous academic training?

Professor Sam Oddie: My view is that there is too much separation between academic and clinical life, and I am not comfortable with the language that Professor Boardman was using about making a choice. I never quite chose to be anything. I have sort of muddled through and done a bit of lots of different things, which has been really exciting and interesting for me. I regard that as a great gift that I was given. More hybrid careers ought to be facilitated.

Q100 **Baroness Watkins of Tavistock:** That moves us on to hybrid research, which is what my question is about. What cohort studies are being done that understand the long-term effects, and should the length of a cohort study ideally be? You talked about five and eight years, but should we be looking from birth to 25?

Professor Sam Oddie: There are a pretty limited number of ongoing cohort studies. There is the ALSPAC study, the Millennium Cohort Study, the Born in Bradford study, and there are other Born in studies in other cities—Born in Doncaster, is one. Those are typically birth cohort studies rather than ones focused on prematurity. With respect to the interests of the committee's work, the challenge with a preterm birth cohort study is that you want to know quite a lot about the woman and the pregnancy as well as the preterm birth. So you really want to recruit before preterm birth occurs, which means more of a birth cohort study, in my view.

The studies need to be long; Professor Boardman has already referred to the limited forward vision of the funding bodies and the important challenge that that presents. You need very large N, very large numbers, in a birth cohort study. Local cohorts of pre-term birth were enormously influential in the early years of neonatology as a speciality, but to understand things in the sort of detail that we need to, we do not just need local cohort studies but large or at least larger populations.

Baroness Watkins of Tavistock: It would help this committee if you could define what large means.

Professor Sam Oddie: The Born in Bradford cohort study, which my daughter is a participant of, has 13,000 participants. That has relatively few preterm babies in it and extremely few of the most immature infants, who perhaps are of interest to some. I draw the committee's attention again to late and moderate preterm birth. They are very numerous and experience developmental disadvantage, so studying those is very important and should be an important aim of any of any cohort study.

We need to use routine data to study the consequences of pre-term birth. The effects that we are looking at are so often manifest at school age, and indeed later in childhood, that it is not realistic to have questionnaires go around every six months or every year, with the decreasing participation rate that we get. It will be very important to use routine data and to link to educational and other data, and general practice data is one of the ways forward.

Baroness Watkins of Tavistock: Do all these cohort studies need to be prospective, or could some be retrospective to get numbers more quickly?

Professor Sam Oddie: It would be very difficult to do retrospective cohort studies in areas without data collection systems that are already established. That would be challenging. It is a fascinating idea. It has never occurred to me, if I am honest.

The Chair: Surely the answer is that you cannot do retrospective cohort studies.

Professor Sam Oddie: I just wanted to say one more thing about cohort studies. To some extent, the neonatal data that we collect and have—Professor Boardman referred to it as the National Neonatal Research Database—is in some sense a preterm birth cohort study. We could go back and retrospectively find out about all the babies born at 25 weeks' gestation 10 years ago, and we would get pretty much total population capture. We could not do the same for babies born at less than 23 weeks' gestation very far back in time at all. So with some caveats it is possible to go back retrospectively, but not to gather some of the stuff that is of great interest—namely, understanding a pregnancy and a woman in her social milieu. Professor Boardman has something to add, I think.

Professor James Boardman: I agree with that somewhat. Let me answer the second part of your question first. We must follow these people into their 20s and 30s. Increasing evidence from countries that do population-level cohort studies shows that there are impacts on employment, wealth and the ability to form romantic relationships. There are adult outcomes here that are important to understand.

To answer the meat of your question, I think that different types of cohort are being alluded to here. The NNRD is extremely important for delivering information about the past 10 years-worth of babies. It can be linked to other routinely collected data surrounding mortality, hospital use, healthcare access, pollution, educational outcomes. These are cohort studies. It speaks to the importance and urgency of sustaining that database in the long run. Currently, it is sustained predominantly by grant cycles.

I mentioned earlier that I believe we need another type of cohort, another UK population-based study of all babies born between 22 and 28 weeks. The time has come to do a similar thing to the EPICure studies of the late 1990s.

The Chair: Is that is a published study?

Professor James Boardman: Yes.

The Chair: We would be grateful for a reference to that.

Professor James Boardman: Okay. Another type of cohort is the one that can capitalise now on the incredible advances in technologies for understanding humans, by which I mean the omics—genomics and epigenomics—as well as the microbiome and how that impacts a child's development. Those sorts of cohort studies can be quite small, perhaps 400 or 500-strong, but they need to be well resourced because the technologies are expensive. With those cohort studies, we can develop biomarkers, which are in my view another important area. We need to have a set of tests that we can do that can better predict which child will have which outcome.

There are exciting developments in big data cohorts. A recent study called the lifespan brain consortium aggregated data from over 100,000 individuals' brain MRI scans from 100 different primary studies in a new way. So there was a sample size of 100,000 MRIs. This type of approach opens up a whole range of other questions that can be asked. What is normal in brain anatomy and function? What is normal population variation? What is the impact of genetics and drugs on the brain? We cannot answer those questions without these sorts of federated approaches. They are forms of cohorts. The UK Biobank is an excellent model for collecting richly phenotyped data from a broad sweep of the population. We should do similar for preterm babies with a newly commissioned national cohort of infants.

Professor Jon Dorling: Obviously there are issues and challenges in sharing data and putting datasets together. We have all these different datasets, but can we match them together and move the data around? A lot of that is tricky and challenging. There are people working on that and trying to improve it, but that is one of the difficulties with research in this area. Again, advocating for that would be helpful.

- Q101 **Lord Winston:** One impressive cohort study is the GUSTO study in Singapore. Your colleague, Professor Seckl, has been on its board. Is that study too small to have value here? One thing it has been doing is intensely studying, right through, every infant that is born. They must be in their 10th year of development now, I think. It has been doing brain scans, for example, as well as the omics studies and epigenetics studies that you mentioned. Could we learn more from a study like that?

Professor James Boardman: That is exactly the type of study that I think we should do.

The Chair: Is that not part of your study?

Professor James Boardman: My study has a similar approach to GUSTO, but we would learn even more by scaling it up and making it a UK-wide omics study of the preterm infant.

- Q102 **Baroness Owen of Alderley Edge:** We are seeing this new trend of people signing up to ZOE, getting the patches, feeding in their own data and, now, using app technology for their birth control instead of the pill. To what extent can you partner up with applications like ZOE and say, "You're proactively feeding in your data. Will you now proactively feed it to us?" To me, that seems like a good way to start capturing someone's health data before they even fall pregnant—and, at the moment, are falling pregnant—with this new trend. Would that data be useful? Is that an opportunity for your research?

Professor James Boardman: Do you mean for a women anticipating pregnancy?

Baroness Owen of Alderley Edge: I mean pregnancy apps. Women are now moving away from traditional forms of birth control and towards methods where they use apps.

Professor James Boardman: In terms of neonatology, it is an area of potential growth that has not been tapped into yet. There is some interest in using apps to monitor real-life sleep habits at home and to ask whether the quality and quantity of sleep matter for child development. It is a very logical question, but we do not really know the answer. That can be answered through this type of technology.

Baroness Owen of Alderley Edge: I mean that, when you already have a population that is ready to feed in private data for their own personal use, surely that is a ripe market to tap into for your cohort studies. Is there an opportunity to partner with the private sector and say, "You're already feeding in data for your own use. Feed it into us"?

Professor James Boardman: There could be. As you rightly identify, there has been a cultural change whereby people want to record their data in that way. With the right consent checks in place, there could be scope for innovation there.

Q103 **The Chair:** I want to be challenging and ask each of you to give three things that you would like to see us recommend: first, something to improve the research chances; secondly, something to improve the outcomes for preterm neonates; and, thirdly, any policy changes, because you mentioned several times the regulation requirements that could be implemented.

Professor James Boardman: Number one would be identifying ways of increasing the cut of UK spend that goes to research into maternal and child health. Number two, for outcome, would be really understanding the impact of multidomain exposures, by which I mean social factors and precision factors like a child's sex, and understanding how they interact with the birth experience to shape outcome.

On policy, I would suggest that this committee recommend a structure whereby professional bodies, learned societies, clinicians, parents and other stakeholder groups could come together into a single advocacy platform for this group and where those advocates could then go to funding bodies and policymakers. Obviously, this is a group that relies entirely on others for advocacy, yet we are not as tightly joined as we could be, nor are we advocating as one.

The Chair: That is an important point because of what we have heard.

Professor Sam Oddie: If I could get this committee to do one thing, it would be to advocate for better linkage between maternity and neonatal routinely collected data. We could be like the great Scandinavian population registries. We have the data; it is just not joined up. That is truly surprising. It is absolutely within our gift. As James is suggesting, it is about prioritisation—what we as a society want to do. As neonatologists, we clearly want to do quite a lot for newborn babies, and preterm babies in particular. For me, that linkage would make an enormous difference and allow us, at the basic big data level, to link the maternal and baby experience.

At a policy level, I salute the committee's interest in the well-being of preterm infants. I would like to see greater resource and societal engagement given to parents and families who find themselves having a really tough time and to where transformational, amazing things are done in neonatal units all across the country. There is probably a resource issue around some of that.

Professor Jon Dorling: The first ask is focused calls from the research funders: can they prioritise by giving us calls to apply for perinatal and neonatal research? I was going to mention the data linkage that Professor Oddie mentioned. The other is the career pathway for the next generation of researchers and academics. How can we make that work, because it

looks quite concerning at the moment, and can they be encouraged to follow into our world of perinatal research?

- Q104 **Baroness Cumberlege:** What you said about the career pathway for research was really interesting. What could we do, as a recommendation, to ensure that that pathway is established and that we get the research not that we want but that is available to be produced?

Professor Jon Dorling: I do not really know the answer to that.

Professor James Boardman: You could stimulate a discussion between NHS chief executives and university vice-chancellors to improve the integration of clinicians and academics into hospital settings.

- Q105 **The Chair:** Baroness Cumberlege asks a very good question, but we have also heard from you today about the problem of people going into the academic side not just of neonatology but, I assume, of the whole of paediatrics. We also heard before about the problem of staffing among clinical neonatologists, specialist nurses and others who work in this area. You just said something about communication between NHS chief executives and academics, both of whom have their own problems. So is not the answer that we need better staffing in neonatology in the first place so that we can overcome the next step of career development, which has a strand that goes into academia and a strand that goes into clinical academics—because there are clinical academics? We need somehow to promote that and have the ammunition to be able to do so.

Professor James Boardman: It is incontrovertibly true that there is a staffing shortage in the neonatal workforce. You are absolutely right. That needs to be tackled.

Professor Jon Dorling: We perhaps have not said it, because it is so obvious. It is just the day-to-day reality that we live with.

Professor James Boardman: It needs to be tackled, but, even so, vice-chancellors could protect or create clinical academic roles, so that when a retiral happens in this speciality, the job is retained in the specialty and not given to another. That is one example. They could give honorary contracts to NHS workers who are participating in research in order to give them access to the grant-writing machinery that the university possesses but which the NHS may not.

In turn, chief executives could reward their NHS teams that are delivering research and create space for them to do so. Even within the current constraints, there are actions where integration could be better. Of course, funders could help to deal with the shortage of people coming in by creating PhD schemes, post-doc schemes, and so on in this area.

The Chair: I think we have exhausted ourselves—and probably our witnesses, too. Thank you very much for today's session. You have been most helpful. Important points have been made. We still have more evidence to come, of course, but we will bring up some of the issues that you have raised about research when we see grant-giving bodies, such as

UKRI and Wellcome. We will also bring it up when we see Ministers and others. Please do send in any other information that you have and which you think might benefit the committee. It will be used as written evidence, with the same weight as the evidence you have given today. Thank you for coming today. We appreciate it very much when you have busy timetables.