



Preterm Birth Committee

Corrected oral evidence: Preterm birth

Monday 22 April 2024

3.10 pm

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

Evidence Session No. 14

Heard in Public

Questions 194 – 205

Witnesses

I: Dr Martine Jeukens-Visser, Research Associate, Amsterdam University Medical Center; Professor John Newnham, Chair, Australian Preterm Birth Prevention Alliance and Professor of Obstetrics and Gynaecology, University of Western Australia; Professor Mikael Norman, Professor in Pediatrics and Neonatal Medicine, Karolinska Institute.

Examination of witnesses

Dr Martine Jeukens-Visser, Professor John Newnham and Professor Mikael Norman.

Q194 **The Chair:** I welcome our visitors. Can you introduce yourselves, so that we get your name and your designation correct and on record, because the transcript of the session will be published? After that, you might also tell me how I should refer to you. We look forward to your evidence.

Dr Martine Jeukens-Visser: I am a senior researcher at the Amsterdam University Medical Center in the Netherlands, focusing on supporting parents and infants who are born very preterm. I am also working as a researcher for the centre of expertise on preterm infants, which is involved in the implementation and evaluation of the TOP programme as well as education.

Professor Mikael Norman: Thank you for inviting me. This is an excellent initiative, because preterm birth is the largest perinatal problem in Sweden. I am a professor of paediatrics and neonatal medicine in Stockholm, and director of the Swedish neonatal quality register. I also

work as an adviser for Swedish patient insurance regarding care damages to newborn babies. It is fine if you call me Mikael.

Professor John Newnham: Thank you for this opportunity to speak to you from Western Australia. I am professor of obstetrics and maternal foetal medicine at the University of Western Australia in Perth. I founded and chair the Australian Preterm Birth Prevention Alliance, which is a national programme designed to safely lower the rate of preterm and early-term birth across Australia.

Q195 **The Chair:** Thank you. My first question is general and for you all. What is the preterm birth rate in your region and country, and has it changed? Is there any differential between different ethnic or social groups? There is a difference in our country, so we would like to learn from you.

Dr Martine Jeukens-Visser: The preterm birth rate in the Netherlands is about 7.3% of live births. Very preterm birth is around 1%. We have seen that there is a decrease over time—a study from 2011 to 2019 showed it decreasing specifically in singletons but not so much in multiples—and that there is a high prevalence rate of preterm birth in mothers of non-western ethnicity as well as of lower socioeconomic class.

The Chair: I will come back with a supplementary in a moment, but can I hear from Professor Norman first?

Professor Mikael Norman: The preterm birth rate in Sweden is 5.6%. That is the last figure we have, from 2022, and it has remained fairly unchanged over 40 years. There was a bit of a rise in the late 1980s and early 1990s when in vitro fertilisation started and before it was guided and regulated properly, but over time more or less there has been no change.

We see regional variations in Sweden and the Nordic countries, some of which are because of population differences, although not all. In Stockholm, my home town of 2.5 million people, with vast immigration in the last 10 years, we have the lowest proportion of preterm births in Sweden and the Nordic countries. So this cannot be explained only by socio-demographic differences.

Professor John Newnham: Our preterm birth rate may seem a little higher because our definition goes from 20 weeks, so we capture the 20 to 24-weekers. Our preterm birth rate was rising. In 1994, it was 6.9%. When we founded the national programme in 2018, it was 8.7%. It appears that we have now lowered it to 8.2%. That is the rate for the nation as a whole. In indigenous Australians, First Nations Australians, the rate is almost double, at about 15%. In parts of the Northern Territory, it is over 20%. They represent 3% of the population.

The Chair: What are the main drivers of preterm births in Australia?

Professor John Newnham: The major causes are preterm labour, pre-labour rupture of membranes, early onset pre-eclampsia, antepartum haemorrhage and multiple pregnancy. But the increase has been largely

due to medical intervention. We lowered it by 20% in our state's major tertiary-level hospital, and we have done that elsewhere. So medical intervention must be a major cause. We can influence this through public education, educating the entire population as well as the healthcare workforce.

So inappropriate medical intervention would appear to be the major cause of the rise, and it is certainly the major cause in the rise in early-term births. Our national programme began as an effort to lower our very early preterm birth rates—the 25 to 26-weekers that people like me have spent our lives delivering. But, now, the big area of political interest in Australia is the early-term birth rate of 37 to 39 weeks because that is one of the main drivers for increasing behavioural and learning problems at school age. It is there that we have had our greatest impact.

Professor Mikael Norman: I am a neonatologist. We do not have a clear picture. The preterm birth rate has been stable for decades. Some things we know. For example, a mother being older increases the risk of preterm birth, as does obesity among pregnant women. At the same time, as I said, the overall preterm birth rate has not changed. We cannot really explain it. Iatrogenic preterm birth is a factor for sure, but the large numbers are babies born at 34, 35 or 36 weeks of gestation, and I do not think the number of iatrogenic births at those ages contributes very much.

Dr Martine Jeukens-Visser: I am also more into the post-discharge, not so much the prevention of preterm birth. Also, the care for infants in the NICU has improved. Our situation is a bit different, as we treat infants from 24 weeks on, which may differ from the Swedish situation. There are a lot of socioeconomic problems that are related to preterm birth.

Q196 **Baroness Wyld:** My question is primarily for Professor Newnham, because it is based on prevention. Professor, you started to talk about the interventions that you have made in Australia. Can you kindly go into in more detail about your approach to preventing preterm birth? It would be very helpful if you could set out what has been particularly effective in your strategy.

Professor John Newnham: Thank you for the question. I will briefly summarise the 10-year story. In 2014, in Western Australia, we started a whole-of-population, whole-of-state programme to lower the rate of preterm birth.

We based it on seven evidence-based strategies. No pregnancy is to be ended before 39 weeks without obstetrical or medical justification. We measure the length of the cervix at all mid-pregnancy ultrasound scans. If the cervix is short, it predicts preterm birth and we begin vaginal progesterone tablets that day, continuing to 36 weeks. We then monitor the length of the cervix on that treatment. If it continues to shorten, we stitch the cervix closed. We also use vaginal progesterone for any woman with a history of spontaneous preterm birth. We beefed up our smoking

campaign to reduce the smoking rates even further, and we promoted continuity of care—midwifery and medical.

Those strategies were coupled with a very intensive public health campaign and an outreach campaign, where I took a team around the entire state from top to bottom to make sure that everybody knew exactly what we were doing. Then, in the first full calendar year, we published that we had lowered the rate of preterm birth by 7.6% in the state and by 20% in the major institution.

We were then funded in 2018, through a competitive grant—an MRC grant in your terminology—to spread the Western Australian programme out over Australia. We quickly noticed that in small population centres where there is very good academic control from the centre, the rate came down very quickly. In Tasmania, the preterm birth rate fell by 20%. In the Australian Capital Territory, it fell by 10% and the early-term birth rate fell by 34%.

But we noticed that in the big states—Queensland, New South Wales and Victoria—we did not have such an effect. We realised that we had the right strategies, but we needed better implementation. In May 2021, we were funded in the Commonwealth budget through Canberra with AUS\$13 million to roll the programme out effectively across the country, and we used a breakthrough collaborative methodology based on the Institute for Healthcare Improvement in Boston.

Essentially, we went with hospitals that were willing, so we took the first hands that went up and did a collaborative of 63 Australian hospitals, representing 54% of Australia's public births. We ran that collaborative for 16 months, ending last month. It has been highly successful and has resulted in a massive engagement. As you may know, a collaborative is a process by which you outline an overall strategy, in this case to lower the rate of preterm and early-term birth in Australia by 20%. We then empower and resource people at all levels in all 63 hospitals to work out how that is best done in their environment.

They then run sub-projects called Plan-Do-Study-Act—PDSA—cycles to work out how to make this work in their environment. There have been 700 such projects run in the 63 hospitals. They compare all the projects running across the 63 hospitals with a common platform called Life QI. We then meet periodically for two-day periods for everybody to share notes, so we have meetings with about 240 people from the 63 hospitals. Then we look at the results.

The results of the national data up to when we started the collaborative—because the complete national data set runs a few years behind—show that we had lowered the rate of preterm birth in Australia from 8.7% to 8.2%. That is a 6.5% decrease, amounting to about 1,700 cases of preterm birth averted each year. The cost-effective analysis showed that this was AUS\$90 million of immediate saving to the federal Government on an annual basis.

In the 63 collaborative hospitals, with our latest data up to October 2023—the final, clean data that we are willing to release—we lowered the early-term birth rate, which had risen in recent years to 31% of all births. One in three Australian babies is born in this 14-day risk period, and we had lowered it from 31% down to 27%. That is a 10% reduction, which is about 4,000 cases averted each year. That is where we are up to now. The data are unpublished and ongoing. We will close off data collection on 30 June and then submit the data for regular publication.

I am happy to share these numbers with you. At a national showcase in the Great Hall of Parliament in Canberra on 19 March, we presented our findings and how successful the programme had been to 240 people, including politicians. We are up for refunding in the next Commonwealth budget, but we are asking people not to publish these data until we publish them in the normal, formal manner.

It seems that the start of our programme nationally has been successful, because we have empowered people at all levels down through the healthcare system, together with a massive education programme for the women and families of Australia.

Baroness Wyld: Thank you. That was a very clear and comprehensive summary. I appreciate that it is a holistic approach, but you listed seven interventions, seven tactics. Is there any evidence that any one or two are particularly powerful, or are you at the holistic focus?

Professor John Newnham: They are all based on evidence. We published the programme at the very beginning and then published the results in 2017. The most powerful is clearly the first one, which is that no pregnancy is to be ended prior to 39 weeks without medical or obstetric justification. There is no way you could lower a rate by 10% or 20% in a hospital very rapidly with any other technique except improving clinical practice. That, however, would not prevent very early preterm births. The cervix length measurement and vaginal progesterone clearly must be working in that regard as well.

It is very hard, though, to separate them out. Randomised controlled trials separate the wheat from the chaff, but implementation research gives us an overall improvement in the community and in our healthcare data overall. It is very difficult to dissect out the relative contribution of each.

The Chair: Do you want to comment on prevention in Sweden and the Netherlands?

Professor Mikael Norman: In Sweden, the health of the population has been fairly good for at least two generations. I am sure you know that in Sweden there is liberal legislation regarding abortion. There is also subsidised anti-conception for teenagers and education for young mothers in school. The system of free antenatal care, which has almost universal attendance in Sweden, also plays a role.

Dr Martine Jeukens-Visser: This is not really within my expertise, so no comment from me on this topic.

Q197 **Viscount Colville of Culross:** Professor Newnham, thank you for your very clear answers. I am very interested by your last answer, that no pregnancy should be ended prior to 39 weeks' gestation unless there is a medical or obstetric reason. What could the other reasons have been for ending a pregnancy that you stopped in order to be able to get this result?

Professor John Newnham: There is high blood pressure, a woman is bleeding, you worry about fetal growth—any one of a host of medical and obstetric reasons why we need to end a pregnancy before 39 weeks for the welfare of the mother and/or the child. They are not negotiable. They are sacrosanct. That comes first.

However, there has been an increasing number of deliveries before 39 weeks for social reasons. One of the major reasons is that we were all taught as young medical students that 37 weeks is term. It is still the definition of term. That came from the fact that previously people weighed babies; 2,500 grams was the cut-off of concern, and 37 weeks is the age at which most babies will weigh 2,500 grams or more. It is not an endpoint based on any scientific investigation. We inherited it from our predecessors, essentially. We now know that massive development occurs, particularly in the brain but also in the heart and the kidneys, between 37 and 39 weeks.

Being born in that 14-day period substantially increases the risk of behavioural and learning problems at school age. In Australia, the rate of birth in that 14-day period had been rising dramatically for many reasons, and it was based on us in the medical profession and the population not appreciating until about 14 or 15 years ago that it is potentially harmful for the child. The data came from our own lifetime cohort study, the Raine study, that we have running here in Perth, but it is the same trend as seen in data from Europe and Eastern Australia: that being born in that 14-day period carries a substantial increased risk of behavioural and learning problems. Those are the antecedents of it.

Q198 **The Chair:** In answer to Baroness Wyld, Professor Newnham, you said that it was not one or two particular aspects of the seven-point prevention strategy being more important than the others, but that every one of them was based on evidence. Is it possible to put any weight on one or two particular aspects which, if they did not work, would prevent the whole programme from working?

Professor John Newnham: I think you are right: we will be able to. When we close off data collection on 30 June, we will have a wealth of data. This programme has encompassed 54% of Australia's public births, so about 130,000 a year. We also have not only the outcome data but process data. In the collaborative you collect a lot of process data, such as the rate at which women are having their cervical length measured, the rate at which they are getting their vaginal progesterone on the day

they need it, and how women are understanding the need to be delivered at 39 weeks or beyond.

The Chair: That was a good example. When you have a nationwide programme, there must be tremendous variability in the measurement. You and I as obstetricians will understand that.

Professor John Newnham: We embarked upon a big training programme through our sonographers' association and our radiologists to make sure that everybody measured the length of the cervix in an appropriate manner. One of our sonographers led the national programme, was made Australian Sonographer of the Year and made a major contribution to standardising the measurement.

The Chair: Okay, so it requires a national programme.

Q199 **Baroness Hughes of Stretford:** Hello everybody, and thank you for speaking to us today. I want to focus on another aspect of the committee's work, which is how we can improve the outcomes for babies who are born preterm. We have been hearing from practitioners in this country that there is a suite of recommendations regarding perinatal and neonatal interventions that should be implemented to optimise the outcome for such babies. We have also heard that the variation in the extent to which all those interventions are implemented in every case where they could be is considerable.

Professor Norman, you have done some work on regional variation in Sweden in the implementation of these kinds of interventions. I am also very interested in anything that Professor Newnham and Dr Jeukens-Visser can add at the end.

Professor Mikael Norman: We look at capacity, processes and outcome, and we have done some work on our quality register. The Swedish quality register was a government initiative 20 years ago, because we had the population registers in Sweden—the medical birth register, and so on—but they were driven by the authorities and usually did not answer questions about processes, capacity and so on. That was the driving force, as was engaging professionals in these measures. That has been one of the things that we work with to benchmark different clinics and regions over time. That has been successful in engaging people in quality work and patient safety. You can learn a lot from cases where safety has not been optimum.

We looked at capacity in the Nordic countries, and it varies a lot within Sweden and between Nordic countries. Centralisation of the most difficult cases, the very preterm babies and pregnancies, is a central part of improving care and having risk-appropriate management during pregnancy and delivery and afterwards.

Also, as Professor Newnham said, we also work with bundles of evidence-based interventions—antenatal steroids, magnesium sulphate, late cord clamping for preterm babies, and so on. We also work a lot with family-centred care. We have designed our NICUs in Sweden with family rooms

so that we can have the family in the neonatal unit as much as possible. Parental leave is fairly good in Sweden compared with other countries. Parents should feel that their reception in neonatal care is excellent. It is to improve excellence in their experience of neonatal care. So today we benchmark all neonatal units in Sweden for excellence on what parents think of them.

Baroness Hughes of Stretford: When you say benchmark, you assess the clinics, the units, in some way. Do you publish all those assessments as a kind of league table, or anything like that?

Professor Mikael Norman: Yes, we publish them openly on a webpage from data on the quality register. Data on the use of antenatal steroids, for example, is updated once a day. We compare the six greater regions, because it is a collaboration with smaller hospitals, and we try to avoid unnecessary variation between regions and hospitals. If the intervention is very well recommended and evidence-based, for example, we do not want much variation; we want every hospital to perform and to provide these interventions. You can read about it on our homepage.

Baroness Hughes of Stretford: Professor Newnham, can you add anything from your experience?

Professor John Newnham: I am very proud to say that Australia and Sweden have learned from each other over the years. For a very long time there has been a lot of talk about what the Swedes are doing, so I think our work with antenatal corticosteroids, magnesium and delayed cord clamping would probably parallel theirs.

We have a particular issue with distances. I am sitting in Perth, in the major centre. Our transfer distances, our referral distances, are up to 3,000 kilometres, which is an eight-hour plane ride. We have a very active and very well-funded Royal Flying Doctor Service that flies in women in preterm labour day and night from our northern and eastern regions, where the mining industry is et cetera. We put a lot of work into aeromedical transfer.

It is perhaps not your committee's business or interest, but it is of great interest to us, that for some reason women do not deliver preterm in aeroplanes. We have been studying this since the late 1970s and have published it several times. We do not understand it, but out of more than 5,000 transfers in preterm labour we have not had a single delivery in the air. There is something happening. I proudly hand this over to the next generation to try to work it out. We have studied it to the best of our abilities, but we do not understand why women do not deliver preterm in little aeroplanes. It is to our very great fortune. They often deliver soon after they arrive in the hospital, but they do not deliver in flight.

They are the peculiarities of Australia. Other than that, Australia and Sweden are very similar in our management and our success in our management. However, those managements do not prevent preterm

birth, and we have now invested heavily in primary prevention as well as secondary prevention, rather than just treatment.

Baroness Hughes of Stretford: Dr Jeukens-Visser, is there anything that you would like to add on this question of optimising the outcomes for the babies who are born before term, any perinatal or neonatal interventions that you recommend in Holland?

Dr Martine Jeukens-Visser: The Netherlands is rather densely populated, so quite different from Sweden and Australia. Infants are generally born in the level 3 NICUs, but once they are doing well they are transferred to nearby hospitals with medium care, usually within half an hour's distance from the family.

We also try to do a lot of family integrated care in the hospitals. More units are also transforming single family rooms, which is also good for when the children are transitioned home. There is a lot of improvement to be gained when the infants are at home with their parents, but the question is related more to their in-hospital care, I think.

Q200 **Baroness Cumberlege:** Professor Newnham, thinking about the work that you have been doing across your huge country, Australia, obviously there are a lot of different areas with different requirements. You had an intensive health campaign in 2018 in South-West Western Australia and Victoria. You told us that you ran it for 16 months and that it was successful at all levels. How much can we learn from that? We are always happy to discover things that are successful. You mentioned politicians. You are talking to a political audience here today. Is there something particular that they did which helped you to be so successful?

Professor John Newnham: Thank you for that question. The collaborative programme was run over all Australia, and we made sure that of our 63 hospitals we had representation in all regions around the country and all sectors, both tertiary and secondary.

What have we learned? The United Kingdom is very advanced in improvement science. We were behind you. You had a lot of improvement science work running in Scotland. I am not well acquainted with it, but I know that the Institute for Healthcare Improvement has been very active in your country. We adapted it to the Australian environment, but the UK is ideal to run a collaborative just like this. Even though we have run it in 63 hospitals and 54% of births—that is a very big collaborative; we have 160 maternity centres overall—it spills over into the others. It contaminates. We have movement of staff, we have our public health campaign running anyway with a lot of social media messaging, so it is not really restricted to 63 hospitals.

I would think that the UK is ideally situated to run a collaborative based on the IHI breakthrough model. It needs to have certain things for it to work. First, it must have well worked-out strategies up front, not something from a half-day meeting with some people throwing some papers on the table. In our case, we worked this up in the state of

Western Australia and had shown it to work. The same strategies were then rolled out across Australia.

Secondly, it must be well resourced and supported at all levels, from government all the way down. Executive leadership in hospitals is crucial. The people who made this work, above all others, were the midwives. We have the British midwifery system. We inherited our medicine from you, but we particularly inherited your midwifery system. The midwives have really embraced this programme. They have absolutely loved it. They have very much been the leaders in the programme, but it is everybody; it is the ward clerk, the woman who does the bookings in the operating theatre when somebody tries to book a patient in for a caesarean section at 38 weeks that could have waited until 39 weeks. It is the anaesthetist. It is everybody. It is a whole-of-healthcare system and a whole-of-population programme. I would have thought that the UK is ideally placed to do it, but it needs to be well resourced. Our politicians appear very pleased that we have shown this to be eminently cost effective.

Baroness Cumberlege: Professor Norman, have you anything to add that from Sweden that we can really learn from?

Professor Mikael Norman: I agree with Professor Newnham. We have learned from Scotland. I remember clearly some years ago that we had visitors from Scotland.

As an example of what we are doing that perhaps you should do, many preterm babies are undernourished and get infections when they are in neonatal care, and many suffer from care injuries. Those things historically have been attributed to the infant—"They are so immature, they are so fragile, they do not grow, they get infections", and so on. Today, we know that none of that is true. Infections are because of poor hygiene standards in the NICUs. Some NICUs are nowadays reporting no secondary infection whatsoever. Malnutrition is also a great problem.

Some years ago, we looked at extremely preterm babies who went blind. We used to think of them as having the most severe retinal disease of all, but we found when we did an audit that these were cases of care damage. They had not been screened according to national recommendations. They had not been diagnosed. They were treated too late. These were terrible damages.

The same goes for deafness sometimes. We have not looked into this, but my belief is that big brain bleeding, seen in extremely preterm babies, is also something that we can improve a lot and learn more about in the future.

Baroness Cumberlege: I would love to take this further, and perhaps can another time as other people have things to say. I just wonder whether there is some difference between a first-time birth as opposed to women who have several births, but perhaps we ought to talk about that at another time.

Q201 **Baroness Seccombe:** We are so pleased that you are all sharing your expertise with us. Are national guidelines available in your country or region regarding the care that should be given to mothers at risk of preterm birth and to preterm babies? If so, how have these been shared and implemented?

Professor Mikael Norman: Thank you. Yes, we have national guidelines, especially for the management of extremely preterm births. It is a question of equity for the women and patients in Sweden, which they should rely on, that, irrespective of which hospital they go to and which doctor or midwife they meet, they will have more or less the same treatment. So we have several guidelines for that, for neonatal care and for follow-up.

Professor John Newnham: Thank you for the question. We have our own guidelines. You will be pleased to know that we looked very much at your NICE guidance. We follow the green-top guidelines from the RCOG. Our college, which Lord Patel is an honorary fellow of, has its own guidelines, the RANZCOG Guidelines, which are probably the ones we follow the most. Hospitals often have their own guidelines.

Our preterm birth programme, though, was restricted to seven simple messages, which were reproduced en masse across the country to keep it very simple and very focused on primary prevention. But yes, we use guidelines just as you do.

Baroness Seccombe: Thank you. Dr Jeukens-Visser?

Dr Martine Jeukens-Visser: We have several national guidelines specifically for neonatal care as well as for follow-up in infants.

Q202 **Baroness Seccombe:** How effective have these guidelines been in ensuring consistency?

Dr Martine Jeukens-Visser: The guidelines that I work with most are the follow-up guidelines. These are used quite frequently. However, for us, they are aimed specifically at the preterm infants below 30 weeks. For infants between 30 and 38 weeks, there is a huge difference between what the different centres are doing. Some follow up and some have no follow up, so there is a huge difference, but below 30 weeks there is quite a lot of consistency throughout the country.

Baroness Seccombe: Thank you. Professor Newnham?

Professor John Newnham: It is a difficult question to answer. Some 75% of Australian births are in public institutions and 25% are in the private sector. For the private sector, it is difficult for us to know exactly what compliance there is with guidelines.

In the public sector, for the major headline things such as antenatal corticosteroid usage, magnesium sulphate usage et cetera, I would think that it is very high across the country. We have the very active Perinatal Society of Australia & New Zealand, where obstetricians, neonatologists

and midwives meet regularly. It is very well attended, very well supported and ensures that everyone knows what is going on.

However, in other parts of the country outside the major centres, it is very hard to know how care is administered. I am not too sure how to answer the question because there is so much variability. A woman in a remote region in the Northern Territory is in a totally different situation from a woman living in central Sydney or Melbourne. There is massive variation across our country.

I can say, though, that our healthcare system is well resourced. Our nation spends a lot of money on healthcare. It is considered a very high priority, particularly for people in remote regions who bring in the nation's wealth. I do not have good data, but every few years the Australian Healthcare Commission puts out what it calls The Atlas. The Fourth Atlas came out in 2021. The commission looks at about 25 areas and healthcare variation—things like the variation across the country for knee arthroscopy. The major focus of the commission in the Fourth Atlas was early-term birth across Australia, which is how I became involved in that organisation.

We have a lot of interest in healthcare variation, which may go to the heart of your question, but if you wish to read about Australia's efforts in studying variation, you can find them in the commission and the atlases, the fourth of which has just come out.

Professor Mikael Norman: I have two comments. First, sometimes a guideline does not help. If you follow it you have to monitor it, because it is a text, like quality register data. What we are going for is a change in behaviour, and sometimes we are not as good as we think we are when we have the data on behaviour.

Secondly, it takes time to implement guidelines. Our follow-up programmes for the very and extremely preterm babies at two and five and a half years are almost half way through now, and the guideline came eight years ago. It takes time to build up capacity and other things in order for these programmes to be really good.

Baroness Secombe: Thank you.

Q203 **Lord Winston:** Thank you for taking the time to help us with this inquiry. Just before I ask my question, would you be kind enough to send us any copies of the guidelines that you have, Professor Norman and Professor Newnham? It would be helpful for us to have those on record in our report when it comes out. Thank you.

One of the big issues, of course, is how babies who are born preterm are being followed up and cared for generally, in Holland for example. How much has that changed over time? Are there different issues with regard to different populations in Holland, the low countries in particular?

Dr Martine Jeukens-Visser: Thank you for the question. In the Netherlands we now offer the TOP programme, which is a responsive

parenting programme, to all infants born below 32 weeks' gestation or birth weight below 1,500 grams. That is standard care, and parents and their infants are guided in the first year after discharge, with a highly trained physical therapist giving home services and writing personalised strength-based reports for the parents. It is based on evidence that we collected in an RCT showing really positive outcomes for the infants as well as the parents, who really appreciated the support at home. We currently reach 80% of the Dutch population, so it implemented throughout the country.

For us, what worked was that we could show that there were positive developmental improvements for the infants, and other savings such as fewer infants having to be readmitted to hospital, fewer visits to the ER, less paramedical care. So there was a positive business case. In our case, the insurance companies were very interested, and the cost to parents is reimbursed, so everyone can participate in the programme without paying, which makes it available for the whole population.

Q204 **Lord Winston:** We heard earlier in our inquiry that babies that are only marginally preterm may have considerable problems later on, particularly in their mental health and neurological development. Would you be kind enough to tell us about that, because we need to look at this very carefully in our inquiry?

Dr Martine Jeukens-Visser: We found quite a gap specifically for the moderate and late preterm infants, in that they are discharged from hospital, there is not much for parents, and their infants are still at risk. So we now have a feasibility trial on providing support to this group too, because they encounter a lot of issues and it is rather difficult for them to find support and information to suit their situation. Public health systems often do not have a lot of expertise on preterm birth, so it is a group that really deserves more attention. We are trying to give that group more support as well, but that is not standard care yet. It is still in progress, but it is certainly needed.

Lord Winston: In Sweden, is there mandatory follow-up with all preterm babies?

Professor Mikael Norman: No, there is not. The national programmes are basically for very preterm babies and especially for extremely preterm babies. My take on the problem with the moderately preterm is that, when the fetus is in the womb, the brain is developing. When you are born you have to focus on surviving, so development will be put on hold for a while. If you are born preterm, it seems that development of the brain stops and you cannot reach a full-term baby's potential, at least not yet.

That is a question for research to answer in the future: why you cannot catch up completely with brain development. It is not a brain injury for babies born at 34, 35, 36 weeks. It is not a brain bleed, it is not asphyxia; it is general lower cognitive ability when you test these children when they become older. We do not know why this happens today.

Lord Winston: We have had a similar answer to that in England, certainly in this inquiry. That is really very interesting. Professor Newnham, what about Australia?

Professor John Newnham: We are very interested in the late preterm and early-term births. As I said, that has been a major focus of our Government. We did an economic analysis of the annual cost of preterm birth to Australia in 2018, and it is AUS\$1.4 billion, but, interestingly, one in four dollars is borne by the education department, not by the ministry for health. The Minister for Education also needs to be interested in early-term and late preterm birth.

The costs are in additional educational needs and in dealing with children with behavioural problems. As Professor Norman said, we do not truly understand exactly what happens to the fetal brain at birth and why being born before 39 weeks carries this increased risk in childhood, but we have better understanding of the heart and the kidneys. The heart and the kidneys stop cell division at birth, so the heart cells and the kidney cells are dividing happily until birth. At birth, there is a massive surge in hormones, particularly the thyroid hormones and cortisol, and those switch off cell division and prepare you for maturation and life. So after preterm birth you are basically born with the number of heart cells and kidney cells that you will now carry for life.

Many of us could overcome that with a good lifestyle. In indigenous Australians, particularly in remote regions in the north, a major issue is the need for dialysis units. Many children who are born very preterm with an inadequate number of kidney cells then have compromised nutrition and lifestyle and recurrent urinary tract infections and need dialysis by the age of 35 or 40. There is far more at play than just the brain, even though it is the brain that we have been heavily focused on with our national programme.

Over the next three or four years, I will try to work much harder on the implications for other organs, because they have been poorly appreciated by the various areas of medicine regarding the vital importance of life before birth in the lifetime propensity for illness and health.

Lord Winston: I thank all three of you. We certainly agree that a lot more research needs to be done as there is a huge number of gaps in this area.

Viscount Colville of Culross: Dr Jeukens-Visser, your TOP programme seems to be extremely interesting and effective. So much of it is about the exchange of information, the majority of which is done face to face between the caregivers and the parents. However, in your parents' information needs study, you say that the internet can be a problem for parents. They go online and find all these horror stories, creating difficulties for them. Obviously, there is your TOP scheme, but people cannot be there to give advice to parents all the time. What are you doing to support parents remotely, on the internet?

Dr Martine Jeukens-Visser: It was an interesting finding that some people stop looking for information, because what they read about all the possible risks scares them. The TOP intervention provides parents with information and answers questions. We always have a short communication line between home visits. If the parents want more information, they can ask their questions. It is easy to then get a quick answer.

We are also developing an app for parents to look at valid information that is written in a style that they can understand. Some of the information is for medical professionals and so difficult for parents to understand. There is certainly a need for good information for parents which also provides them with insight that they can use to help their infant. However, that is more for general information. During the home visits, the interventionist can give more personalised information, addressing the situation that they are in.

It is good to have good information for the parents. It is such a new field for them and they are overwhelmed by all that is going on. When the infant is home, they are the one who takes care of them for the coming years, so they need to be knowledgeable. We know that the more knowledge parents have about child development, the better the outcomes are for the infant.

Q205 **Lord Hampton:** Thank you for this fascinating addition to our inquiry. Professor Norman described having the family around as much as possible and talked about excellence in parents' experience. Would you describe the experience of parents of babies born preterm with you as excellent, on average?

Professor John Newnham: I am an obstetrician. It is not that I lose interest after birth, but my area of expertise is pre-birth. However, in our many Plan-Do-Study-Act cycle sub-experiments in our national programme, we have collected a lot of information on the parents. We have very active consumer groups. We have consumers built into the system at all levels. We have very active CALD groups and very active First Nations groups. We work hard to ensure that we have their opinions and thoughts built into all levels of our work.

Dr Martine Jeukens-Visser: Parental experience and satisfaction we measure after the one-year TOP programme. Parents are very positive. They would recommend it to other parents, even those who do not have a preterm infant, because they learn so much about it. They are very satisfied. We also see it in the rate of attrition. Most parents and their infants finish the programme, which is good. I am not so familiar with neonatal care.

The Chair: Thank you all for your help today. It has been extremely useful. The transcript will be sent to you. Please inform us of any corrections. Any information that you can send us, including the guidelines that Lord Winston mentioned, would be very helpful and would be part of the official record of our deliberations and included in the

subsequent publication. I know that it is early evening in Sweden and the Netherlands and nearly midnight in Perth, Australia, so, despite your time differences, thank you for helping us. It is very much appreciated.