



Cynulliad Cenedlaethol Cymru **The National Assembly for Wales**

Y Pwyllgor Iechyd a Gofal Cymdeithasol **The Health and Social Care Committee**

Dydd Iau, 28 Mehefin 2012
Thursday, 28 June 2012

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Motion under Standing Order No. 17.42(vi) to Resolve to Exclude the Public from the Meeting

Cofnodir y trafodion yn yr iaith y llefarwyd hwy ynddi yn y pwyllgor. Yn ogystal, cynhwysir trawsgrifiad o'r cyfieithu ar y pryd.

The proceedings are reported in the language in which they were spoken in the committee. In addition, a transcription of the simultaneous interpretation is included.

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Mick Antoniw	Llafur Labour
Mark Drakeford	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
Rebecca Evans	Llafur Labour
Vaughan Gething	Llafur Labour
William Graham	Ceidwadwyr Cymreig Welsh Conservatives
Elin Jones	Plaid Cymru The Party of Wales
Lynne Neagle	Llafur Labour
Lindsay Whittle	Plaid Cymru The Party of Wales
Kirsty Williams	Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats

Eraill yn bresennol
Others in attendance

Mr Phil Banfield	Aelod o Gyngor BMA Cymru Member of BMA Welsh Council
Mr Bryan Beattie	Coleg Brenhinol yr Obstetryddion a'r Gynaecolegwyr Royal College of Obstetricians and Gynaecologists
Julia Chandler	Swyddog Cenedlaethol, Coleg Brenhinol y Bydwraeddd National Officer, Royal College of Midwives
Elizabeth Duff	Uwch-gynghorydd Polisi, NCT Senior Policy Adviser, NCT
Polly Ferguson	Iechyd Atgennhedlol Menywod, Llywodraeth Cymru Women's Reproductive Health, Welsh Government
Yr Athro/Professor Jason Gardosi	Cyfarwyddwr, Sefydliad Amenedigol Gorllewin Canolbarth Lloegr Director, West Midlands Perinatal Institute
Fiona Giraud	Pennaeth Staff Cyswllt ar gyfer Gwasanaethau i Fenywod, Bwrdd Iechyd Lleol Prifysgol Betsi Cadwaladr Associate Chief of Staff for Women's Services, Betsi Cadwaladr University Local Health Board
Shirley Gittoes	Ymddiriedolwr ac Is-gadeirydd Rhwydwaith Sands yng Nghymru Trustee and Vice Chair of Sands Welsh Network
Dr Alexander Heazell	Canolfan Gwyddorau Iechyd Academaidd Manceinion Manchester Academic Health Science Centre
Angela Hopkins	Cyfarwyddwr Nysio, Bwrdd Iechyd Lleol Cwm Taf Director of Nursing, Cwm Taf Local Health Board

Ms Siobhan Jones	Ymgynghorydd mewn Iechyd Cyhoeddus a Chyfarwyddwr Cyswllt Iechyd Cyhoeddus, Iechyd Cyhoeddus Cymru Consultant in Public Health and Associate Director of Public Health, Public Health Wales
Isobel Martin	Cronfa Ymchwil Marw-enedigaeth Holly Martin Holly Martin Stillbirth Research Fund
Dr Shantini Paranjothy	Arolwg Amenedigol Cymru Gyfan, Iechyd Cyhoeddus Cymru All Wales Perinatal Survey, Public Health Wales
Dr Heather Payne	Uwch-swyddog Meddygol, Iechyd Mamau a Phlant, Llywodraeth Cymru Senior Medical Officer, Maternal and Child Health, Welsh Government
Janet Scott	Rheolwr Ymchwil ac Atal, Sands Research and Prevention Manager, Sands
Yr Athro/Professor Gordon Smith	Y Gynghrair Marw-enedigaethau Rhyngwladol International Stillbirth Alliance
Dr Mark Temple	Cadeirydd, Pwyllgor Meddygaeth Iechyd y Cyhoedd Cymru, BMA Cymru Chair, Welsh Committee of Public Health Medicine, BMA Wales
Yr Athro/Professor Jean White	Prif Swyddog Nyrsio, Llywodraeth Cymru Chief Nursing Officer, Welsh Government
Marilyn Wills	Cynghorydd Polisi, NCT Policy Adviser, NCT

Swyddogion Cynulliad Cenedlaethol Cymru yn bresennol
National Assembly for Wales officials in attendance

Llinos Dafydd	Clerc Clerc
Mike Lewis	Dirprwy Glerc Deputy Clerk
Victoria Paris	Y Gwasanaeth Ymchwil Research Service

Dechreuodd y cyfarfod am 9 a.m.
The meeting started at 9 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introductions, Apologies and Substitutions

[1] **Mark Drakeford:** Bore da a chroeso i chi i gyd i'r cyfarfod hwn o'r Pwyllgor Iechyd a Gofal Cymdeithasol. **Mark Drakeford:** Good morning to you all and welcome to this meeting of the Health and Social Care Committee.

[2] We will make a start because we have a great deal to get through during the day. We will shortly be joined by other members of the committee who are on their way. However, rather than wait for everybody, I think that we will just push ahead so that we do not lose any time.

9.01 a.m.

Ymchwiliad Undydd i Farw-enedigaethau yng Nghymru—Tystiolaeth Lafar One-day Inquiry into Stillbirths in Wales—Oral Evidence

[3] **Mark Drakeford:** Thank you, all, for being with us today to help us with our inquiry. This is a one-day inquiry, and so we will look pretty rapidly into the issue of stillbirths in Wales, and hear from quite a large number of people.

[4] Isobel, I was going to see whether you might want to begin. We will spend a lot of our time today hearing from professionals and experts and the people who provide services, but we do not have an opportunity to hear quite so much from people who have used services in this field, so I was going to see whether you would be willing to lead us. I will then see whether just one of you would like to offer a few opening remarks, and then we will go into questions from members of the committee.

[5] **Ms Martin:** Okay, thank you. My name is Isobel and I started a charity called the Holly Martin Stillbirth Research Fund a couple of years ago in memory of my baby who was stillborn in 1985. When I was pregnant, I was 25 years old, I was a professional physiotherapist, and I was healthy. I was married, I lived in the middle of a well-off town, in my own home. There were absolutely no health problems at all, so mine was considered a low-risk pregnancy. Everything was completely fine up to 37 weeks. I went to all the antenatal appointments and classes. I did absolutely everything that I was told. I was very much prepared for my first baby, which was very much wanted.

[6] I got to 37 weeks and the movements started to decrease, so I went to the midwife and told her, and they tested the heart and did a CTG scan. The heart rate was a bit flat when they would have expected it to go up and down a bit. The movements remained reduced and so I ended up going for a CTG scan every two days. Nobody seemed particularly worried about it except for me. At no point did anyone say that there was a risk that the baby might die. I kept going every two days for nearly three weeks to have her heart rate monitored. They used to poke me and ask me to move this way and that way to try to make the baby wake up. I was doing a kick chart, but nobody really explained to me that, if the kicks are reduced, there is a risk that the baby might die. So, I kept doing that and, sometimes, the baby did not reach 10 kicks until mid afternoon. Nobody seemed worried. I never saw a consultant. I just saw different people every week.

[7] That went on, and eventually the heart rate on the monitor came down to 60 beats per minute, which is about half what it should be, and so the doctor told me to come in to hospital. I went home to get my stuff. This was three days before she was due to be born. We got to the hospital, and it was the August bank holiday. The doctor went on holiday and I never saw the doctor again. I never saw anybody again for the rest of the day. So, I just sat in the hospital. The next morning, I was waiting to start counting the kicks at 9 a.m.. At 7.30 a.m., she was jumping around inside me. It got to 9 a.m. and I was waiting for the kicks, but there were not any. My husband came to visit me at 10 a.m. and the midwife arrived at the same time, with a CTG monitor. The midwife was looking for a heartbeat, but did not say a word. She went off and came back with somebody else, who also tried to find the heartbeat. She went away and never said anything; she just left us there. After a while, my husband went to find out what was happening and they were all standing in the office saying that we needed

an ultrasound scan to see what had happened, because they feared that the baby had died. We had the ultrasound scan, and you could see that the heartbeat was still; there was no movement at all. That is the worst moment of anybody's life. I would not wish that on anybody. You hope that they might be able to wake the baby up; I was thinking that perhaps they could give it an electric shock or something, but there is nothing you can do. Losing a child is the most devastating feeling that any woman can have.

[8] The fact that she had not been born does not mean that she was not a child that I had been waiting for and loved. I had all the clothes, the pram and everything, but I was left with absolutely nothing. It is the most horrendous feeling that anyone could ever suffer. Then, I had to be induced and I went through 16 hours of labour. As it was a bank holiday, there were no doctors; there was one doctor in the hospital, who told me 'Well, your baby is dead. It does not matter about you; we are going to concentrate on the babies that are living.' I had to push for three hours, and ended with a forceps delivery at 4 a.m., which was not very nice. I saw the baby the next morning in the chapel of rest and then we went home. There was no bereavement service at that hospital at that time. One of the midwives who came to visit me was very nice and helpful, but the other one had no understanding of what it was to lose a baby. She was completely embarrassed and did not want to talk about it, because she felt that it would upset her. She would not look at my photograph. She said that I would not be complaining about the stitches if I had a baby to look after.

[9] I am quite a strong person, and I had to make the decision that I was not going to let this ruin my life. I had a happy marriage and I was not going to let this ruin it. The fact that I am here, 27 years later, shows that it does not go away. It is not a case of being able to think that it was not really a baby as it had not lived, or being able to forget about it and have another one. I have had six more children since then, but Holly is still very much part of my family and a massive part of my life.

[10] I am doing this now because I do not want this to keep happening, and the fact that it is still happening to people, 27 years later, is absolutely shocking. The numbers have not reduced. To let women go through this and not give them the very best treatment available is not acceptable. That is why I am here, fighting for these women. I want them to get the best treatment, and I do not want anyone else to go through what I went through unnecessarily. I know that many of these babies can be saved, because when I had my sixth baby, I very nearly had the same problem. I got to 36 weeks and the movements were reduced. I knew about stillbirth—I had not known about it the first time—and I was not going to let it happen again. I made them get the baby out; it was just in time. She was very small and the placenta was grey. If they had left her one more day, she would not have survived. That is because I knew about stillbirth, and I was not going to let it happen. Women do not know about stillbirth. When I talk to people, they do not know about it. It is not considered a possibility. The fact that they do not know about it is not good enough. It is a massive risk: one in 200 pregnancies ends in stillbirth, which is a lot. In 2010, 190 women and families lost babies in Wales, and that is happening year on year, and has a massive impact on those people for the rest of their lives.

[11] It has to change, because it has been a taboo subject for so long. People do not want to upset you, they do not want to talk about it and they are frightened that you might cry. People need to talk about it; this is a massive part of their lives. For somebody not to acknowledge that it was a real person and a real baby is very upsetting. If nobody will talk to you, it is the most isolating thing. People used to cross the road to avoid me, because they did not want to talk to me about it—they changed the subject. Even working in a hospital, people changed the subject because they were frightened of upsetting me or they were embarrassed. They would not acknowledge that it was a real person I had lost. It needs to be more out in the open.

[12] **Mark Drakeford:** Thank you for telling us about that this morning; it is a powerful start to our day. The reason that we are holding the inquiry is to reflect many of the things that you said towards the end—to try to get some extra attention for the topic and to get it talked about. In particular, as we go through the day, we want to see what practical things we might identify that could begin to make a difference to those figures, which, as you have said, have not changed in the last 20 years.

[13] **Ms Martin:** Thank you for giving me the opportunity to speak.

[14] **Mark Drakeford:** Would you like to make a few introductory remarks, Janet? Thank you for your written evidence, which we all will have seen.

[15] **Ms Scott:** Thank you, Chair and committee members, for inviting us to give evidence today. Thank you also for holding this inquiry, which we hope will shed some light on this neglected area. It is good that you started the inquiry with evidence from Sands and Isobel to hear from the perspective of parents, which is at the heart of this inquiry. Isobel has described very eloquently the impact of the death of a baby; it is important that we remember that today. Stillbirths are no less significant than the death of any other child. This issue has been ignored for too long.

[16] As Isobel has said, no-one likes to talk about stillbirths; it is a taboo subject. That is perhaps why so little has been done to date to tackle stillbirths. We think that many people think that stillbirths just do not happen. Most people are not aware that one baby in every 200 is a stillbirth. We think that that is not an uncommon event; stillbirths are not rare. Stillbirths are 10 times more common than cot deaths and they are more common than Down's syndrome. Stillbirth is the most common form of child mortality. Stillbirths are as common as road deaths. That is not to underestimate or understate any of those other deaths; it just emphasises that all of those deaths are given considerable attention and action. We would like to see the same happen with stillbirths.

[17] We know that many of the stillbirths that happen in Wales and across the UK are preventable. Only a minority of stillbirths are of babies who have a significant congenital abnormality where nothing at all could be done. We know that other countries have seen a fall in their stillbirth rates, so it is evident that something can be done, whereas in the UK and Wales, we have seen very little change to the stillbirth rates over the last 15 to 20 years.

[18] So, what can we do? We know that this is a complex issue. At Sands, we have done a lot of work over the last few years to try to understand what could be done. We have tried to bring all of those issues together in our 'Preventing Babies' Deaths: what needs to be done' report and in the evidence that we have given to you. We are quite unusual, because we look at it from the perspective of parents and across a broad range of issues. I think that a lot of the evidence that you will hear later today will be from particular perspectives; what we can do is draw that together.

[19] It is a complex issue. There are many things that lead to a baby's death. There are lifestyle issues, deaths where poor care plays a part, deaths where risks are not identified or acted on and deaths that occur because resources are stretched, which has to be acknowledged. There are also deaths that happen because we just do not know enough about what is going on in pregnancy. This is an under-researched area, and there is just too little known about what is happening and what is going wrong.

9.15 a.m.

[20] So, we would like to see a comprehensive strategy come out of this to tackle stillbirths in Wales. We do not think that it is enough to pick off the easy hits. We think that

you need to look at everything and you need to consider all angles. I hope that this inquiry will add to this and to the work that has already started; I am really happy that a stillbirth working group has started in Wales. Sands and Isobel Martin were a part of that group. I am very optimistic about that, but we would like to see support for that group.

[21] **Mark Drakeford:** Thank you. I am now going to turn to committee members, who I know will have questions that they would like to ask of you.

[22] **Kirsty Williams:** Thank you for coming this morning. What can we do to encourage midwives to have conversations with expectant mums about stillbirth? No-one wants to frighten a woman, but if there was a greater awareness, women might be more alert to pick up on some of the signs, which would allow them to ask for appropriate help. How can we get that communication going about a very difficult subject, without frightening pregnant women unnecessarily?

[23] **Ms Scott:** There is a lack of awareness, not just among prospective parents, but among some health professionals, about the rate of stillbirth, the risk factors and what the appropriate interventions are if there are risks. So, training is an important aspect. This needs to be a significant part of the curriculum for midwives. Even among professionals, there is a real reluctance to talk about stillbirths. That taboo exists, even in the medical sphere. So, I think that you have to raise the issue, because once it is out in the open and people can talk about it, you can start thinking seriously about what the risks are and what to do about them.

[24] Unless you have an awareness that this is something that can happen, it is not something that you are looking out for. If they have not come across stillbirth in their own practice, or if they have not had enough information in their training, midwives are not looking out for it. So, things may be missed because of that.

[25] **Kirsty Williams:** We know that small-for-date babies and those with reduced fetal movement are potentially more at risk, yet we usually measure babies' development with a scan at about 12 weeks, and another scan at about 20 weeks. Many women will not be scanned then for the rest of their pregnancy, and the size of the baby is measured really crudely by measuring a woman's bump with a tape measure. Could you explain what the scanning regime would be for women in countries that have seen a fall in their stillbirth rates? Would they have access to more regular scanning so that there would be a more accurate understanding of how the baby was developing and growing?

[26] **Ms Scott:** I do not have an answer to the question about the exact scanning regimes in other countries, but one of the problems for us is that there is no evidence for having a scan in the third trimester. There is no evidence that, in low-risk pregnancies, that will make a difference to outcomes—people who are to give evidence later will tell you more about that—which is why it is not standard practice in the UK. In other countries, they use scans more frequently because resources are more plentiful, so they do not have the necessity to be very careful about how often they scan. In Northern Ireland, for instance, where the rates are lower than in the rest of the UK, third trimester scanning is much more common. However—I am sorry, I have lost the thread of your question.

[27] **Kirsty Williams:** That is fine. In Northern Ireland, rates are lower, but scanning in the third trimester is more prevalent.

[28] **Ms Scott:** This is one area in which we really need research to demonstrate how scans can be used more effectively, particularly because it is in the low-risk pregnancies that you have fewer scans. However, it is in the low-risk pregnancies that most stillbirths occur. So, something is going badly wrong in how we pick up stillbirth.

[29] **Ms Martin:** The problem is that people are slipping through the net during the last few weeks because it is assumed that they are low risk, so the care is not taken to follow on if someone is reporting reduced movement or if the fetus feels small for the dates. There needs to be a protocol that comes into play so that those people do not get missed, because you can sit in hospital like I did and you get missed. There is no fixed protocol. If someone reports a problem, something needs to happen. For those who report a problem, at least there would be some starting point. If there is no problem and if the baby is moving fine and is growing well—

[30] **Ms Scott:** There are a number of risks that could potentially be picked up, but are being missed. So, there are things going wrong in practice at the moment where risks are missed, but we do not have adequate tools to be able to predict accurately which pregnancies are going to end in stillbirth. That is a fundamental problem underlying this. We can improve the standards for fetal growth and for the detection of reduced fetal movement and how you manage those. A lot can be done as a result of what we already know, but we also need more research to find out what else can be done.

[31] **Ms Gittoes:** I deal with a lot of bereaved parents across Wales and I am also a bereaved parent myself. Something that parents always ask me when I befriend them is why, for the next pregnancy, did they get all of the care that they should have had the first time around but did not, which meant that that first child had to die because they were not willing to put that care in place. However, it was all right the second time around.

[32] **Ms Scott:** When a baby is identified as being high risk, the care is good and we rarely lose those babies; it is among the low-risk pregnancies that the deaths happen.

[33] **Lynne Neagle:** Have you observed any difference in levels of problems between obstetric-managed pregnancies and ones where the women had solely midwife-led care?

[34] **Ms Scott:** The women who were on the low-risk pathways were obviously being looked after by midwives and the high-risk ones were being looked after by obstetricians and, as I said, when a pregnancy is identified as being high risk, surveillance and the obstetric care kicks in and it is very good. That is not to lay blame at the feet of midwives at all, but they need to be better equipped to detect risk in those low-risk pregnancies so that those women can be transferred to the appropriate pathway.

[35] **Lynne Neagle:** Are you aware of any problems with midwives not wanting to transfer that care because they want the care to remain midwifery led?

[36] **Ms Gittoes:** I deal with the parents themselves rather than with the professionals, so I know that some of the parents will stay within midwifery-led units, not through ill advice, but because they feel comfortable there. It can take up to an hour's journey time to get some women to a district general hospital. So, a lot of midwives also have to take transportation time into account and, at some point, it is too late to transport them because they do not have enough time left. So, it is not just about the midwifery-led pathway. I agree with Janet that grass-roots training is important so that they can identify risks a lot sooner and request transport a lot sooner so that they can get to the district general hospitals and to the more qualified professionals. That is important, but this is also down to the choice of the parent and we have to keep in mind that people have choices, although sometimes they are not the result of good advice, which takes us back to the quality of training in the first place.

[37] **Ms Scott:** On the information that parents have, maternity care is all about choice, but we would argue that sometimes women are not fully informed about what the risks are and, therefore, perhaps those choices are not fully informed.

[38] **Mick Antoniw:** Are there similar groups and organisations to yourselves in other European countries and have you had contact with them? Has anything been learnt from those groups?

[39] **Ms Scott:** There is an organisation called the International Stillbirth Alliance that Sands is very closely involved with. We have contact with colleagues across the world. So, we have asked that question a lot, particularly in Norway, the Netherlands and Australia, where the stillbirth rates are coming down. We all have our own kinds of healthcare system, which plays a part. In other countries, maternity care is better resourced. That is an issue. There is better staffing and much better review of deaths, which is a key point, particularly in the Netherlands and Australia. They put a lot of resources and thought and care into looking at every death that happens in great detail and understanding what has gone wrong not just in terms of what is wrong with the baby, but what has happened in the care leading up to that death. They have very good post-mortem services. They include post-mortem information in far more of the reviews, in trying to understand the deaths. They have much better feedback from the deaths into care for future pregnancies.

[40] Systematic mistakes—and mistakes do happen—can be addressed and changed. That is a key thing that we must address in this country. Resourcing, reviewing and general health of the population are all issues. Norway, for instance, follows NICE guidelines for antenatal care and has much better stillbirth rates than we do. They say that it is partly because its population is very much healthier, so they are starting from a better base.

[41] **Mick Antoniw:** First, I would like to ask a little about the coroners system and the statistics that they produce and whether they assist. Taking for example the Netherlands, what would you say is the key difference in what they do that may have made a difference in terms of they reducing the rate?

[42] **Ms Scott:** There has been no real analysis of what goes on in other countries, so I can only tell you what we learn from talking to our colleagues elsewhere. There is a combination of things, such as the review, the resources and all the things that I have mentioned. One thing that struck me regarding Norway is that Sir Frederick Frøen, who is one of the leading stillbirth researchers in Norway, spoke recently at an event and said that people in Norway just consider stillbirths to be unacceptable. They do not think that they should happen. So, there is just a completely different attitude. It is not something that is hidden and not talked about. It is out in the open and considered unacceptable. So, all the care is focused on making sure that they do not happen. There are other things in Norway. For instance, it had a comprehensive strategy for improving its management of decreased fetal movements. That was probably a key part of its reduction in stillbirth rates. There is no definitive evidence to say that, but the reduction accompanied this programme of tackling decreased fetal movement management.

[43] **Mick Antoniw:** One thing that arises out of that which seems to be important is the collation of information, knowledge and research. That seems to appear all through the written evidence that I have seen so far. In all these cases, presumably, there is an inquest.

[44] **Ms Scott:** No.

[45] **Mick Antoniw:** Does it happen in any of them?

[46] **Ms Scott:** I am afraid that I am not totally sure about the situation in Wales. In England, coroners can order inquests, but it is certainly not routine.

[47] **Mick Antoniw:** Do you have a view as to whether that is something that should be done?

[48] **Ms Scott:** Our view in Sands is that we should not automatically have a coroner's investigation, because that is a legal process, it can be a very intimidating process and it can take the control of the circumstances away from parents. It is an incredibly traumatic time, and to then bring in all of those aspects will add to the distress. If it is not necessary, why do it? We would advocate much better perinatal reviews in the hospitals, which are standardised and audited as that would lead to change in the hospitals. That is a preferable route. Parents sometimes ask for a coroner's inquest, but it is out of desperation because they feel that their own baby's death has not been taken seriously and that those investigations have not happened. They also feel that they have not been informed about it. It is critical to have the parents' view and input and to involve them and communicate with them in this process.

9.30 a.m.

[49] **Ms Gittos:** The uptake of post-mortems in Wales is extremely low. That is partly because of the lack of perinatal pathologists to undertake them. People will turn away from having a post-mortem because they cannot lay their baby to rest in a timely manner. It is at least two weeks before their baby is returned to them for a funeral, and then they are looking at six to eight weeks or more before they get the results of the post-mortem. Whereas, for an adult, you are talking about a 24-hour turnaround.

[50] **Mick Antoniw:** Do you think that there should be a comprehensive perinatal analysis with set guidelines and so on?

[51] **Ms Scott:** Yes. With regard to what is happening elsewhere in the UK, we work in Scotland, where they are starting to pilot some approaches to that. In England, we are setting up a working group to come up with some good agreed standards for perinatal review. At the moment, there is no standardised process, and the way in which perinatal reviews are carried out varies hugely from unit to unit. It depends on who is in charge and how much time they have. It is very hit and miss whether you get a really good investigation into what has happened for your baby. Often, parents have a different perspective, and it is really important to bring them into this. They are the only people who have seen the process all the way through. You have many different professionals coming in, but parents are the ones who have the overall perspective, and it is really important to involve their views as well.

[52] **Mick Antoniw:** Thank you, that is helpful.

[53] **Mark Drakeford:** I want to make sure that everyone who has a question has a chance to ask it. Elin, Rebecca and William Graham all have questions. We will go straight to Elin.

[54] **Elin Jones:** Thank you for your evidence this morning. I must say that I was shocked by some of the comparative statistics you provided, such as stillbirths being 10 times more common than cot deaths and 40 times more common than child road deaths. I did not expect those figures. However, I want to ask you about training. Your second recommendation notes that you would like to see stillbirth and associated risks more prominently featured in the Welsh midwifery and obstetric training curricula. Where do you think the deficiencies are currently in the training? Where, specifically, do you think improvements could be made? What areas in the current training could be improved? Is it the ongoing training or the initial training?

[55] **Ms Scott:** It is probably all of the training. Stillbirths are not given sufficient prominence. As I have said before, there is a reluctance to acknowledge that stillbirths happen. No-one wants to think that they happen, but it could be more openly acknowledged in training and the risks could be more specifically discussed. Obviously, training in obstetrics

and midwifery talks about how to avoid poor pregnancy outcomes, as they are called. However, it is rarely taken to the point of saying, 'This can lead to stillbirth'. I know this because we talk to lots of midwives, who tell us that they did not know that stillbirths were so much more common than cot deaths and that they did not know what some of the risk factors were. The evidence we get is that many midwives are not adequately aware of these issues. That must mean that the information is missing, either at the start or during their training.

[56] I would add that better training in bereavement care is terribly important for midwives. I do not think that it is an automatic part of their training. As you have heard, sometimes it is about the simple things that people say to parents, and, if they say the wrong thing, it can have an impact that lasts for the rest of their lives. Parents always tell us, 'Somebody said this awful thing to me and, 20 years later, I still remember it'. Most people working in maternity services want to do their best, but sometimes they just do not know what the best thing to do is when looking after a bereaved parent. People are very scared about what to do with them. So, midwives need that training and all health professionals need much better training in seeking consent for a post-mortem. You will hear evidence later from Alex Heazell, who has done research that has shown that health professionals are very underprepared for seeking consent, which, I am sure, has an impact on the low post-mortem rates in this country as well.

[57] **Rebecca Evans:** In your document, you refer to the different steps forward that have been taken in other parts of the UK. In England, new working groups have been set up. It is probably too early to learn much from them, because they have only been going for a couple of months, but I see that the Scottish work has been going on for a couple of years. Are there any things that are happening in Scotland that we can learn from in Wales?

[58] **Ms Scott:** Yes, and, in fact, the stillbirth working group in Wales has been closely linking up with the Scottish group, and Cath Calderwood from the Scottish group came to the last meeting, which was really good. I am on that working group in Scotland, and we started by thinking, 'What can we do now with the care that is being delivered today?' There is a real variability in the standards of care around Scotland on fetal movement management, detection of poor growth, bereavement services and perinatal review. So, it is trying to standardise across Scotland the best way of delivering care in all those different aspects. It is also very interested in research that will improve understanding of what the best care is. So, there is a possibility that it might do a big fetal movement study in Scotland to find the evidence that we need on how to present information and whether presenting information and improving the management of fetal movements will make a difference to outcomes.

[59] So, the group is coming at it from a variety of angles and the great thing in Scotland is that it can, as you have the potential to do in Wales, bring everyone together to get things moving really quickly. I hope that that will happen with the working group in Wales as well. The big disadvantage for England is that it is too big. It is really fragmented and difficult to make change happen quickly there, but we have real potential here to move quickly.

[60] **Rebecca Evans:** You mentioned the standardisation of care, and I noticed that that is also referred to in recommendation 3, where you say that standards of practice need to be raised across the board. Are you aware of differences in the provision of services and care across Wales?

[61] **Ms Scott:** At the stillbirth working group, we have already had three meetings, and a similar process was carried out where it surveyed all the different health boards around Wales. I have not seen the detail of what came back from that, but there is variability. Everybody acknowledges that and agrees that there is variability. Looking through the evidence that other people have submitted to the inquiry, I see that echoed. I think that that is the case everywhere, so it definitely needs to be tackled here, too.

[62] **William Graham:** You will have seen the terms of reference that the Minister has drawn up for the working group. Should any in particular be emphasised?

[63] **Ms Scott:** Sorry, let me just grab some water. Can you repeat that question, please?

[64] **William Graham:** You will have seen the terms of reference for the stillbirth working group that the Minister has set up. Among those terms of reference, is there anything particular that you think should be emphasised?

[65] **Ms Scott:** Do you mean the stillbirth working group within the maternity collaborative—

[66] **William Graham:** Yes.

[67] **Ms Scott:** I do not think that it was the Minister that set those out, was it?

[68] **William Graham:** That is what we are told.

[69] **Mark Drakeford:** There is a group established by the Minister.

[70] **Ms Scott:** Oh, right.

[71] **William Graham:** You are listed as being a—

[72] **Ms Scott:** Yes, but I did not think that that was established by the Minister. I thought that was within the maternity collaborative. Forgive me if I have got that wrong.

[73] **Mark Drakeford:** The Minister lies behind it somewhere. *[Laughter.]*

[74] **Ms Scott:** Okay. My apologies to the Minister. I am afraid that I cannot remember the exact terms of reference sitting here today. I apologise.

[75] **William Graham:** I will ask you another question then. You state in your evidence that growth restriction is a major indicator of stillbirth. You also state that growth monitoring varies in practice and quality from unit to unit, and does not receive adequate audit. Is that one of the main indicators of stillbirth that should be emphasised?

[76] **Ms Scott:** Absolutely. Growth restriction is strongly associated with stillbirth; 60% of stillborn babies are growth restricted.

[77] **William Graham:** So, that should definitely be included in the reference group for further examination and also as a recommendation for audit?

[78] **Ms Scott:** Absolutely. It is critical. At the moment, the Royal College of Obstetricians and Gynaecologists is revising its guidelines on small for gestational age babies. Those are out for consultation at the moment. You will hear evidence later today about the ways in which growth restriction can be better monitored. It is a tragedy when a baby dies and, after the event, the parent is told, 'Well, your baby was small'. Parents want to know why that was not detected during the pregnancy.

[79] **Mark Drakeford:** Janet, just to perhaps reinforce a point that you made earlier on the basis of international evidence, a research report from England, I think, was published earlier this week that said that, even within apparently low-risk pregnancies, you are twice as likely to have a stillbirth if you are from social class 4 and 5, as the registrar has it, than if you are

from social class 1 or 2. So, the underlying state of the individual's health clearly has a part to play too.

[80] **Ms Scott:** Being from an ethnic minority is also a strong social risk factor. These are things that are hard to modify, obviously, whereas the other risk factors, such as obesity and smoking, are modifiable. So, perhaps we should start by looking at those and what can be done about them.

[81] **Mark Drakeford:** Thank you all very much indeed. It has been very important for us to begin the day by hearing about the experience of parents directly. It will be really helpful for us, as we work through the day, to be able to draw on what you have told us already. Thank you all very much indeed; we are very grateful to you.

[82] **Ms Scott:** Thank you.

[83] **Mark Drakeford:** O ran ein cofnodion, rydym wedi derbyn ymddiheuriadau gan Darren Millar a Lindsay Whittle. Bydd Lindsay yn ymuno â ni am y prynhawn.

Mark Drakeford: In terms of our minutes, we have received apologies from Darren Millar and Lindsay Whittle. Lindsay will join us for the afternoon session.

[84] Bore da a chroeso i chi i gyd i'r Pwyllgor Iechyd a Gofal Cymdeithasol. Rydym am fwrw'n syth ymlaen i'r ail banel sydd gennym y bore yma. Rwyf yn croesawu y bobl sydd ar y panel, sef Elizabeth Duff, uwch-gynghorydd polisi yr NCT, Marilyn Wills, hefyd o'r NCT, yr Athro Gordon Smith o'r Gynghrair Marw-enedigaethau Rhyngwladol a Dr Alex Heazell o ganolfan gwyddorau iechyd academiaidd Manceinion. Croeso mawr i chi gyd i'r pwyllgor. Rydym yn gofyn i chi am wneud unrhyw sylwadau agoriadol byr sydd gennych cyn i ni droi at aelodau'r pwyllgor i ofyn cwestiynau.

Good morning and welcome to you all to the Health and Social Care Committee. We are moving straight ahead to the second panel that we have this morning. I welcome those on the panel, namely Elizabeth Duff, senior policy adviser to the NCT, Marilyn Wills, also from the NCT, Professor Gordon Smith of the International Stillbirth Alliance and Dr Alex Heazell of the Manchester Academic Health Science Centre. A warm welcome to the committee to you all. We invite you to make any brief opening remarks that you have before we turn to members of the committee for questions.

[85] I invite you to make some brief introductory remarks. I am sorry to put an emphasis on 'brief', but we have only 40 minutes with you all as a panel and I know that there will be many questions that committee members will want to put to you. Elizabeth, are you going to lead off by saying something to us on behalf of NCT?

9.45 a.m.

[86] **Ms Duff:** I would be very happy to do so. Good morning and thank you very much for asking us to come and give evidence. We have submitted a written paper, which I expect you have all had. What I want to say is based on that.

[87] You will understand that the NCT is a UK Charity that aims to help and support and represent, as far as we can, all parents. So, we are not a specialist charity for parents who have experienced stillbirth or are at a high risk of it, but we hope to do what we can for parents in either of those categories and provide information.

[88] The principal part of our evidence was about our strong feelings that high-quality midwifery care is one of the most important things for women in pregnancy, in labour and in birth. The particular aspects of good midwifery care that we hope to see are the continuity of

care during pregnancy that allows a woman and her midwife, or perhaps a small team of midwives, to establish a relationship so that the woman trusts her midwife and can therefore talk to the midwife about any anxieties and concerns, and the midwife is able to get to know the woman and her family and understand any underlying problems, or in any case the clinical progress of the pregnancy and the growth of the fetus. That is particularly important in the late stages of pregnancy, when the woman is feeling fetal movements. If she feels that there is any difference, whether that is based on the counting of kicks or not—I am of the opinion, having looked at the evidence, that counting kicks is not particularly helpful; it is about the woman's intuitive experience of how her baby moves—her confidence in being able to report that to somebody she can trust to take the right action is very important.

[89] Finally, when women are in labour, stillbirths can happen during intrapartum care, which, if you can make such a comparison, is almost the most devastating and regrettable kind, because it is a time when a woman should be receiving care that is absolutely continuous and focused on her. We have always been very much in favour of, and have lobbied for, the type of care where women get one-to-one focused care from a midwife at least and, if necessary, other health professionals during her labour. That is the emphasis that I would like to put on what we have said in our paper. In reading the other evidence, I was pleased to see that some of the medical views support the fact that women's own ideas on, and expressions of, what they feel is happening in late pregnancy are very important—their assessment of fetal movements can be a better indicator than fetal heart rate, for example, or something that happens earlier.

[90] **Mark Drakeford:** Thank you very much indeed. Professor Smith, do you want to say something for the International Stillbirth Alliance?

[91] **Professor Smith:** The perspective that I would put is that, simply, this is a problem that is both potentially solvable and one that has been relatively neglected. In the UK, there are over 4,000 stillbirths a year—190 in Wales—and about a third of those deaths are babies at term without structural abnormality. These are babies that, if delivered prior to the event, would have had a normal life and normal survival. When we compare the numbers to other focuses of public health, we can see that there is demonstrable relative neglect. Looking at stillbirth as an entirety, it is as common as death in the first year of life. If you think about death in the first year of life—infant death—you are looking at all prematurity, sudden infant death syndrome, a proportion of abuse, infection, such as group B streptococcus and other infections acquired around the time of birth. If you put all those together, then you see a huge focus of research and public health interest. It is then difficult to see that there is a commensurate magnitude of interest in the problem of stillbirth. That is manifested in the essentially static rates of stillbirth over the last 20 to 30 years.

[92] The introduction of basic obstetric care in the second half of the twentieth century had a massive effect on overall rates of stillbirth, but there is a persistent and difficult-to-remove rate that remains unacceptably high. Examination of the individual deaths indicates that many of those would have been situations where, had we better tools for identifying the baby at risk, we could have done something about it. So, that is one thing to say: you are looking at a problem that is both important and potentially tractable, but that has been relatively neglected and is, therefore, a worthy focus for you.

[93] On how I would see the way ahead, one key point is to ensure that in the hospitals under your control, the best quality care is being delivered at the moment—that you have a careful investigation of deaths after they have occurred to try to identify whether there were any potential failings in care and whether you could make changes in the way that care is provided to try to address the problems and prevent them from occurring in the future. One thing that you can do is take the existing knowledge and ask whether it is being appropriately applied in the cases that are occurring at the moment.

[94] I would perhaps caution against thinking about reorganising obstetric care and asking whether there is something that everyone has missed. The National Institute for Health and Clinical Excellence has taken a close look at the basic patterns of provision of antenatal care for low-risk women and in certain high-risk situations and has done a detailed examination of the evidence. It has come up with guidelines that provide the pattern for antenatal care. As was mentioned earlier, the country in Europe that has the lowest rate of stillbirth is Norway, which uses the NICE guideline on antenatal care. So, I would largely caution against thinking that you should go in and make recommendations that obstetric care be changed.

[95] The third point is the potential for research in that we know that there are certain associations with many of these deaths, for example, advanced maternal age, obesity and smoking, but none of those are sufficiently discriminating to be able to say to someone that they are at such a high risk that we should be doing something dramatically different with their pregnancy. There are ways of discriminating risk that are relatively crude; there is a background risk of one in 200 and most of the risk factors that we have marginally increase or decrease that according to whether the risk factor is or is not there. What we really need is the research that identifies stillbirth, for example, a screening test for stillbirth, in the way that we have a highly effective screening test for Down's syndrome. We have a method of screening for Down's syndrome, where we can screen the whole population and identify less than 5% of them as being high risk and in that figure of less than 5%, we can identify 90% of cases of Down's syndrome. If we can do that for Down's syndrome, it would seem to me that there is potential of doing that for at least some types of stillbirth, but the reality is that we are not trying to do that through research because the funding is not there.

[96] **Dr Heazell:** I concur with pretty much everything that Professor Smith has said. There are some areas that we need to learn from in the way that we deliver obstetric care. There is potential to identify women who are at a higher risk of stillbirth close to the event by listening to women who present with reduced fetal movement. The majority of those women go on to have normal pregnancies, and although they have a modest increased risk, some of the research from Norway would suggest that if we provide careful assessment of those babies, we may be able to identify some who are at an increased risk of stillbirth. In 33% of pregnancies at term that are currently stillborn, there is a safe and effective treatment, which is delivery of the baby. Recent evidence from analysis of the Scottish database suggests that that can be done with a minimum in the increase of operative intervention from an obstetric perspective.

[97] **Mark Drakeford:** Thank you. I will now turn to committee members for their questions. Given the amount of time that we have and the number of questions, it would be helpful for Members to direct their questions to particular members of the panel, because I doubt that we will get every member of the panel to answer every question and get through all of the questions.

[98] **William Graham:** Professor Smith, thank you for your evidence. You said that it would be necessary to focus efforts on women who might ordinarily be regarded as being low risk. Could you amplify that?

[99] **Professor Smith:** There are certain groups among which we know that there are definitely significantly higher rates of stillbirth. For example, in twin pregnancies, and in particular with identical twins, where they share a membrane, there is a very high risk of stillbirth, as there is for women with pre-existing diabetes. However, when we look at the total number of stillbirths that occur, we see that most stillbirths occur to women who lack risk factors. So, if you are going to impact the overall rate of stillbirths, you are going to have to reduce the number of stillbirths in those women who appear to be low risk. It is not that we should necessarily be intervening in the pregnancies of all of these women, but we should be

doing something to try to better identify whether they are at risk of stillbirth and should be channelled towards the high-risk pattern of care or whether they have a healthy placenta, and maybe do not need to see a doctor again for the rest of the pregnancy. That is the key; it is not that we should be intervening, but we need a better way of discriminating the low-risk women who have a high-risk placenta.

[100] **William Graham:** So, identification is the key, is it?

[101] **Professor Smith:** Yes, it is about screening.

[102] **William Graham:** My second question is for Dr Heazell. You comment on the new national guideline, which was peer reviewed and published last year. Is it too soon to speculate on the results?

[103] **Dr Heazell:** We are currently carrying out a survey to determine how much of the guideline has made it into local practice. Writing a guideline is no guarantee that people follow it. Although we should be aware of women presenting with reduced movements, further research is needed to identify those women who are in a low-risk category, either to reassure them that they remain at a low risk of stillbirth or to say that they now have a high risk of stillbirth because the placenta is not working properly. That research is still needed. We hope to find out in the latter half of this year how much of the guideline has been implemented. If the guideline has been successfully implemented, we can assess whether that has had any impact on the stillbirth rate.

[104] **William Graham:** How is the audit of the guideline published?

[105] **Dr Heazell:** Hopefully, it will be submitted for peer-review publication by the end of the year.

[106] **Mick Antoniwi:** To Professor Gordon Smith and Dr Heazell, but not exclusively, when a stillbirth occurs, how is it categorised by the medical profession for the purpose of the death certificate? What categorisation do you put? Is it 'death by natural causes' or 'death by stillbirth'? How do you categorise it?

[107] **Professor Smith:** First, in terms of the legal sorts of things around the registration of births and deaths, I would not identify myself as being particularly expert in that. I understand that there is a record of stillbirth certificate. In terms of the cause of death, there is a whole range of different ways that people have attempted to classify why a baby dies. The results of those are dependent on the classification system. One way that people do it with stillbirth certificates in Scotland is to use the diagnostic categories of the international classification of disease, but they are not particularly well-suited for stillbirth. There are many conditions that would be responsible for stillbirth that would not be present in the standard ICD categories. I have worked with the National Institutes of Health in the US on a classification system for stillbirths. In the region of 40 or 50 different classification systems have been described, and it is an area where there is something of an inconsistency of approach.

[108] **Mick Antoniwi:** Would it help if there was a more consistent system of categorisation? I am leading towards the investigation, analysis and research that arise from the analysis of stillbirths.

[109] **Professor Smith:** You actually then get into an area of some scientific uncertainty. I have close links with placental pathologists, and there are diverse opinions within the profession of pathologists as they examine the placenta. The reality is that if you look carefully enough at the placenta of a perfectly healthy woman who has had a perfectly normal birth of a baby that survived and did perfectly well, you can see many apparently histological

abnormalities in what appears to be a normal pregnancy outcome. The danger then with an adverse event is that a pathologist going over the placenta in detail might describe a whole series of findings that they would regard as abnormal, but the information that says what is causally related to the death is missing.

10.00 a.m.

[110] When you encounter the classification of death, you have this spectrum where there are some deaths—a small minority—where we have a really good mechanistic understanding of why the baby died on one end, to the other end of the spectrum where we have no idea why the baby died; there is every shade of grey across that spectrum, with increasing uncertainty. That is the buffer that every classification system hits—where do you end the uncertainty? Personally, my feeling is that the measurements that we make before the stillbirth are the things that are ultimately going to be clinically useful. We can pick through the histopathology, but what is it that we can measure in the blood of the woman two, four or eight weeks before the stillbirth? That is the way that we will ultimately make progress.

[111] **Mick Antoniwi:** Do you think, therefore, that there should be a consistent comprehensive evaluation where stillbirth occurs? I am thinking about research knowledge and understanding, because the indicators seem to be that there is a lot of inconsistency. There is an awful lot of information to be gleaned and analysed to try to find out why stillbirths occur. Is there a benefit in going down that particular road? Is that something that you think is worth doing and would be recommended?

[112] **Professor Smith:** I would see that as being one element of a comprehensive programme of review of losses so that, when a baby is stillborn, there would be a review of the clinical circumstances leading up to the loss. There would then be a review of the evidence around why the loss happened, which would include examination of the placenta. However, I say that with the caution that that has to be in the knowledge that abnormalities in the placenta can be relatively common in straightforward pregnancy as well.

[113] **Dr Heazell:** I would add that we have looked at quality of data. As Professor Smith said, there is the medical certificate of stillbirth that is issued shortly after the loss happens to enable the parents to register that death. An audit of those certificates showed that the quality of data on those was extremely poor. That data is fed back to the Office for National Statistics, so the level of data there is not good.

[114] One of the other problems is that the quality of perinatal review is extremely variable, depending on different organisations. There is no compulsion on any institution to meet a minimum quality standard for their perinatal review, which I think is critical. The analogy that I would use is that many crimes would be unsolved if nobody ever looked for any fingerprints or evidence. As Professor Smith alluded to, causality can be a difficult thing to infer, but that is also the case in adult and child deaths at times. Sometimes, there are sudden unexplained deaths in infancy. We have to accept that there may be an analogy in stillbirth. However, if we do not have proper review and we do not look for a cause, we almost certainly will not find one.

[115] **Kirsty Williams:** Professor Smith, this morning you said that a country on the continent that is doing well is just implementing our guidelines. Are you saying, therefore, that this committee could not recommend anything more useful than ensuring that established and published guidelines of what constitutes good care are adhered to and that that would lead to a drop in the number of stillbirths?

[116] **Professor Smith:** I think that there are two elements. The first is to ensure that what we know at the moment is implemented completely. The second is that we should then be

working to generate the research that will transform the guidelines in five or ten years' time. I would say that the question is what is happening that will mean that the NICE guidelines in ten years' time are going to look any different from the NICE guidelines of 2008. I personally agree that the use of tape measures to measure the fundal height in the twenty-first century is almost bizarre, particularly when you look at it against Down's syndrome screening, where we have the ultrasonic measurement of nuchal translucency, four biomarkers in the second trimester and two biomarkers in the first trimester. That is twenty-first century screening, whereas the screening for stillbirth in the third trimester with a tape measure looks rather crude in comparison. You want to be ensuring that your existing knowledge is implemented, but at the same time, we need to be doing the research that tells us what we should be doing in future.

[117] On the issue around routine scanning, which I heard being mentioned earlier, the problem is that there have been randomised control trials of literally tens of thousands of women that failed to show a benefit. However, that then points to re-examining the research base and coming up with new approaches and methods that would make it more effective.

[118] **Kirsty Williams:** Dr Heazell, you talk about what happens to a woman if she reports reduced fetal heart movements and attends. So, first of all, we have the issue of making sure that people attend and that, when they do attend, everyone is put on a monitor, or a hand-held listening device is used, but only a small percentage of women go on to have more in-depth investigations by way of scanning and looking at liquor volume and the health of the placenta. Forgive my ignorance, but do the NICE guidelines say that that is what should happen if a woman attends for reduced fetal movements?

[119] **Dr Heazell:** The 2008 NICE guidelines were completed prior to that research being in the public domain, so it was not subject to its evaluation. I think that the data from Norway are still relatively preliminary, although they give us an idea that doing an ultrasound scan identifies a percentage of babies that are small and where the placenta is not working as well as it should be. The NICE guidelines are clear that counting to a specific number does not help to identify stillbirths. So, there has been an extensive randomised controlled trial of the idea that you should have 10 movements in 12 hours, which showed that there was no reduction in perinatal mortality. However, that study also identified that women who were identified in the counting group came to hospital more often and had a live baby when they came, but sadly the management at that point was not able to tell which babies to deliver. So, the royal college guideline recommends that all women should have a fetal heart rate trace to identify those who are in imminent danger and, subsequently, if the clinician has a high index of suspicion that the baby may have fetal growth restriction, an ultrasound scan should be performed.

[120] **Mark Drakeford:** I will go to Rebecca next and then Elin, but I will pause for a moment to see whether the NCT would like to add any comments to that little basket of questions that we have had so far.

[121] **Ms Duff:** Marilyn has not spoken, and she is one of our antenatal teachers who works locally, so I just want to give her the chance to contribute.

[122] **Ms Wills:** I would just reinforce that listening to what women are saying is the most important thing, really. Women are the ones who are aware of their baby and aware of their baby's movements. If they feel that it is different, listening to them and acting on that is important.

[123] **Rebecca Evans:** That leads me to the question I wanted to raise with the NCT. You talked about the importance of women's instinct regarding fetal movements and so on, but how aware do you think women are when they are pregnant of the significance of fetal

movement? How are they being made aware of that, and what improvements can be made?

[124] **Ms Wills:** I see a lot of pregnant women, usually towards the end of their pregnancy, so from 28 weeks onwards. I see couples—not just the mums, but both parents—and they like to talk about their baby. Certainly, in classes, I will get them to describe what they know about their baby, and a lot of them will say, ‘It always wakes up when I go to bed’. They are aware of when the baby moves, from that point of view. They have regular antenatal care with their midwives, and their midwives will ask them about their baby, too.

[125] **Rebecca Evans:** As well as asking about the baby, will you, in your teaching role, or the midwives make the woman aware that, if there is a change, it could potentially be very serious?

[126] **Ms Wills:** Certainly, in the classes that I teach, one of the things that I would say is that they are the ones in touch with their baby, and so if they notice anything unusual, they should contact their midwife or the unit straight away, and they will always talk to them and see them. So, I give the parents the reassurance that there is someone to go to, even if it is for something trivial. During the course of our teaching those antenatal classes, women very often come in and say that, over the weekend, they felt that the baby was not moving and was very quiet and so they went to get checked and got put on the monitors. It does happen and people take note of that. I am very much aware that the people who come to our classes do not represent everyone in Wales; they are a small amount. However, women are in tune with this. They are thrilled when they see their baby on a scan. It makes the baby real to them. They are thrilled when they feel the baby move. Very often, the dads also get quite excited when they see the baby move. So, it is something that they are aware of and take notice of.

[127] **Rebecca Evans:** The only thing that concerns me is that, with such a focus on the woman knowing her baby and her body, there is a lot of pressure on the woman to know when there is something wrong and to identify that. In due course, if there were to be a stillbirth, that could lead to the woman questioning whether she should have known better, whether it was her fault or whether she had missed something. It is a delicate balance to strike.

[128] **Ms Wills:** It is a dilemma. Over the years, I have known women who had stillbirths, including those in the medical profession who you might have thought would have a little more insight. It is still an unknown thing. It is difficult to know who they will want to blame. I have seen some women who do not blame anyone, who just accept that it was one of those things and get on. There are others who go into quite a deep depression and think that it was all their fault.

[129] **Elin Jones:** You have said that a weakness is the failure to fully implement the NICE guidance. Is that related to deficiencies in the training of midwives and clinicians? We heard a bit about that in the evidence given in our previous session, so I am interested in whether any of you have any comments to make on the initial and ongoing training of midwives and clinicians.

[130] **Dr Heazell:** We surveyed a number of curricula and, surprisingly, in many midwifery colleges, stillbirth is covered for perhaps a day during a three-year course. There is not necessarily a requirement within those curricula for midwives to have cared for a parent who has experienced a stillbirth, either during the time of that loss or in a subsequent pregnancy, although, if a student feels that it is relevant, it is encouraged. However, it seems to me that we should extend that. If one in 200 people they look after is going to experience this, there needs to be a greater focus on it in the course. That is even more the case with medical curricula because there is such a pressure to fit a great deal in. Many medical schools are reducing their obstetric curricula rather than extending them. However, we have recently been

able to develop the stillbirth curriculum within the training programme for trainees in obstetrics and gynaecology. It is now formally recognised that there is a need to develop that. However, I would argue that midwifery training seems to be particularly deficient in that regard.

[131] **Professor Smith:** Another possibility might be to investigate whether there is any evidence of a failure of knowledge on the part of an individual practitioner where there has been a loss. For example, did a woman report reduced movements to a midwife or doctor who did not then act on it—not because they did not care whether the baby was stillborn but simply because they did not attach any significance to it? Was there a general taking-into-account of the risk setting? For example, if a woman of 41 in her first pregnancy attends with reduced movements at term, there are issues there that should make you focus even more on a particular presentation. We should also look at whether there is a structure for the provision of maternal fetal medicine-oriented specialists in every hospital so that, if there is a possible problem, there is someone to refer the woman to. That is where the detailed review of deaths allows you to audit whether people might not have been trained or might not be retaining what they were trained in, so it could be an issue of continuing medical or nursing education. One way in which you will identify these gaps is by the more detailed investigation of adverse events.

10.15 a.m.

[132] **Kirsty Williams:** With regard to specialists in fetal medicine, are those individuals available? I am aware that the expert in fetal medicine in Abergavenny who looked after me has retired and has not been replaced by anyone with similar skills, so that service is lost. I wonder whether that is an important feature to have, whether those people are out there and what we need to do to train them.

[133] **Professor Smith:** There are certainly training programmes in maternal-fetal medicine in every teaching hospital around the country—or that would be my perception. There is almost a perception that too many sub-specialists have been trained and that hospitals require more generalists, because you have only a certain number of consultants. So, my response to that would be that I do not know of any national shortage of maternal-fetal medicine practitioners. People have been trained, but the hospital has to have the resource to take one of its consultant positions or create a new consultant position to focus on high-risk pregnancies. A lot of small hospitals will need somebody to be on call for gynaecology and to do everything else, so the hospital might choose not to appoint a maternal-fetal medicine specialist, because it has another, more general rota to cover.

[134] **Mark Drakeford:** I am afraid that we are very close to the end of our session already, and so what I will do, which is probably a bit unfair, is invite each of you to offer us some thoughts on this. It seems that the weight of the evidence that we have had on paper and from what we have heard already this morning is that, if you are identified early as someone who is in a high-risk group, you will get a sound service in respect of monitoring and being looked after, but there is a group of people who are low risk in all sorts of other ways, and that is where we have to make some progress if we are to make any inroads into the figures that have stayed so stubbornly similar over the past 20 or 30 years. At the end of the day, I expect that we as a committee will scratch our heads and wonder what key recommendations we should make to try to begin the process of making those inroads. If you could suggest to us what your one or two top recommendations would be, what would you leave us with?

[135] **Dr Heazell:** Given that the bulk of women are low risk, I would say that if a low-risk woman presents with a significant reduction in fetal movements, she needs to be evaluated to see whether she remains low risk or whether she then becomes at a higher risk of stillbirth. That may be because she is 41 years old and she is at term, and we will offer her an induction.

So, I would say that my top two would be to constantly re-evaluate people's risk status and to act on it when someone says that there are reduced movements, so questioning the low-risk status of that woman.

[136] **Professor Smith:** I would recommend a system of reviewing stillbirths and other perinatal deaths, to really try to understand why a baby died and take that death seriously. You could work out in what cases there were avoidable components, and whether there were ways to address those avoidable components for the future in how your services are constructed. That is one. The second is what is being done by way of funding for research. This is an area where there is no major charity. There is no British Heart Foundation or Cancer Research UK, which sponsor huge programmes of work in their areas. There is very little in the way of charitable funding for this area, so what is the Government doing to fund the research that will generate the tools for five to 10 years' time?

[137] **Ms Duff:** I will stay with the continuity of midwifery care during pregnancy with women, hopefully, seeing only a small number of midwives and, as far as possible, receiving one-to-one midwifery care during labour. I am aware that we have not touched on the issue of the birth setting, whether women give birth in an obstetric unit, a birth centre outside of hospital or at home. Parts of Wales have what I regard as a commendable and safe record of quite high levels of home births, and I hope that they will remain as high or higher, because I have not seen any evidence that that leads to adverse events. Our belief is that there are some excellent models of care for out-of-hospital birth settings, so long as the woman remains on a low-risk pathway. That is not particularly a recommendation, but there is no reason to move away from that.

[138] **Ms Wills:** It would be good if public awareness could be raised about stillbirth in the way that it has with safe sleeping for babies and things like that. That has had a huge effect on bringing down the number of cot deaths. It is a hard thing to do, but trying to raise public awareness would be a huge step forward, and then having steps or things to do to help to prevent stillbirths: calling your midwife if you are concerned, and that sort of idea.

[139] **Mark Drakeford:** Thanks to you all. It has been helpful to us, so thank you for your time this morning.

[140] Cymern egwyl yn awr am 10 munud. We will now take a break for 10 minutes.

*Gohiriwyd y cyfarfod rhwng 10.21 a.m. a 10.31 a.m.
The meeting adjourned between 10.21 a.m. and 10.31 a.m.*

[141] **Mark Drakeford:** Bore da, a chroeso. Rydym am fwrw ymlaen â'r trydydd panel y bore yma. Croeso i Mr Bryan Beattie o bwyllgor gweithredol Cymru Coleg Brenhinol yr Obstetryddion a'r Gynaecolegwyr, a'r Athro Jason Gardosi, cyfarwyddwr Sefydliad Amenedigol Gorllewin Canolbarth Lloegr. Diolch i chi'ch dau am ddod yma bore yma. Rydym am ddechrau, fel arfer, gan ofyn ichi am unrhyw sylwadau agoriadol byr cyn imi droi at aelodau'r pwyllgor.

Mark Drakeford: Good morning, and welcome. We will now proceed with our third panel of the morning. I welcome Mr Bryan Beattie from the Welsh executive committee of the Royal College of Obstetricians and Gynaecologists, and Professor Jason Gardosi, director of the West Midlands Perinatal Institute. Thank you both for coming this morning. We will start, as usual, by inviting you to make some brief opening remarks, before I turn to committee members.

[142] I will ask, in the way we normally do, whether there are any brief opening remarks you would like to make. We have had your written evidence, so thank you for that. If there is anything that you want to draw to the surface of it briefly, please do, and then we will go

straight to questions from committee members.

[143] **Professor Gardosi:** I would like to express my support for the ability to talk about stillbirth at this high level. Very often, it is not regarded as something very important. It is an essential part of maternity care and needs to be recognised as such. I am here because we have tried to address perinatal mortality and stillbirths, in particular, in the west midlands over the past few years in a combined programme of looking at our local evidence and implementing the available learning points we have derived from that. We feel that we have made good progress, and I would like to share what we have developed, because it may be relevant to the problems you are facing.

[144] **Mr Beattie:** I work as an obstetrician at the University Hospital of Wales and have been fortunate enough to be there for about 20 years. One of the overarching and recurrent themes is that, as an obstetrician, we often have to sit down with parents who have lost a baby and look at what has happened and at how we could get it right the next time round. The frustration is that, 20 years on, we do not seem to be doing that any less and we do not seem to be making very much progress. In some ways, stillbirth is just the tip of the iceberg; it is the very bad end of what happens when maternity care is not as good as it could be. It is a very wide and encompassing brief. It is not just about addressing the issue of stillbirth, but about looking at ways of improving maternity care generally and, as a consequence of that, hopefully, reducing the number of babies lost every year.

[145] **Mark Drakeford:** Thank you. We will go straight to questions from committee members, and start with Kirsty.

[146] **Kirsty Williams:** Mr Beattie, could you elaborate on point 3 of your paper, around clinical networks, commissioning and workforce issues? In our last evidence session, we were told about the importance of being able to refer to a specialist in fetal and maternal medicine. Do you have any figures for how many people are employed in Wales to provide that service? Also, could you say why a clinical network would be valuable?

[147] **Mr Beattie:** There are two issues, one of which is to do with the specialist end of maternity services. Currently, there are two full subspecialty trained fetal medicine consultants in the whole of Wales. The Royal College of Obstetricians and Gynaecologists conducted a review of the service about three years ago and suggested that a region of this size would probably need another two full-time fetal medicine specialists. It also made recommendations in relation to the number of maternal medicine specialists—fetal medicine specialists tend to focus on problems with the baby, whereas the maternal medicine specialist would focus on mothers with heart disease, kidney problems and so on. In many other regions of the United Kingdom, those are tertiary commissioned services, so they take them off the main budget for the individual hospital providing them, and they are funded and monitored completely separately.

[148] One of the difficulties we have had in Wales is that those services are just lumped in with the general obstetrics services in hospitals. Therefore, you are competing with gynaecology waiting lists and various other normal, general obstetrics and gynaecology pressures and are not in a position to develop the service. We had an extra colleague a few years ago who was not replaced when he left. So, currently, patients who are resident in Gwent need to travel across the bridge to Bristol to access fetal medicine services, and although the estimated cost of that is considerably more than providing the service in-house, we have not been able to move to that point.

[149] **Kirsty Williams:** You referred to two colleagues; where are they based?

[150] **Mr Beattie:** Christine Conner and I are both based at the University Hospital of

Wales.

[151] **Kirsty Williams:** So, what happens to women in north Wales who require this service?

[152] **Mr Beattie:** They would probably be referred to the Liverpool maternity hospital. Again, the presence of a suitably trained consultant in north Wales would mean that patients could be looked after much closer to their homes.

[153] **Mick Antoniw:** Looking at the statistics, one of the points you make is that the risk assessment for stillbirth is not very advanced. You also produced some very interesting statistics for the number of pregnancies—the top 5% that do not end in stillbirth, and the 95% of stillbirths that occur in pregnancies that are not predicted to be at risk. You also mention—I am putting this together because they seem linked—the risks between 24 and 43 weeks of gestation. Is there any particular medical reason for the number of pregnancies that go quite a number of weeks beyond nine months where birth is not induced? Is that of statistical relevance to risk factors in stillbirths?

[154] **Mr Beattie:** Yes, once you go beyond that time—certainly beyond 42 weeks—there is a well-recognised increase in the risk of placental insufficiency and stillbirth. So, for some time now the recommendation in the UK has been to induce labour at around 10 to 12 days past the due date, because we know that there is increasing placental failure beyond that point. Given pressures on maternity services, one problem is that women who may be scheduled for induction at 12 days past their due date may not be brought into hospital until 13 or 14 days past their due date, and because the ripening process to prepare the cervix before labour can take one or two days, you have some mums delivering 14, 15 or 16 days past their due date.

[155] One group consists of those who have been identified as being in a higher risk group, because they have gone significantly beyond their due date, but we are not able to bring them into hospital and get them delivered. With the other group, it is an educational issue, in that there are some women who are reluctant to have any intervention. That is something that requires a lot of time and effort, not to force people to do something different to what they want to do, but to ensure that they really understand the significant increase in risk of declining that intervention. Certainly, one thing that would be useful to review on an ongoing basis would be the number of women in Wales who deliver at more than term plus 13, to look at the outcome for those pregnancies and whether it was a maternal choice issue or a resource issue that meant that they could not be delivered in a more appropriate time.

[156] Some very interesting work has also been done recently suggesting that induction of labour in and around the due date is not associated with an increased risk of caesarean section. One of the reasons for avoiding intervention is that there was a concern that many people end up having unnecessary caesarean sections, but there is fairly good evidence now to suggest that that is not the case. For women with other risk factors, such as advanced maternal age, smoking or obesity, there may well be advantages in having a rethink and perhaps even inducing them around about their due date, rather than letting them go significantly past that point.

[157] **Mick Antoniw:** You say that there is a lack of knowledge of pathology. In order to help us pull some of this information together, could you outline exactly what happens where stillbirth occurs, in terms of the recording, evaluation and analysis of what has happened? What information is put together and how consistent is it? What are your views on that?

[158] **Mr Beattie:** One thing that is standardised—there is a lack of a detailed standardised approach—is a pro forma that is normally completed by the senior midwife or a doctor, which is submitted to the all-Wales perinatal survey. You will have representatives from that group

in later today to discuss that function in more detail. That captures some basic clinical information about the pregnancy and any investigations that were done.

[159] In terms of investigations, a post-mortem would be advised in all cases, although the problem is that uptake is poor, because a lot of people decline to have a post-mortem, mostly because the parents are completely grief-stricken at that time. There is also no time for a senior health professional to spend an hour with a couple at that difficult time to broach the subject and to explain to them the importance of understanding what has happened, but also what might be looked for or done better in a subsequent pregnancy. There is some ongoing work being done to look at training healthcare professionals to give them a greater degree of confidence in being able to talk about post-mortem and, hopefully, leading a greater number of couples to make the decision to go ahead with that.

[160] The other thing that runs alongside that is a standard batch of blood tests to look for things such as viral infections, chromosome abnormalities, clotting defects and so on. However, it is variable, because it tends to depend on which hospital you are in and which batch of tests were done. One of the things that the 1000 Lives campaign will be looking at in its stillbirth working group is trying to build, alongside the all-Wales perinatal survey reports, an agreed minimum dataset of blood test investigations that would be advised.

[161] The other thing that needs to be done is to have a much more detailed look and evaluation of the pregnancy. In the past, they used to have a confidential inquiry into all stillbirths, and that process has been lost. Some very useful data can be gained from that, whereby an obstetrician, a midwife, a pathologist and perhaps one or two other healthcare professionals sit down and review the case notes, looking to see what aspects of the care could be improved upon and then use that as a learning process, disseminating that information to other people.

[162] **Mick Antoniw:** Are you any aware of any parts of Europe, the United States or wherever, where there is an ideal system in place that carries out all these things?

[163] **Mr Beattie:** Jason has done quite a lot of work on this, and he might like to pick up on that, in terms of looking at a structured perinatal review.

[164] **Professor Gardosi:** Yes, we had the same observation that, in many instances, the hospital-based investigation of an adverse outcome was haphazard and very heterogeneous. It might have just been a presentation in front of a perinatal meeting, a small group getting together, or a letter to the GP and so on, but there was no structured or forensic way of looking at the causes and the clinical pathway of that mother and baby. So, we implemented a confidential inquiry programme with the support of the strategic health authority and the primary care trust in the west midlands.

10.45 a.m.

[165] Over the past few years, we have refined what we wanted to look at, including, for example, stillbirths with fetal growth restriction, intrapartum stillbirths and stillbirths to migrant mothers and so on in order to look at the particular problems. We found that, first, in the case of more or less whatever we looked at, most of these deaths—up to 85% of them—excluding congenital anomalies, were potentially avoidable and were associated with substandard care—care that the hospital was accepting as, ‘That is how our care should be and it should not be according to someone else’s standards’.

[166] Secondly, we shared the results of this external review of a multidisciplinary group, as Bryan described, with the hospital concerned and compared it with the result of its own internal review of that case. We found that 74% or three quarters of the learning points from

the independent committee were not reflected by the in-house review. So, many learning points were missed. We feel that there needs to be a reaction to what can be learned from these cases and, secondly, there needs to be a standard way in which these cases are being reviewed. So, we are implementing a score to standardise the clinical outcome review for stillbirths and neonatal deaths. That allows the hospital-based group to look at their own cases in a standard way and ask, 'Was this done?'. There is also the need for a quality assurance programme where independently external people, in a round-robin way, can assess what the unit itself has found and whether or not that was up to the review standard that should be expected.

[167] This is almost like a small version of doing a plane-crash-type of review, and if we take stillbirths seriously enough, then there should be a proper review of what has gone wrong. If you do that, you find that most of these deaths are, in fact, avoidable.

[168] **Mr Beattie:** Presumably, the sharing of that information would be the next step, once you have gleaned it.

[169] **Professor Gardosi:** That is a good point. We have had around 200 cases across the region over several years, involving around 170 or 180 clinicians, including senior midwives, obstetricians and neonatologists. They are the ones who would spend an afternoon looking at four or five cases; it is a hard grind that involves looking through the cases in a confidential manner. In other words, everything is anonymised. However, during that process, those professionals are learning from others' mistakes, while other people are learning from their mistakes in turn. That is a very important learning process, which raises the awareness of the avoidability and the importance of sticking to the standards and ensuring that they are implemented.

[170] **Mark Drakeford:** Is there a publicly available paper that sets out the score system and how you are implementing it?

[171] **Professor Gardosi:** Yes, we are currently piloting it, but, on our website, there is a full description of what it is and I think I have included it in my evidence.

[172] **Mark Drakeford:** Thank you; that is very helpful. Many Members have questions to ask, so I will move straight to William Graham.

[173] **William Graham:** We have learnt this morning that the focus is on identifying people who are thought to be low risk but are not. What emphasis would you put on the growth function and placental function and how important are those in raising awareness?

[174] **Mr Beattie:** One problem is that we can identify pregnancies where there are maternal risk factors, and some high-risk mothers will then have babies who are at risk, but what we cannot do particularly well is identify the baby that is in trouble in a mother who is otherwise healthy. This is similar in some ways to screening for Down's syndrome. We know that the babies of mothers who are over 35 have a much higher chance of being diagnosed with Down's syndrome, but just as many babies are born to younger mothers as to older mothers because there are more mums under the age of 35. So, instead of saying to the over-35s 'Have an amniocentesis' and, to the under-35s, 'Don't worry', we have moved on and we say, 'In any pregnancy, the mother might have a baby with Down's syndrome and, therefore, you should offer universal screening'. The same approach has to be taken to pregnancy. There is no such thing as a low-risk baby that we can identify antenatally. Therefore, our antenatal care needs to be geared towards looking for babies who are in trouble and continuing to re-evaluate that pregnancy.

[175] Although it is an expensive resource, if you look at what happens in some other

European countries, you will see that there is a much greater emphasis on ultrasound and serial ultrasound assessment for all pregnancies. At the University Hospital of Wales, we have a rotational trainee from Belgium every year as part of an exchange programme, and it is useful to listen to what happens in other countries in Europe. They have virtually abandoned the inch tape in favour of a much more scientific approach to monitoring.

[176] So, there are two messages. One is that there is no such thing as a low risk until the baby is in the cot, and the second is that, therefore, we need to look at monitoring all pregnancies effectively and not just the high-risk ones. We know that when we monitor high-risk pregnancies, we get a good outcome, so it is not unreasonable to expect the same if we were to do the same for the low-risk pregnancies.

[177] **Professor Gardosi:** The challenge at the beginning of the pregnancy is to identify which mother is at high risk. She can be at high risk for a number of reasons. We have identified in our audits that high-risk mothers are often not identified, and, even after they are identified, perhaps because they have a past history of, for example, a growth-restricted baby, they are not receiving the care that they should be and that everybody would agree they should have. Typically, if they had a previous history of a fetal growth-restricted baby, they should be monitored much more intensively by serial ultrasound. They do not get that to a large extent because, in our region at least, there is a shortage of ultrasound services and much of them have been diverted towards early pregnancy screening while there has not been that injection of additional resources to make sure that these mothers receive it. So, even if they are at high risk and recognised, that does not necessarily mean that they are being managed in the way they should be.

[178] The low-risk mothers are also not being treated the way they ought to be according to available evidence. Not all of that evidence turns up in NICE guidelines, because NICE and other guideline developers base their evidence, to a large extent, on randomised controlled trials and, in our opinion, do not give sufficient regard to evidence that has been derived from looking at outcomes in a structured and methodical manner. If you have heard already today that there needs to be more research, that, in itself, supports the point that if guidelines are based on research, there is not that much research at present on which to base them. So, additional evidence needs to be brought forward, and we have been doing that on the basis of structured case reviews.

[179] I need to add a little in defence of the tape measure, which has been mentioned repeatedly and not in favourable ways. It is a good measure if it is used properly. It will not be a good measure if you do not train the staff on how to use it and if you do not make sure that it is properly applied to the right mothers in this instance, not mothers who have twins, if they are obese or have a fibroid pregnancy and so on. It is a good measure if you stick to the standard of how to plot it and what to do if the serial plotting, which is a powerful way of monitoring growth, is managed accordingly and has the appropriate referral. The midwife is encouraged to refer, rather than discouraged because the ultrasonographers are overworked and do not want to see referrals on the basis of the screening test, which, by definition, gets more referrals than necessary, because many will be false positive. So, therefore, if you have a system like that, you can significantly increase, as we have shown in our audits and published papers, the detection of fetal growth restriction through tape measures, supported by protocols and appropriate ultrasounds. As a result, there is a significant reduction in stillbirths with fetal growth restriction.

[180] **William Graham:** To help me to understand a little more, why do you think that these deaths do not get the recognition that they deserve, because they have always occurred?

[181] **Mr Beattie:** One of the problems is that there has been a big public drive during the past five to 10 years to normalise pregnancy. It is not an unreasonable criticism to say that,

about 10 years ago, there was an overly medicalised and interventional approach to the management of pregnancy. When I was training, when women were in labour they had catheters put inside their uterus to measure the pressure and their contractions were all plotted out. However, the problem is that we have bounced too far the other way now into assuming that everything will be okay, without a proper awareness of the risks of stillbirth.

[182] A few people have said to me that you should not really talk about things like that because it is very negative and it spoils the mother's bonding with the baby. However, we do it quite effectively with Down's syndrome screening. We say that any mum can have a baby with Down's syndrome. Some parents may choose not to continue pregnancy where a baby has Down's syndrome. We can offer you a test that will give you an idea of what the likely risk will be and then you can make a decision about whether to have a diagnostic test. So, if you take the stillbirth analogy, I think that, at the beginning of the pregnancy, it is not unreasonable to say, 'There is a small risk in any pregnancy, even if everything is going well, that a baby may die. Therefore, it is important that you attend all of your antenatal clinics to have your appropriate checks, and, in the later part of the pregnancy, you pay attention to the movement pattern of the baby and, if there is a change in that movement pattern, you need to go to your local hospital.' So, I think that there is a way of bringing the subject up that will direct people towards taking greater responsibility for their pregnancy, without necessarily scaremongering.

[183] Another example is smoking. We play at trying to deal with smoking and pregnancy. We ask people if they smoke, and if they do we give them a phone number and say, 'If you ring this number, they will help you cut down'. However, there is not really a big drive to reduce it. If you tack onto that conversation that smoking is a significant risk factor for stillbirth and say, 'We appreciate that it is difficult to give up smoking if you are an established smoker, but you need to understand that you are putting that baby at considerable risk every day that you smoke', and then introduce a wide range of interventions, that might help that individual.

[184] One of the things that people have talked about is using carbon monoxide meters at the booking visit for people who smoke so that you can show them by asking them to blow into it—it is a bit like a breathalyser—and then say, 'You do smoke, this is carbon monoxide and it should not be in your bloodstream or in the baby's bloodstream'. So, there are ways of introducing the subject and then directing it towards better behaviour and understanding of what the mother could do to improve the outcome.

[185] **Professor Gardosi:** The other way to answer your question, with regard to the example of smoking, is not only to rely on mothers stopping smoking overnight, but to recognise that if they smoke they are at a higher risk and, therefore, need to be monitored more, particularly for fetal growth restriction. Therefore, the policies and protocols need to be there to allow for that fact while, at the same time, there is support for mothers. Again, if you think about the classification of stillbirths traditionally over the past two decades—and this came up in a previous session—two thirds of them have been considered unexplained. 'Unexplained' suggests unavoidable, and therefore it is not something that people feel they need to do much about to try to address it. If the implication is that it is unavoidable, it will not get the focus it deserves.

11.00 a.m.

[186] We have applied a different classification system where we do not necessarily want to look at the cause of the accident, but at the clinical conditions that led up to it. In fact, in your own statistics, the pie chart in the Welsh report shows that 42% are more or less unexplained. We found that most of these unexplained ones are babies who are growth restricted, and 85% of those among stillbirths have not been recognised before birth. Therefore the focus needs to

be on improving antenatal recognition through a concerted programme of improving the training of midwives and doctors in how to detect fetal growth problems among low-risk pregnancies and how to monitor fetal growth better in high-risk pregnancies and by ensuring that there are referral pathways and generally raising awareness of this as a major problem. I think that is why we have been able to make significant progress.

[187] **Mick Antoniw:** Therefore, is it your view that the high percentage of stillbirths to women categorised as low risk may be due to the fact that they are not being categorised properly?

[188] **Professor Gardosi:** Yes, absolutely.

[189] **Elin Jones:** I think that you have started to answer my question. Mr Beattie, I want to refer to what you say in your paper about increased awareness. You talk about the need to ensure that health professionals are made fully aware of the risk of stillbirth as part of their education. Do you include generalist obstetricians in that definition of health professionals because most hospitals in Wales will possibly have only generalist obstetricians and not specialists? In answering William Graham, you said that the weakness of current education and training is that there is no real training in how to talk to parents about stillbirth as part of antenatal education. Therefore, would your ideal scenario be that a health professional talked to every woman, whether low or high risk, about the potential risk of stillbirth? Would that be good practice?

[190] **Mr Beattie:** Yes, I think it should be part of the booking visit. I do not think it is necessarily something you would want the obstetricians to do because it would overemphasise it. I would like to see it becoming part of the normal dialogue between the woman and her midwife, with whom it is hoped she will build up a relationship during the course of the pregnancy. It is something she should be made aware of very early on, and that should be balanced with the things that she could do to improve the outcome and how she monitors the pregnancy. These are things such as the importance of attending antenatal appointments and classes—attendance at which is very variable—with regard to improving her knowledge of how to look after herself during the pregnancy. It should be made part of the normal care package rather than it being the case that the woman would go to speak to someone specifically about stillbirth.

[191] **Elin Jones:** So, currently, there is almost a culture of not raising awareness of the potential risk of stillbirth because you do not want to scare the mother.

[192] **Mr Beattie:** I think that people are uncomfortable with it. They are not confident because they see it as being something negative that causes worry. However, if you can link that concern to something constructive that the healthcare professionals can offer and that the woman can do for herself, I think it is an acceptable way of bringing up the subject.

[193] **Professor Gardosi:** Training needs to be better reinforced and co-ordinated. As an example, if we stick with the fetal growth restriction problem as one of the major problems that contribute to stillbirth, there is very patchy training of midwives and doctors in the assessment of fundal height and referral pathways on fetal growth. This applies to Wales as well as far as we know because we run accreditation programmes for the customised growth charts we have developed. They are in place in 13 units in Wales, but we have had the opportunity to train only a small minority of midwives. Whereas, in the west midlands and elsewhere, there has been a much more concerted programme. So, here there is almost a quick-win situation, if you focus on the causes of the relevant conditions leading to stillbirth, and upstream make sure that the care providers are fully trained and agree on the pathways that need to be followed for a mother to move from a low-risk to a high-risk situation.

[194] **Lynne Neagle:** Some of my questions on the issue of low risk have been answered, but it is an important issue. I was struck by what you said, Mr Beattie, about there being no such thing as a low-risk baby until it is in the cot. That flies in the face of a lot of the attempts to non-medicalise pregnancy, and of course so much of a woman's journey through her pregnancy is determined by that initial classification as either low risk or high risk. I was wondering if we need to be taking a look at that more fundamentally, with a view to shifting the pendulum back a bit from where we are now.

[195] **Mr Beattie:** Yes, we have gone too far the other way, and it is always important, when you look at any intervention or test, to balance the potential benefits against the potential harm. If it is done in a sensitive way, what we need to be saying to pregnant women is that we need to look after them, and help them to look after themselves during pregnancy, but we also need to look after their baby. Just because they are well, it does not necessarily follow that the baby is. There needs to be a fundamental public shift, not to worry people, but for people to understand that you cannot monitor the wellbeing of the baby by just looking at the mother.

[196] **Lynne Neagle:** I have a couple of other questions. In your paper you refer to the possibility of all pregnancies having the option of another third trimester scan, which you have said should be supported by evidence of their effectiveness. Do you want to elaborate on that? Should the Government be looking to obtain that evidence of their effectiveness so that maybe we could introduce that kind of scan? I have one other question on fetal movement. We have heard quite a bit of evidence about that this morning. Certainly it seems that the experience is variable of the way that it is monitored by midwives. Some women use kick charts, others count kicks, and some are just asked, 'How is the baby moving?', in my experience. Is that something that we need to do something about so that there is a more uniform approach to that?

[197] **Mr Beattie:** This is one of the things that hopefully the 1000 Lives campaign may be able to pick up through its stillbirth group. There needs to be a much more standardised approach to how women are educated about the importance of fetal movements, what constitutes a change and what healthcare professionals do with it. The only concern that I have about the current NICE guidance is that, if you have reduced fetal movement, the normal response is to do cardiotocography, unless there are any other risk factors. However, we know that we are not very good at identifying babies who are otherwise in trouble. The justification is that they say that something like 60-odd per cent of women who present just once with reduced fetal movement and a normal CTG will have a good outcome, and therefore they do not do a scan. To my mind, if a third therefore are not going to have a good outcome, the standard response to reduced fetal movement should be a CTG and then an ultrasound scan on the next working day to make sure that this really is a low-risk baby. Then, from a resource point of view, you can reliably confirm to that woman that she is in a low-risk category—you can put her back into low risk, but only because you have looked.

[198] In terms of routine scanning during pregnancy, it is something that would be useful to do on a proper piloted research trial basis. One of the difficulties with looking at any intervention, whether it is symphysis-fundal height or the scans, is that there are two sides to the equation. One is whether the test actually picked up the problem—symphysis-fundal height will pick up some and ultrasound will potentially pick up more—but the second thing is whether you improve the outcome because you have followed the appropriate protocol on aftercare, and converted that knowledge and information about the pregnancy into improving outcomes. If you just look at a randomised trial of ultrasound versus stillbirth, you will not necessarily see the benefit, even if ultrasound is identifying pregnancies that should be managed differently, if you do not, as part of a package, follow up with the appropriate protocol about what to do next, having done your test.

[199] **Professor Gardosi:** There is currently not much evidence in the literature about the one-off third-trimester scan being beneficial in detecting risk. That is why I was talking earlier about the importance of serial assessment, even if it is by tape measure, but properly done. In terms of fetal movements, our region standardised the information that mothers are given several years ago through the hand-held notes, and midwives have to tick boxes to say that they have administered this information and mothers understand. Regrettably, at present I do not think that there is any mention of it in your national notes here. Six of your units are using our notes, and I would strongly recommend that there should be some standardised information for them. However, I would caution against putting too much hope on a focus on decreased fetal movements reducing stillbirths. In our regional database, we now have over 100,000 cases and only 20% of mothers with live births or stillbirths present at any stage with decreased fetal movement. In terms of stillbirths, when they do present, the baby is delivered dead within two or three days in most instances. So, it is a late presentation. It is almost like trying to prevent motor vehicle accidents by looking for the blue lights of the ambulance. It is a late presentation. It is important, and it is important that mothers are aware and that they come as soon as possible, but in terms of an overall strategy to reduce stillbirth rates in your country, I would suggest that you ought to also focus on other issues, some of which have already been explained.

[200] **Mark Drakeford:** Finally—because I am afraid that we have run out of time already—I would like to make sure that I have understood you, Professor Gardosi, because in some ways your evidence has some slightly different emphases to some of the other evidence that we have had. Am I faithfully reflecting what you have said to us if I say that your analysis suggests that 80% to 85% of stillbirths are potentially avoidable?

[201] **Professor Gardosi:** If you exclude congenital anomalies, yes.

[202] **Mark Drakeford:** And for you, the key way of doing that is the identification and management of small-for-gestational-age fetuses. The proper identification and management of that is the key.

[203] **Professor Gardosi:** Yes, but the other part is that there needs to be a rolling programme of standardised audit for units, clinicians and everybody concerned to learn from adverse outcomes. That will reinforce the first part, but will also make sure that other reasons—and I am not ignorant of many other causes of stillbirths—are also dealt with in the proper manner. That was not the case in our area, and we feel that by doing what we have, we have been able to raise awareness and bring about significant improvements in stillbirth rates.

[204] **Mark Drakeford:** Are there figures yet available that show that—the different rates in the west midlands, for example?

[205] **Professor Gardosi:** Yes, and they are at the link that I showed you. In fact, the latest data, for 2011—which we are now analysing—show that between 2003-05 and 2009-11 we are able to demonstrate a 40% drop in stillbirths past 30 weeks with fetal growth restriction. These are the more mature ones, in the second half of the third trimester. We are focusing on the largest proportion of perinatal mortality, and the largest proportion of stillbirths excluding congenital anomalies, and we are finding that we can do something about it through a concerted programme. We have done this, and to some degree we were there, where you are now, a few years ago, and I am here to suggest to you that we would be very happy to share our experience in how this could be progressed in a concerted manner.

[206] **Mark Drakeford:** Thank you both very much indeed. This has been very helpful to us this morning. I am grateful to you both for your time and expertise.

11.15 a.m.

[207] Bore da a chroeso i sesiwn olaf y bore. Rydym yn mynd i symud yn syth ymlaen at y pedwerydd panel. Croeso i Julia Chandler, Swyddog Cenedlaethol Coleg Brenhinol y Bydwraed; Dr Mark Temple, Cadeirydd Pwyllgor Meddygaeth Iechyd y Cyhoedd Cymru, BMA Cymru; a Phil Banfield, aelod o Gyngor BMA Cymru. Diolch i chi am ddod y bore yma. Fel arfer, gofynnaf a oes unrhyw sylwadau agoriadol byr yr hoffech eu gwneud i'n helpu. Rydym wedi cael cyfle i ystyried eich tystiolaeth ysgrifenedig, a diolch yn fawr i chi am ei darparu. Ar ôl y sylwadau agoriadol, rydym yn mynd i droi'n syth at aelodau'r pwyllgor iddynt ofyn cwestiynau.

Good morning and welcome to the final session of the morning. We are moving immediately to our fourth panel. I welcome Julia Chandler, National Officer of the Royal College of Midwives; Dr Mark Temple, Chair of the Welsh Committee of Public Health Medicine, BMA Wales; and Phil Banfield, a member of the BMA Welsh Council. Thank you for coming this morning. I ask, as usual, whether there are any brief opening remarks that you would like to make to assist us. We have had an opportunity to consider your written evidence, and thank you very much for providing it. After the opening remarks, we will turn immediately to committee members for them to ask questions.

[208] Julia, do you want to go first with any brief opening remarks for us, highlighting key points from your evidence?

[209] **Ms Chandler:** Yes, thank you. I will just say that, in the long term, we need to have more research into stillbirth. Having said that, in the short term, the midwife plays a very important role in public health, in teaching about smoking and obesity, and in raising awareness in women of fetal movements and their relationship to fetal wellbeing. Perhaps more resource needs to be targeted at those who need it most. Obviously, the increasing demands on midwife roles make delivering a public health agenda more difficult.

[210] The other thing is a focus on continuity of care from a named midwife, because a midwife will be more able to pick up problems and the mother will feel more able to raise problems if they have built a relationship.

[211] Finally, more and better training is needed, which will lead to a more consistent application of the guidelines that are already in place.

[212] **Mark Drakeford:** I am not sure who is going to offer the BMA view. Phil, would you lead?

[213] **Mr Banfield:** Yes. I am a consultant obstetrician; that is my background. We are acutely aware of the lack of a fall in stillbirth rates in Wales. The response from the midwifery side, the public health side and the Royal College of Obstetricians and Gynaecologists is to take part in the 1000 Lives Plus: Transforming Maternity Care mini-collaborative, for which I am the national faculty lead. Having done some work in other areas over the previous year, we have been able to introduce stillbirth as our next work stream. The advantage of that is that it takes policies and protocols and instigates practical implementation of those across Wales. It will not be lost on members of this committee that the stillbirth rates in Wales are intimately associated with areas of increased deprivation in Wales. If we are to make changes or monitor practice interventions, we will need to ensure that we have accurate clinical data readily available for clinicians and policy makers. At the moment, there is a deficiency in that regard in Wales.

[214] **Elin Jones:** I want to focus on training. We heard evidence earlier this morning on the training of midwives and the curriculum of training. An assessment of one three-year curriculum showed that it included only one day of training on stillbirth. Do you think that

that is sufficient? I think that you hinted at an answer in your presentation, but I wanted to ask specifically what increases or changes to the current training you would see specifically that would aid midwives in their work in the future.

[215] Again, on training for midwives, in a previous evidence session witnesses talked about good practice being that every woman should have a conversation with a midwife about the risk of stillbirth and how that risk could be taken on board by the mother. That should be every woman, whether in the low-risk or high-risk category. They said that, currently, that does not seem to be happening, possibly because it was not thought to be a good thing to happen, because it could scare the mother. Do you think that midwives need to be trained to do that for every woman or is it just that it should be implemented, because midwives are already sufficiently well trained to have that conversation?

[216] **Ms Chandler:** I will start with the first part of your question. Midwives get training as part of their student training on stillbirth. There could possibly be more of that. I believe that there should be more training on supporting women afterwards. One area that is possibly lacking in Wales is bereavement support and the counselling that goes with it. It might increase the uptake of post-mortems if that was done properly. However, there is a shortage of bereavement support or specialised midwives in that area in Wales. Part of that would be ongoing training for midwives. They have to have mandatory training every year and perhaps that should become something that becomes part of the mandatory training and update on the latest research and things in relation to stillbirth and how to support mothers and how to provide bereavement support. It is something that every midwife should be able to do. Can you just remind me of the second part of your question?

[217] **Elin Jones:** Representatives from the Royal College of Obstetricians and Gynaecologists said that good practice would be that every woman has a conversation with a midwife about the potential risk of stillbirth. Do you think that that is something that, culturally, midwives do not see as part of their role? Do they need additional training for that or does it just need to be part of the guidance that that is what should happen?

[218] **Ms Chandler:** The conversation in general if a midwife, for example, picked up on the baby being small, would be, 'You've got a small baby, so we need to monitor it' rather than, 'You've got a small baby, so there might be a risk of stillbirth'. There is an issue around midwives not wanting to scare mothers. The risk overall, as we have looked at in Wales, is one in 200, which could seem quite daunting to some mothers, because it seems quite high. However, it is something that we need to get over, and we have managed it with cot death and things such as that. We probably need some training to get that off the ground.

[219] **Kirsty Williams:** Julia, in your paper, you say that the RCM is aware that many of the relevant guidelines have not been implemented consistently throughout Wales. It is a source of ongoing frustration in this committee, with regard to a whole variety of medical care, that it is quite clear what good care looks like—there is usually a consensus around that—and what people should be doing, but it does not happen. What are the barriers to that? If we know what should happen to a woman in her pregnancy, what are the barriers that stop that from happening?

[220] I would be grateful to hear a response from Mr Banfield. In the previous evidence session, and in their paper, representatives from the Royal College of Obstetricians and Gynaecologists, talked about the lack of specialists in fetal medicine in Wales and about the need for a maternity network. If we did set up a maternity network under the chair of an obstetrician, would that help us to ensure that there was consistency of application and practice across Wales? What do you think, from the medical side of things, we could do to ensure that there is take-up of existing guidance?

[221] **Mr Banfield:** It is difficult, because evidence is in the eye of the beholder and, sometimes, it applies to some situations more than others. Scientifically, for example, the usefulness of a test is affected by how likely the condition is to occur in the population, so some of the tests that you have heard about today are more useful in high-risk women than low-risk women, for example. However, a low-risk woman does not necessarily have a low-risk baby, and that is part of what we are having difficulty in picking up.

[222] One of things that we are working hard to do within 1000 Lives Plus is to build a consensus for Wales that overcomes these obstacles, asks why people are not doing it and whether there is a particular part of a particular guideline that is stopping them from implementing the other 90% of the guideline. We have been quite successful in overcoming that. For something like management of reduced fetal movement, we see that as relatively straightforward. It would be very nice to come back to committee in a year's time and say, 'Actually, we have standardised practice throughout Wales'. Things such as fetal growth and access to growth scans are much more controversial because the science is much less proven. One of the things that we need to have a discussion about is customised growth charts, which you heard about today, and the observation that a boy baby is expected to weigh differently from a girl baby. As soon as the baby is born, you get different charts. There are also different expectations of the size of the baby depending on whether it is your first. That is linked with Jason's work about trying to reduce the number of unexplained stillbirths.

[223] We are fortunate in that charities have offered great help in helping us to educate all of the professionals and the public in Wales. In answer to your question about how we get the protocols agreed, we will agree Welsh implementation of them with a multidisciplinary team that includes midwives, obstetricians and the women themselves. You cannot underestimate the power of a woman sitting there saying, 'It doesn't feel right to me'. Scientifically, her saying that may be as accurate as any of our tests.

[224] **Kirsty Williams:** I am still not clear as to why it does not happen. We have heard evidence this morning that, on the continent, there are some really good figures for stillbirth, and they follow the NICE guidance—British guidance. Why is it that we can convince another country to follow our guidance and yet, by our own admission, our own practitioners do not follow it? As a lay person, I find that really hard to understand. There must be good reasons for it. I do not believe that people are being deliberately negligent or difficult, but I just do not have a feeling for why that happens.

[225] **Ms Chandler:** We would say that, in some respects, there is a failure of training. For example, with regard to using the customised growth charts, there is a lot of training when they first come in. However, that may not be followed up so that, when new practitioners move in, if they have not had that training that may not be picked up because it is a small part of a very large induction process for people coming to work at a new hospital. That is just an example. We believe that part of the ongoing training needs to be ensuring that everyone is up to speed with all the guidelines. That is part of their professional responsibility as well, but there need to be some checks and balances to go with that.

[226] **Mr Banfield:** Some of this is about the availability of resources. If we suddenly decided that everyone would have a scan at term, for argument's sake, that gives a choice as to whether that resource will be made available or whether the alternative, of inducing someone at term, is used as a management option. We have not played these out in Wales in terms of looking at what is easy to implement, which may have a bigger impact than worrying about some of the things that might be termed peripheral in the end.

[227] **Mick Antoniwi:** In your evidence, you say that most stillbirths currently occur in situations where no excessive maternal risk has been identified. Of course, that depends on the accuracy of the data, and Professor Gardosi, in his evidence earlier, basically said that he

felt that the categorisation of significant numbers of people as low risk is effectively miscategorisation, because of inaccurate data. Would you agree with that?

11.30 a.m.

[228] **Mr Banfield:** Yes, but the data are available only in retrospect. You know the birth weight of the baby only after delivery.

[229] **Mick Antoniw:** However, you would agree that, effectively, although someone is categorised as being low risk, because of the significant number of stillbirths that occur, there is clearly a weakness in the categorisation process.

[230] **Mr Banfield:** Yes, it is the fourth category that is missing. You have high-risk mother, high-risk baby and then low-risk mother. The challenge is to identify when the low-risk baby actually is not low risk. The challenge for us is to prove that 'normal' is normal without either panicking the population or intervening too much.

[231] **Mick Antoniw:** You mentioned earlier in your evidence the need for a standardised audit. Could you elaborate a little on the form that you would like to see a standardised audit take?

[232] **Dr Temple:** The important thing is to move away from a research-based approach towards a much more surveillance-based approach. I make no secret of the fact that I work in the surveillance unit for communicable diseases, which is why I come with a surveillance hat on. It is quite evident that sometimes, although the evidence is strong that something will be beneficial for a particular group or sub-group, that benefit may extract a very high price for other groups. That is why surveillance that looks at a whole population is essential. You have to be very careful, because sometimes what you do may accidentally cause more harm than good.

[233] One of the problems if you audit the process, which is what people tend to do—'You followed the guidance', for example—is that you tend to ignore the outcome, and sometimes doing the right thing gives you the wrong answer and sometimes doing the wrong thing gives you a better answer. We ought to be trying to find out when people deviate from the standard and achieve excellence, because 'standard' is bog standard and I would like every woman and every baby to be given excellent care. That means that they must all have non-standard care, and that is a very difficult concept for people to accept.

[234] If you are in the front line, your aim is always to give excellence, and my two clinical colleagues here, as it were, are in the front line, so they are always aiming for excellence. They are not happy with 'standard'. However, as a population person, I am always looking at what is right for the average, and I have yet to meet an average person. I was in clinical practice for 15 years, in the Valleys, and I can tell you that I never met an average pregnant woman. All my women were unique, and I was very pleased to help them, with the midwives, to have healthy babies. However, we had some stillbirths, and they were horrible. It is a real issue and we have to focus on the individual as well as look at the average. I am not sure whether that helps.

[235] **Mr Banfield:** In practical terms, I think that you will hear this afternoon about the all-Wales perinatal survey, and that is a reasonably cheap and easy thing to extend into the realm of obstetrics, to have a more accurate view of what is going on with stillbirths in Wales.

[236] **William Graham:** We have heard in evidence that the number of caesarean sections has more than doubled in the past two decades without having a measurable impact on stillbirths, so medicalisation, as it were, is not overly helpful. Are we right to emphasise that it

is in fact the quality—and you say the excellence—of care throughout the pregnancy that is the right route to focus on?

[237] **Dr Temple:** Clearly, there is an element when the clinical care, whether it is the midwife, the obstetrician or, hopefully, the team, is important. However, in most public health interventions, we know that the clinical element explains only a third of the effect. There is a rule of thumb, so do not quote me on the exact figures, but about a third of the benefit comes from improvements in clinical care, and a third comes from societal changes such as improved sanitation, improved hygiene and improved nutrition. If you want to improve the health of babies, you have to improve the health of their mothers when they themselves are babies, because we must remember that there is an epigenetic effect. So, we may not see the effect of an action that we take now to reduce stillbirths for 60 years until the generation of female babies born now have their babies. So, there is a delay there. For those of you who have a shorter timescale to take care of, 30 to 60 years is a long time—it certainly is in politics and in medicine—but that is one of the difficulties that we face. You will not see the benefits of some of the actions that my colleagues are taking now until the next generation, because the women will be healthier at birth and so, when they come to have their babies, they will have healthier babies.

[238] The remaining third of the benefit comes from the intangibles. That is about relationships, whether society cares. These are very difficult to measure, but you know when you are living in a society that cares for its members. You know that the society is nice and looks after people, and that children are loved and looked after. That also applies to the way in which we look after pregnant women. One of the difficulties has been a move towards isolation, in that we look at people as individuals rather than in their social context. It is strange for me to say this, but we are talking about a woman, but normally there is a man involved, too. We tend not to consider the role of the father of the child in this. I do not know whether anyone has done any work on the role of fathers in stillbirths, but I am sure that that is an avenue that we could cheaply explore, simply by asking a few sensible questions. It may be that that is important.

[239] **Mr Banfield:** This comes back to the lack of interrogable data. Over the same time that the caesarean rate has gone up, we know that the rate of obesity in Wales has shot up as well, which is directly related to caesarean section rates. It is a small example but it nonetheless shows how they are not necessarily independent of each other.

[240] **William Graham:** As practitioners, are you confident that, where problems are identified, whether they are low risk or high risk, those pathways are identifiable and acted upon?

[241] **Ms Chandler:** The pathways are there; the question is about their interpretation, the application of the guidelines and whether they are followed. So, I would echo the view that there needs to be more training to make sure that there is consistent application by everyone working in the maternity service.

[242] **Mr Banfield:** Sometimes, of course, you have an impossible choice. Sometimes, you know that, by interfering, you are delivering a very pre-term baby but, by not interfering, you are risking stillbirth. You may have to deliver the baby of someone who is haemorrhaging at 24 weeks of their pregnancy for maternal reasons. If you have someone with ruptured membranes at 25 or 26 weeks, you may want to manage that pregnancy conservatively because of the risk of delivery with prematurity. Leaving that baby in utero runs the risk that you will go to listen one day, and the baby will not be alive. So, there is a constant balance of risk in some of these dilemmas.

[243] **Mark Drakeford:** While I wait to see whether colleagues have any other questions, I

want to ask you one question, and I will come to Elin next. The bulk of the evidence that we have heard this morning, and what we have seen on paper, says things such as we need to raise awareness, we need more research, we need a better understanding of the problem from the perinatal perspective, we need correct categorisation, proper training, implementation of NICE guidelines and so on. I do not think that our last witness, Professor Gardosi, would have dissented from any of that, but what he said to us was that, while all that is going on, if you shine a sharp spotlight on the identification and management of problematic fetal growth, you can reduce stillbirths by 42% in his case, in the west midlands—and not in 60 years, but in less than a decade. He is one voice, and what he says rather goes against the trend of the other evidence. Can you help us here, as a committee? What weight should we give to the approach that he suggests?

[244] **Mr Banfield:** The problem here is in identifying when someone is at an increased risk of something. Even if you identify that a baby is small, that does not necessarily lead to immediate delivery. It can lead to increased surveillance. One thing that we are looking at in the 1000 Lives campaign is the practical introduction of customised growth charts. There are some good data from Jason and from Liverpool. I would see that as a relatively easy and cheap hit for Wales. On the comments that have been made about judging how big a baby is, we can train people to be more accurate, but the reality is that, with a population that has a raised body mass index, you are not necessarily measuring the baby when you are measuring how big the bump is. There is some science, but we must not overestimate that science, and listening to a woman who says, ‘Actually, my bump is small’, or ‘Actually, my bump is big’, should carry as much weight. Sometimes, we are quite bad at listening to that and asking, ‘Is this still normal?’ and if it is not, at investigating it just to prove that everything is okay. If you do that, you start to focus your scanning efforts and your resources, as opposed to ending up scanning everyone three or four times during pregnancy, which may have the detrimental effect of increasing anxiety and interventions.

[245] **Mark Drakeford:** Thank you, that is very helpful. Do you wish to add to that, Julia?

[246] **Ms Chandler:** I just want to emphasise that, in order to pick these things up, it is good to have continuity with the same midwife in the relationship between the mother and the midwife, so that, when that mother says that she thinks that something is wrong, the midwife knows what the mother is normally like and takes it seriously.

[247] **Dr Temple:** It is an old story. In all forms of care, continuity is essential. As a society, we have moved away from continuity. Work-life balance actually goes against continuity when you have a 24-hour process like a pregnancy. We have to think about how we accommodate continuity of care. I am afraid that the way that the NHS works does not encourage continuity—but that is something for another day.

[248] **Elin Jones:** Following Kirsty’s question on the royal college evidence asking for the development of a maternity network, I am not sure whether we got a clear view from you on whether that was a good idea. I understood what you said about the work that is going on with 1000 Lives, but that is a current Government programme. Would a maternity network provide longer term continuity for the standardisation of care and treatment that you want to see?

[249] **Mr Banfield:** There is a very short answer, which is ‘yes’. The longer answer is about where and how that would sit, and whether there are the resources to have a separately funded network. One thing that everyone around the table is trying to sort out is how a physical or a virtual network can be made so within a country that is the size of an English health region. We firmly believe that, either as a physical or virtual entity, that is achievable.

11.45 a.m.

[250] **Mark Drakeford:** We are almost at the end of our morning evidence-taking session. By the end of today, we will be thinking about the key recommendations that we might want to make, coming out of today's inquiry. If there were two or three top-line issues that you could share with us that could help to reduce that stubbornly and persistently high number of stillbirths in Wales, what would your priorities be? What should be our key recommendations? I will go down the line and start with you, Julie.

[251] **Ms Chandler:** From the midwifery perspective, I will repeat the importance of the continuity of that named midwife in the antenatal period and in building up that relationship. There is also the ongoing training to ensure that guidelines are applied consistently, because if they are there, we should be using them. Finally, more time for midwives to promote the public health agenda, because the pressure on midwives at the moment means that they do not always have the time that they need to promote that.

[252] **Dr Temple:** My view, coming from a public health perspective, is that there should be more and better data of a higher quality, because we can then help our clinical colleagues by giving them information on which they can act. At the moment, we do not have that.

[253] **Mr Banfield:** We have to be not afraid to discuss this. When you take your driving test, you discuss that you are going to put a seatbelt on because you might write yourself off in the car; that is a rare event, but we think about it every time we put a seatbelt on. Cot death is 10 times less common than stillbirth and we are shying away from discussing this. If we discuss stillbirth openly, people will know what to look for and will be able to park it in context so that they can get on with enjoying their normal pregnancy.

[254] **Mark Drakeford:** Thank you all for your help with today's inquiry. That has all been very useful to us and we are grateful to you all for taking the trouble to come here to help us today.

[255] **Diolch hefyd i aelodau'r pwyllgor** I also thank committee members for being am fod yma drwy'r bore. Byddwn yn here all morning. We will return at 1 p.m.. dychwelyd am 1 p.m.. Y prynhawn yma, This afternoon, we will hear from the byddwn yn clywed gan y Llywodraeth a'r Government and the local health boards. byrddau iechyd lleol.

*Gohiriwyd y cyfarfod rhwng 11.45 a.m. ac 1 p.m.
The meeting adjourned between 11.45 a.m. and 1 p.m.*

[256] **Mark Drakeford:** Croeso i bawb sydd wedi ymuno â ni ar gyfer y prynhawn. Rydym yn parhau â'n hymchwiliad undydd i farw-enedigaethau yng Nghymru. Dyma ein pumed panel, a byddwn yn cael tystiolaeth gan Lywodraeth Cymru. Croeso i'r Athro Jean White, y prif swyddog nyrsio; Dr Heather Payne, uwch-swyddog meddygol, iechyd mamau a phlant; a Polly Ferguson, o'r uned iechyd atgenhedlol menywod. Diolch am ddod yma'r prynhawn yma. Rydym wedi cael eich tystiolaeth ysgrifenedig. A oes gennych unrhyw sylwadau agoriadol byr yr hoffech eu gwneud cyn inni droi at aelodau'r pwyllgor am eu cwestiynau?

Mark Drakeford: Welcome to everyone who has joined us for the afternoon. We continue with our one-day inquiry into stillbirths in Wales. This is our fifth panel, and we will be taking evidence from the Welsh Government. Welcome to Professor Jean White, the chief nursing officer; Dr Heather Payne, senior medical officer, maternal and child health; and Polly Ferguson, from the women's reproductive health unit. Thank you for your attendance this afternoon. We have received your written evidence. Do you have any opening remarks that you wish to make before we turn to committee members for their questions?

[257] We only have 40 minutes, so your opening remarks must be brief, please. Jean, are

you going to lead off?

[258] **Professor White:** Yes. Thank you for inviting us to give evidence. We are in an interesting place, looking at stillbirths in Wales. As you will have seen from the evidence that you have gathered already today, there has been little change in the stillbirth rates for probably the last 20 years, not only in Wales, but in the UK. There is now quite a lot of interest in trying to work out what to do to make the next step change. Today's evidence will hopefully describe to you some of the things that we are doing and how we are linking with other UK countries to take forward work to make that next step. The other thing that I should say is that it is rather difficult to make changes in this area, because many of the individual causes of stillbirths are not known—we do not know what causes over half the stillbirths. Therefore, making a step change is not without its challenges. That is probably sufficient, as you said that I should keep it brief.

[259] **Mark Drakeford:** Polly or Heather, do either of you want to add anything at this stage? I see that you do not, so we will go to questions.

[260] **Vaughan Gething:** We heard a range of interesting evidence this morning, with some recurrent themes. I would like to go back to the point about it being difficult to make a difference. Much of the evidence that we heard this morning focused on issues about the risk status of the unborn child and, in particular, about fetal growth restriction and reduced fetal movement. We had some quite striking evidence about reduced fetal movement being a fairly late sign of problems, but Professor Gardosi from the west midlands said that they had been able to make a 40% reduction by concentrating on fetal growth restriction. There is, therefore, a conflict between those who say that this is a long-term issue and that they do not understand enough about it and him saying that the west midlands has made a real and identifiable difference within the space of about nine years.

[261] **Professor White:** There is a range of ways of working out how the child is growing, and I am sure that you will have heard that some of the methods involve scanning or using a tape measure to measure fundal height to palpate the uterus. All of them have pros and cons and not all of them, I would say, are the answer; they have a variety of applications depending on how they are carried out. They do not all pick up those fetuses that are at risk. A new national stillbirth committee has been set up under the 1000 Lives Plus: Transforming Maternity Services mini-collaborative. One of the things that we have asked that group to look at in particular is what we in Wales should be doing around measuring fetal growth and whether there is something that we should be doing as a national approach. At the moment, there are a variety of approaches across Wales. I will bring in Polly at this point, because, as a practising midwife, she does this on a regular basis.

[262] **Ms Ferguson:** I think that the issue is inconsistency. If everywhere in Wales is doing something different, we cannot get a handle on what works and what is best. The national stillbirth committee is looking at what people in Wales use, and at what each local health board uses, as a measure of fetal growth. It is going to suggest, based on evidence from Jason Gardosi and from Scandinavia, what we think that we should be doing to see whether that improves the rate. We are well aware of Jason's work and the work in Scandinavia. We will look to see what we think is appropriate in Wales and suggest that it is promulgated across Wales, and hope that it makes a difference.

[263] **Vaughan Gething:** The inconsistency was something that I wanted to come on to, because what has been quite striking is that, despite people saying that they do not understand completely why this happens, we have also had a persistent stream of evidence that says, both from the individual case studies and the more objective studies, if you like, that the quality of care makes a big difference. There is an issue about the way in which medical professionals are looking after the mother and child during the pregnancy. One figure claimed that 45% of

women who experience stillbirth had suboptimal care, which is a nice way of saying that the care was not up to standard. Jason Gardosi referred to a figure of 80% to 85% for the cases that they reviewed where the death was potentially preventable, which suggests that the point about inconsistency is obvious. It is also a point of frustration across the committee about why there is that inconsistency and why it has not been dealt with, given that we have all seen the figures that there are many more instances of stillbirth than of cot death and Down's syndrome.

[264] **Ms Ferguson:** Over the years, we have been focusing on other causes of stillbirth, like prematurity and ill mothers, such as diabetic mothers who, 40 years ago, would not have had babies and now do. We now have to stop and focus on the almost 50% that we say are due to unknown causes. However, if we look harder, we will find things that we could do that would improve those stillbirth rates. That is why we are unpicking this now. The inconsistency is the thing that we need to look at—the inconsistency in the way that we monitor fetal growth and the way that we manage that when we have found it. We cannot underestimate the challenge there. It is inevitable that, if you have 14 maternity units in Wales, they might be doing things differently. However, now that we have the national stillbirth committee, which is focusing on what we know works from places like Scandinavia, we can start dictating how things should be done. We have had to wait to see what works; we still do not really know. Jason Gardosi says that he has some great results, and I do not dispute that, but it is all a bit unknown.

[265] **Vaughan Gething:** That does not fill me with a huge amount of confidence.

[266] **Ms Ferguson:** That is how life is.

[267] **Vaughan Gething:** On the point that guidelines are not being implemented at the moment, what confidence or assurance should we take that the Government, health boards and professional bodies will ensure a greater level of adherence to a new set of professional practice?

[268] **Ms Ferguson:** That is very important. First, we must have all-Wales guidance.

[269] **Dr Payne:** I do not think that any of us disagree with the thrust of what you are saying—we all want the best for our children and for our mothers. While Jason Gardosi has done some excellent work, he is in the west midlands, and the stillbirth rate for 2010 there was 5.3 per 1,000 births. The Wales rate in 2010 was 5.3 per 1,000 births. So, if they have improved things by 40%, which might be marvellous, they were a lot worse before. So, it may well be that they have addressed the things that we have already addressed by looking at the precursors. We know that smoking and maternal obesity are issues. Smoking has come down; we still have the highest rate. However, we have already started to address that, and it takes a while for those factors to roll through.

[270] In terms of the quick hits, if you like, I think that what his work may have done was realise the benefits of the things that they could modify. That might well bring them into line with other regions in England. Again, I do not want to go into the stuff that you will hear from Dr Shantini Paranjothy, who is coming next, but we fund the all-Wales perinatal survey in order to give us these answers, and these are the reports that are produced so that we can feed them into the strategic initiatives to deliver the sort of care that we all want.

[271] In response to the specific point about why we are not monitoring fetal movements better and why we are not monitoring antenatal growth better, the reason everyone is doing it differently is because there is no known best way. That is the point. It would be different if there were NICE guidelines saying everyone must do this. With absolute respect to Jason Gardosi, NICE guidelines are based on evidence from everywhere. It gets the evidence from

everywhere. It does systematic reviews that smooth out individual variations and say, 'There is real hard evidence of five standards that this will make a difference'.

[272] As regards the illusion of doing something and causing a change, you have to be careful that you do not cause unintended effects. So, to go back to the question of why we are not doing things, no-one knows what the best thing to do is yet, but the stillbirth working group is looking very carefully across the four countries, working with colleagues in our other UK countries and making sure that we work towards working out what is an effective intervention.

[273] **Kirsty Williams:** You say in your paper that the chief executive of NHS Wales will be issuing a set of population-level outcome indicators at the end of June, and he will also be setting out a national performance measure so that the Government strategy has something that we can judge it against. Will that include a specific measure of stillbirth?

[274] **Ms Ferguson:** It will not include one on stillbirth, but it will include measures on smoking, obesity, diet, drugs, alcohol and low-birth-weight babies as indications of ill health.

[275] **Kirsty Williams:** The royal college, in its evidence to us today, said that it believes that health boards should have stillbirth as part of their quality indicators. Why has the Government not decided to make stillbirth a specific indicator?

[276] **Ms Ferguson:** We will measure the rates of stillbirth. That will still happen and you will hear about that.

[277] **Kirsty Williams:** I did not say that you were going to stop measuring it; I am asking why that is not a strategic objective as a measure of the success of your policy.

[278] **Ms Ferguson:** It is because we think that a lot of the causes of stillbirth are related to the health of the population, so it would be better to focus on improving the health of the population because, in turn, that should reduce the stillbirth rate. If we are collecting the stillbirth rate, we will be able to see if we are right. If we can impact on smoking, for example, which is very important, we would trust that the stillbirth rate would go down. So, our focus for local health boards will be on something very much more specific, such as smoking. Then, we can measure how well they are doing in terms of their performance measures related to smoking and the rates of stillbirth. So, we hope that the two will go together.

1.15 p.m.

[279] **Kirsty Williams:** We have heard today that one of the reasons existing guidance and good practice are not routinely implemented across the NHS in Wales can come down to resourcing issues. That is the evidence we received today. The royal colleges and the clinicians have been quite open about the fact that national agreed standards are not always implemented and that part of the reason for that is resourcing. Can you talk us through how you identify the resources that go into services? Do you have any checks and balances for how individual local health boards handle their resource allocation for these services?

[280] **Professor White:** Resources can be described in a number of ways. If we are just talking about funding, that is obviously given to the local health boards under particular arrangements, and we do close financial monitoring throughout the year. The resources you are talking about here are possibly more about ensuring that you have the right number of staff with the right skill set and that you are enabling them to conduct business as they should be—

[281] **Kirsty Williams:** The two are interlinked because if you do not have the money you cannot employ the staff.

[282] **Professor White:** Sure. Indeed. However, health boards can make choices about where they put the funding that we give them for that. We are certainly monitoring very closely the compliance with particular standards around staffing levels. All health boards in Wales are required to meet Birthrate Plus, which is the number of midwives, and we keep a very close eye to ensure that they do not deviate from that. That includes the ratio of registered midwives to support staff as well as physical numbers employed. The same is true for the medical staff; we ensure that the health boards are monitoring that. There have been some challenges. I do not deny that. Some of the evidence we have recently given to the Wales Neonatal Network certainly illustrated some of the challenges of the medical vacancies we have at the moment in some of the training rotas. There are plans under way to address those issues. However, there are national problems with some of these things. We certainly commission and ensure that the right number of training places exists. It is about recruitment to and maintaining the training programmes. It is a bit of a complicated answer, but—

[283] **Kirsty Williams:** So the Welsh Government is satisfied with the decisions individual local health boards are making with regard to resource allocation and the calls they are making in properly funding the service.

[284] **Professor White:** It is more complicated than that because we are going through reconfiguration, and the reconfiguration plans certainly have to identify how they are going to ensure that the resources they are allocating to where the services are going to be are appropriate. We are taking a very close interest in the reconfiguration plans as well as in how the business is being delivered at the moment. Certainly, for maternity and neonatal services, we have been taking a very close look at this because some challenges have been identified, particularly with medical recruitment to paediatric and neonatal rotas and so on.

[285] **William Graham:** This morning, we heard that the profile, shall we say, of the risk of stillbirth is rising but that, previously, it was almost ignored. Do you think that that is a cultural thing or is it a clinical issue? What priority do you think that the Welsh Government would give to it?

[286] **Professor White:** When you say that it is rising, over the past 20 years—

[287] **William Graham:** No, I am talking about the profile of stillbirth.

[288] **Professor White:** Oh, the profile, okay. It is quite a positive thing to have a rise in the profile of stillbirth because it is something that professionals have been rather reluctant to talk to mothers about. We talk about Down's syndrome and cot death in quite an open way, but we tend not to have the same level of conversation about stillbirth. I think that it is probably a positive thing that we are now a bit more open about it. In that way, we can say to mothers-to-be to think about whether the child is moving and whether they have noticed any differences. We can make sure that they realise that they need to look after themselves, cut down on their smoking, make sure they eat healthily and do the sort of things that can contribute to avoiding stillbirth. Until now, there has been a bit of reluctance because we obviously do not want to scare mothers about this. However, there are potentially four babies a week in Wales stillborn, so quite a significant number of individuals are affected. I think that it would be a fair comment to say that we have been a bit reluctant. It is only because it is a difficult thing to say to someone who is expecting, 'You do know that you might lose the child'. It is a hard thing to say. Hopefully, everything goes well.

[289] **William Graham:** With regard to resources that the Welsh Government can make available for training, would you be confident that, if the research shows how important this

is, which it seems to indicate from what we have heard this morning, those could be made available, particularly for midwives?

[290] **Professor White:** Indeed. In fact, we are already conducting a piece of work to improve one aspect of training, which is to do with fetal monitoring—the cardiotocographic monitoring. I held a meeting of a task and finish group just Monday of this week to look at the training standards to make sure that medical, nursing and midwifery practitioners know well how to use this because monitoring the fetus is an important skill. There is a lot of attention to making sure that not only do we have the right number of people, but that they have the right skills to do things. So, we have specific pieces of work looking at aspects of training.

[291] The Government funds some training anyway, because we pay for midwife, maternity assistant and medical preparation. There are mechanisms that we have that can apply to support the training of individuals. A lot of this is actually the health boards' responsibility, so that they make sure that their employees also have their core set of skills. So, we can mandate that the health boards ensure that their staff have particular skills. We can not only make sure that the basic training is right, but mandate certain things and lead groups to set national standards around the training, and CTG is an example of that.

[292] **Ms Ferguson:** We are also working with the Royal College of Midwives on auditing some training for midwives in relation to motivational interviewing, which aims to improve midwives' communication skills and, particularly, their ability to ask difficult questions and to discuss difficult issues such as weight, smoking and the fact that stillbirths happen. We are piloting that across Wales with a group of midwives to see whether the training in motivational interviewing will support them in having more open, transparent and clear communication with women through their pregnancy and discussing those difficult issues that we need to talk about if we are going to make any impact in this area.

[293] **Dr Payne:** The other important area in training that we have been specifically looking at in the national stillbirth working group is training medical staff in particular to have better skills in asking for post-mortems. We know that less than half of stillbirths go to a complete post-mortem. It is totally understandable that people in a terribly vulnerable situation are reluctant to consent to this. There is no question of coercion here; it is about helping people to understand, at a very difficult time, the potential value for themselves for potential future pregnancies, and for knowledge generally. Sands, from which I know you have heard this morning, has produced an excellent training package to improve the skills of clinicians in imparting enough information to try to increase the consent rate. Many people in Wales are asked, but we think that they could probably be asked in a better way that could help them get to the point of agreeing. Again, that is a specific action from the stillbirth working group that we are taking forward.

[294] **Rebecca Evans:** I want to pick up on the maternal awareness of fetal movement. We heard this morning that this kind of awareness really can make all the difference. Perhaps, you would only really be aware of the significance of changes if you had had those difficult conversations with people. I welcome the pilot project that you referred to, but I was wondering whether best use is made of the pregnancy book. I have not seen a copy, so I am wondering how well stillbirth is discussed in that book, because it seems like a perfect opportunity to start raising these issues. Also, does the Start4Life programme specifically mention stillbirth? We all know that it is good to give up smoking and so on, but if the gravity of giving up smoking and what that can mean for a pregnant woman is not put up there as the top line, rather than as a reason beneath it, it might not have so much—

[295] **Professor White:** I agree. We need to be much clearer in our message to mothers-to-be about some of the risk factors and make it much more obvious to them. In the past,

professionals have been reluctant to raise it, and, as you heard, we are trying to do something about that. Did you want to come in on the specifics, Polly?

[296] **Ms Ferguson:** We are working with Sands, as part of the national stillbirth committee work—Sands sits on the committee—to discuss how to raise this with women. Health professionals are reluctant to talk about it because they do not want to upset women, but Sands is saying, ‘You need to’. So, we are working with Sands and taking its advice about the appropriate way to do that. The people in Sands know; they have that experience. So, we will be working with them on looking at the best way to give women information through the pregnancy book and conversations and how best to raise that issue. It is part of the agenda of the national stillbirth committee.

[297] **Rebecca Evans:** I am surprised at how we seem to be at such an early stage with this, because people have known about healthy pregnancies and about stillbirths for a long time, but things have not changed. We seem to be slow in going forward. That is not a criticism, just an observation as to at how early a stage we seem to be. So, at the moment, there is nothing particular in the pregnancy book referring explicitly to—

[298] **Ms Ferguson:** Not directly in relation to the things that you can do to prevent it, no.

[299] **Mark Drakeford:** I will go to Mick and then to Lynne.

[300] **Mick Antoniw:** I have a couple of short questions and one slightly longer one. Some of the evidence that we have had on the categorisation of risk, that is, the incidence of stillbirths in women who are categorised as being low risk, is that that categorisation is inadequate and wrong. Do you agree with that?

[301] **Professor White:** We have asked the national stillbirth group to look at that specifically, because we need to be much cleverer about identifying the women who are at risk. However, sometimes, you will have a low-risk woman who will have a stillbirth and we will not understand it, because there are some things that we do not understand fully about the mechanisms of stillbirth. With about half, we really do not know, and because there has been some reluctance from parents, understandably, to have a post-mortem, developing the evidence base to understand some of the mechanisms is also challenging. So far, I would say that that is the case.

[302] **Dr Payne:** May I add to that? We have done quite a lot to address the higher risk, that is, everybody now knows that you have to have active management after 40 weeks. You have to think about post-term delivery and anticipate it, and people are not left to go for 43 or 44 weeks and then suddenly have a stillbirth like in the old days. The trouble is that once you have dealt with what you can clearly identify as a high risk, with your population distribution, you have a situation in which most of your cases happen in the low-risk population. That is the problem once you have dealt with the high-risk situations. So, that will happen, and the only way that you can do that is to shift the curve. The Geoffrey Rose curve basically says that if you want to improve the incidence of strokes in the population, you should reduce everybody’s blood pressure by a little bit. It is the same here. If you want to reduce stillbirths when they are in the low-risk population, you have to reduce everybody’s smoking and reduce the amount by which everybody is overweight and push the curve in that direction. So, it is inevitable.

[303] **Mick Antoniw:** Following on from that, one of the other points that were made was on the audit of statistics, that is, the evidence base that you have that enables you to make some of these judgments and evaluations and to try to develop strategies. One of the suggestions that were made was that you need a surveillance base that would monitor the treatment from start to finish and to the perinatal as well. Is that an important part of your

work?

[304] **Professor White:** Absolutely, and we already do some surveillance. We have the all-Wales perinatal survey, which is available, and we want to do more on that. Heather will probably give you some more detail, because she has been a bit more involved than I have in that.

[305] **Dr Payne:** We are working hard on getting the data that are there in order to make those population decisions and amalgamate outcomes, and to decide whether or not things have been effective. That currently happens, but, as Polly always says, it is in 30,000 women's handbags throughout Wales as opposed to being on a database. We are working on getting it in the right place so that it can inform clinical decision making.

1.30 p.m.

[306] **Mick Antoniw:** One of the problems is inconsistency and a lack of a strategy for the way information is collated. A lot of it is of limited value. If you look regionally across the United Kingdom, you will see that every area seems to be within about 5% of the average—between 4.5% and 5.5%—and when you start looking at the breakdown in Wales between different health boards, there is a variation that goes from just under 8% down to just over 2%. That seems to indicate that there is an immense amount of variation going on. Is that something that you will be incorporating into your work and your analysis?

[307] **Dr Payne:** Sorry, what figures are you referring to?

[308] **Mick Antoniw:** These are stillbirths adjusted according to the three-year rolling rate by local authorities.

[309] **Dr Payne:** They are per thousand, not per cent.

[310] **Mick Antoniw:** I beg your pardon, sorry. I meant per thousand.

[311] **Dr Payne:** There is huge variability. You will get that year on year with small numbers. They publish them as three-year rolling averages because you may get fourfold differences, and with small numbers it is not statistically significant. I emphasise 'statistically'—every single one of those stillbirths is highly significant to everyone in the family. However, when you are talking on a population basis, you have to work on the evidence of what makes a difference, and look at whether there is a difference between them. We know that we have issues with inequalities in Wales. The prime mediator of inequality, we know—and you will see this in the report of the chief medical officer—is smoking. You will have seen the tobacco report that came out earlier in the week. There is smoking, alcohol, exercise—the usual suspects. There will be variation with those things. It also depends which figures you are looking at, and whether they are measured by ordinary residence of the woman or where the delivery takes place. There will be an excess in some areas, and it will be in Cardiff, and sometimes Swansea, because that is where high-risk mothers are transferred for delivery. If they then have an intrapartum stillbirth, or a stillbirth, then that is where it will be recorded. You just have to be aware of how the data are collected.

[312] **Mick Antoniw:** My final point on all of this is that we appear to be adopting a number of fairly broadbrush approaches in terms of generic health and the way that leads into reductions in stillbirth, and so on, and I accept a lot of that in general terms. Is not the crux of the problem of actually making an impact on these statistics that we do not have any comprehensive, consistent and effective data analyses and surveillance assessments that enable us to focus on achieving specific targets for reduction? Is that an issue for you?

[313] **Professor White:** It is a combination of things, is it not? We know how many stillbirths occur, and where. We know the details of the individuals, and we are not talking about thousands—there were 167, I think, in 2010—so we can analyse every one. What we are not very good at is learning the national lessons from that. An incident will happen, and the team will explore it, and perhaps it will share it within the health board, so it goes wider than the team, but it does not spread much further than that. We have identified a significant need for a much better national approach to learning lessons, and actually understanding what is going on. That is a key step change for us that we hope will take us forward. We have been in this position, with this rate of stillbirths, for about 20 years. What we need now is something significant to move us on. It has to be about learning lessons, refining how we measure things like fetal growth and fetal movement, and better identifying those women who are at risk, as well as making the pregnant population healthier, because that will have a knock-on effect.

[314] **Dr Payne:** Due to the fact that the work of the Confidential Enquiry into Maternal and Child Health and the Centre for Maternal and Child Enquiries stopped, there was talk of stillbirths not being monitored. That is not true. The all-Wales perinatal survey, which you will be hearing from, is probably the best in the UK. It has continued to monitor and that has never stopped. It is the confidential inquiries that were interrupted by the contracting process, but that is starting up again and Polly will be going to the first meeting in July of Mothers and Babies—Reducing Risk through Audits and Confidential Enquiries across the UK. The Healthcare Quality Improvement Partnership is running it and MBRRACE-UK is delivering it. That will focus on intrapartum stillbirth. Regarding your question on whether we are using the statistics, yes, we are; we have extremely good-quality local statistics—

[315] **Mick Antoniw:** Are they good enough?

[316] **Dr Payne:** Yes, ours are excellent, and they feed into the UK-wide ones. We will be getting the messages from them. So, although there was an interruption in contracting, it does not make any difference to the reporting, because they did not report every year in any case.

[317] **Ms Ferguson:** The key is to learn the lessons from that, as Professor White said—

[318] **Mark Drakeford:** I am sorry; I do not mean to interrupt, but I want to make sure that I squeeze Lynne's questions in before the end.

[319] **Lynne Neagle:** I will ask them all in one go because of the lack of time. The first is in relation to Kirsty Williams's question. I am a bit confused by your response to her. Are you saying that the chief executive of the NHS is going to issue a set of national performance measures on which you will hold the NHS to account in terms of how women and their babies are better off as a result of NHS maternity care, without any reference to stillbirths?

[320] **Professor White:** Yes, without explicit reference. However, the indicators all relate to it.

[321] **Lynne Neagle:** Do you think that that makes sense, given what you have said about this being a four-babies-a-week occurrence in Wales, for that to be completely left out of a set of indicators? It is not going to tackle what is the worst thing that can go wrong for someone who is pregnant.

[322] **Professor White:** The indicators tackle it. What we have not used is an explicit question around stillbirth. We are asking questions on smoking, obesity and low birth weight, which are the factors that affect stillbirths. It is about the way in which it is phrased.

[323] **Lynne Neagle:** If we are to drive this forward centrally, would it not be better to have

an indicator that sets a reduction in the number of stillbirths as a measure of the quality that we hope to achieve?

[324] **Ms Ferguson:** I take your point; it is about where you start. If you have an indicator of rates of stillbirth, what action would the local health board take to reduce that? We want LHBs to act on the indicators and performance measures that we are writing, so we have written the performance measures related to obesity and smoking because we want them to act on those issues, which we think will contribute to reducing the rates of stillbirth.

[325] **Kirsty Williams:** What they could do is that they could make sure that patients are receiving optimal care. It is quite clear from the evidence that we have received today that, in many cases, the patient has not received optimal care. So, if we set a stillbirth target, the LHBs could carry out action to ensure that every woman and every unborn child is in receipt of optimal care. That is what they would do, surely?

[326] **Ms Ferguson:** I hope that they are doing that anyway.

[327] **Mark Drakeford:** Those are slightly different questions. The answer I think we are getting is that while there is no specific target in relation to stillbirths, the programme will focus on those factors that are believed to be most likely to have an impact on incidence.

[328] **Lynne Neagle:** In relation to pilot projects such as those for midwives to learn to talk to people about difficult issues such as smoking, are you saying that that is not happening routinely at the moment? Surely that is a really fundamental thing that all midwives should be talking to all pregnant women about now. It is a little worrying that we are only now having a pilot project to help them to do that.

[329] **Professor White:** They do it, but we wanted to make sure that they were using those conversations in the most effective way. We are trying to teach them a methodology that has proven to be an effective way of doing it. So, they are already required to have public health-type conversations, but we wanted to make sure that we were teaching them a particular methodology that has recently been shown to be an effective way of doing it.

[330] **Ms Ferguson:** It is an effective way of encouraging change.

[331] **Lynne Neagle:** Finally, are there plans for the national stillbirth working group to look at scanning lower risk women? Alternatively, would you look at putting protocols in place to ensure that more low-risk women are picked up if they present with reduced fetal movement?

[332] **Dr Payne:** Certainly. That is all on the agenda and the work plan of the national stillbirth working group.

[333] **Mark Drakeford:** We are just out of time, Dr White, but I want to ask you one question that goes right back to what you said at the beginning, when you talked about the need for a step change in the way that stillbirth is reduced. Do you think that that is the most sensible way of thinking about this? Some of the written evidence that we have had states that perhaps one reason why so little has been done over the past 20 years is because of the search for some sort of action that would make a step change. It is because there is not anything like that that the small, incremental things have been neglected, but, if all those little things were done, together they would add up to a start on this journey. The search for a step change is what stops that from happening, because there is no such thing. I think that we heard from you that there is nothing that you can point to and say, 'If only we were doing that, this problem would be significantly reduced'.

[334] **Dr White:** Indeed. Perhaps I did not articulate it terribly well, but what I was trying to say was that we have seen 20 years of little movement. Through the national stillbirth committee, we would like to find a combination of things to move us on from this almost steady state and to make a step change in that position. I am not looking for the golden bullet, or whatever the phrase is. There is probably a collection of things that we can do around the health of the population, behaviours, monitoring and setting standards and guidance on specific practices. Hopefully, instead of a steady state for another 20 years, we will see a step change in the rate. That is what I meant.

[335] **Mark Drakeford:** Thank you very much, and thank you all for your help with the inquiry this afternoon.

[336] Prynawn da a chroeso. Diolch am ddod i helpu'r Pwyllgor Iechyd a Gofal Cymdeithasol yn ein hymchwiliad undydd. Croeso i Siobhan Jones, ymgynghorydd iechyd cyhoeddus a chyfarwyddwr cyswllt Iechyd Cyhoeddus Cymru, ac i Dr Shantini Paranjothy, uwch-ddarlithydd clinigol gyda'r Sefydliad Gofal Sylfaenol ac Iechyd Cyhoeddus yn yr Ysgol Meddygaeth, Prifysgol Caerdydd. Good afternoon and welcome. Thank you for coming to help the Health and Social Care Committee in our one-day inquiry. Welcome to Siobhan Jones, public health consultant and assistant director at Public Health Wales, and to Dr Shantini Paranjothy, senior clinical lecturer with the Institute of Primary Care and Public Health in the School of Medicine, Cardiff University.

[337] We normally start by asking witnesses whether they would like to make a few brief introductory remarks, just to highlight a few things from the written evidence, which we have seen. I will then turn to members of the committee, who I know will have questions for you. Siobhan, are you happy to go first?

[338] **Dr Jones:** Fine. Thank you very much for the opportunity to give evidence and speak to you all this afternoon. I will talk about some of the key issues. We have heard that, in a lot of cases, the cause of stillbirths is not known. What we do know, however, at a population health level, is that certain key and important public health issues contribute to stillbirths, and I think that we have heard about some of those today. Maternal smoking, maternal obesity and advanced maternal age have been shown to be the highest modifiable risk factors for stillbirth, and a recent study that we in Public Health Wales did highlighted that up to 7% of stillbirths can be attributed to maternal smoking. We feel that we need to ensure that addressing smoking and maternal obesity specifically should be given a high priority by the NHS and partners. We also know that rates are higher in areas of high deprivation. We need to ensure that we are implementing public health and the evidence base in a systematic and co-ordinated way across the NHS and among its partners throughout Wales.

1.45 p.m.

[339] We also feel that the public health role of maternity services and midwives is extremely important. They have a unique opportunity to work with families on lifestyle factors and on health during pregnancy and staff time, knowledge and resources should be available to undertake this public health role. We need to target some of our resource at areas of high deprivation and work through our family-focused approaches and programmes in Wales to do some of that work.

[340] Preconception advice and support are also extremely important. It is really difficult to address some of the issues, like smoking and obesity, once a pregnancy has started. So, it is key that we raise the profile of preconception advice and care in Wales so that primary care, sexual health and family-planning-type services are maximising opportunities to give advice and to support women to be healthy before they get pregnant.

[341] **Mark Drakeford:** Thank you very much. Dr Paranjothy, we have been looking forward to hearing more about the all-Wales perinatal survey. It has been referred to quite extensively by earlier witnesses, so thank you for coming to help us with that.

[342] **Dr Paranjothy:** Thank you for the opportunity. I think that it is excellent to have an inquiry like this that shines light on this issue. The all-Wales perinatal survey is the routine data collection for Wales on stillbirths and perinatal deaths. So, we collate the statistics and have excellent reporting from all of the hospitals and maternity units and we produce an annual report on rates with comparisons over time and by place. As a result of that, we have the data and can see quite clearly how stillbirth rates have remained static over the last 10 years or so. That is in contrast to the neonatal mortality rate, which has clearly come down and a lot of that is to do with advances in dealing with premature babies when they are born.

[343] So, the next step is to take the perinatal survey the next step forward. As you heard this morning, perinatal audit has a clear role to play. We have referred to perinatal audit as a confidential inquiry in our written submission, but we are talking about the same thing, and that is a detailed investigation of each stillbirth as it occurs, where there is a detailed review of case notes and the clinical circumstances leading up to the stillbirth by a multidisciplinary expert panel. That will help us to identify those things that were avoidable, leading up to the stillbirth, and it will facilitate the sharing of lessons across organisations, which can then help us to make recommendations to help improve clinical practice. Clearly, the next step is to implement the perinatal audit on a national basis in Wales in a systematic way.

[344] You have also heard that more than half of stillbirths are unexplained. In a lot of cases, we just do not know the reason for them and we need to look at them in more detail and get a lot more information through post-mortem and pathology to try to get to the bottom of why stillbirths occur.

[345] **Mark Drakeford:** Thank you very much. Before I go to other Members, I will say that we have heard a little so far about the national stillbirth working group, which comes under the umbrella of 1000 Lives Plus. Members might want to ask you more detail about the work programme and the timings of the working group. If you have that information, you can offer it, but we will see whether it arises.

[346] **Lynne Neagle:** On deprived communities, you mention in your evidence the prevalence of women smoking during pregnancy in deprived communities. When you spoke just now, you said that Public Health Wales is trying to target resources towards that. Could you say more about how you are focusing resources on the real pressure points in Wales in this area?

[347] **Dr Jones:** There is an issue. The reasons why health outcomes are often worse in deprived areas are quite complex, and we do not understand all of them fully. However, some of the explanation is related to such things as smoking. We have high rates of smoking in pregnancy in Wales compared to other UK countries. We know that about 33% of our mums in Wales smoke at some point before or during pregnancy. It can vary as much as between 14% in the least deprived areas and 40% in the most deprived areas. We know that smoking in pregnancy is linked strongly to stillbirths, but also to things like pre-term births. Up to nearly 30% of low birth-weight rates can be attributed to smoking. There is definitely an issue there with regard to how we target our resources and how we ensure that we are putting the right resources into the right areas.

[348] There has been a lot of work recently in terms of Public Health Wales. The early years are a high-priority area for us. A particular piece of work and programme is going on around the early years, which is specifically looking to identify what the evidence base says

that we should be doing, what the population health impact likely to be if we follow the evidence base, particularly around such things as smoking, and what we need to do with regard to improving data, monitoring and outcomes on all aspects of this issue. We need to work closely with the health boards, the Government and local authorities. Specific programmes are in place, such as Flying Start, that work in deprived areas; Families First is another key programme, as is Communities First. In our work with our early years programme, and influencing and working closely with the health boards, we would like to see such things as maternal smoking and maternal obesity being given a high priority, so that all front-line staff working with families in those areas are giving out consistent messages and opportunities to be referred to services and things that can help. A lot of work is happening with that, but we still have some way to go to ensure that it is consistent across Wales and that everyone sees that there is a need to prioritise these areas.

[349] **William Graham:** Do you have an opinion on the amount of time and training that is available to staff to implement some of the things that you have rightly identified?

[350] **Dr Jones:** Yes, and I think that is quite a big issue. There are a lot of competing pressures on staff who work in maternity services and early years programmes regarding the sort of things that they are expected to cover and address with families. In a recent piece of work that we did in looking at the evidence base, we looked at what professionals would say the barriers were to implementing public health and some of this agenda, particularly around smoking. Those barriers included such things as time, a perceived lack of knowledge of some of the latest guidance and a perception of the effectiveness of the interventions if they were going to deliver them. So, I think that we know what some of the barriers are, and we have heard today about the importance of building the public health agenda into training for new midwives, but also into training for midwives who are already trained, and for health visitors as well, because this is a team that works around families and is seeing families at this time in their lives. It is about ensuring that the training is built in, that there is enough time to go on the training and that it is given a high priority in that way. In Public Health Wales, we are working closely with health boards to support this. It is challenging, but I think that we can move forward and improve.

[351] **William Graham:** Secondly, arising from that point, how about education as partners, with mothers in general, presumably before they become mothers?

[352] **Dr Jones:** Again, with smoking, you can take it back to the school setting. The tobacco report that came out this week showed again the issue that we have with more teenage girls than teenage boys taking up smoking. That is a concern for us, because they are the mums of the future. We know that mothers aged under 20 are much more likely to smoke than older mothers. Targeting specific groups in the population has to be a priority, and the prevention of uptake in the school setting would be the starting point for that. Then, it is about how we do preconception advice and support better, where you have women coming in for opportunistic contacts to get family planning and screening and so on. There are lots of times when you can give advice to women who may be thinking of pregnancy in the future. It does happen, but we need to do it systematically so that these issues are high on everyone's agenda and foremost in their minds when they see women and families, so that they know to talk about smoking and to say to someone who is planning a pregnancy that it is very important to be a healthy weight before conception. We have more work to do in that area, in supporting services for that.

[353] **Mick Antoniw:** I am interested in some of the data, which I found helpful in getting the picture—and I want to ask in a minute about the way-forward study that you propose in your paper. On the statistics that you have, the adjusted stillbirth figure in Wales by deprivation seems to indicate that, in actual fact, there has been a coming together of the actual rate, so the most deprived category is reducing but there is a contrary increase within

the least deprived category. Is that an accurate interpretation? I am not very good with these things. Secondly, were there any data that led you to any reasons for why that may be?

[354] **Dr Paranjothy:** The graph tends to indicate that the two rates are coming together, but we are dealing with small numbers here so there will be a lot of fluctuation. If you look earlier on in the graph, you can see that there is a widening, then it comes together, and then it widens up again and it looks like it is coming back together now. Is that just a random fluctuation playing its way out? It looks as though it is coming together but, because we are the size we are, the actual number of stillbirths that we have is under 200 every year. Even when you add the cumulative years together, we have quite a small number. An analysis came out earlier this week from England, which looked across England and which dealt with at least 3,000 stillbirths. It looked at the rate in the least deprived tenth and the most deprived tenth and found that there was a consistent gap and a twofold increase when comparing the most deprived with the least deprived. So, I suspect that this is actually down to the small numbers and the fluctuation that you see.

[355] **Mick Antoni:** That is helpful. Within some of the other data there, 60% or so falls within the 'unexplained' category. Looking at some of the other data as well, we see quite substantial variations from area to area and between health boards, which, again, I suspect may be down to particular numbers. You say in your evidence:

[356] 'A detailed study of stillbirths is required if we are to understand the reasons for stillbirth and identify modifiable risk factors that can be addressed to prevent them from occurring.'

[357] Could you explain a little more about what you want to achieve and how you see yourself actually achieving it, and the purpose of it? It seems to me that you come to quite an important conclusion.

[358] **Dr Paranjothy:** We are describing very much what you have heard Jason Gardosi describe they have done in the west midlands. They did a confidential inquiry, which is sometimes described as a perinatal audit. We are talking about looking at a consecutive series of stillbirths prospectively, so as they occur, you get a multidisciplinary team together including obstetricians, midwives and people who have been involved in the care, and you look at the case and the clinical circumstances leading up to the case and at whether there were any areas where, if something different had happened, it might have been avoidable. When you do that across a series of cases, you start to come up with themes and then it becomes clear where things could be done differently or where there may be lessons learned that ought to be shared across organisations. What is happening at the moment is that individual health boards tend to do them locally, so you do not have the sharing of lessons.

2.00 p.m.

[359] There is some evidence to suggest that, when you have an independent expert panel coming together to look at this systematically at a national level, there is some advantage to be gained from that independence in reviewing it. With some of the evidence that you heard about from the west midlands, we need to look at whether those issues hold here. The only way we can do that is by getting the additional detail on the stillbirths that are occurring at the moment. We are halfway there because we have the survey up and running. We are already collecting data, but it is about enhancing the data that we collect and bringing the panel together to do the systematic reviewing, and then starting to put together a strategy that can be implemented to actively reduce the stillbirth rate.

[360] **Kirsty Williams:** Assuming that that is what this committee decided needed to happen, who needs to do that? Whose role is it to make that audit happen? Is that the Welsh

Government's? What we need to do to make that a reality for you?

[361] **Dr Paranjothy:** The all-Wales perinatal survey will be perfectly placed to do that, and we are all geared up to take it forward. We get our funding from the Welsh Government, so it just needs to be made part of our remit to go ahead and do it—

[362] **Kirsty Williams:** Do you need more people? What would the Welsh Government need to provide you with in order for you to carry out this role?

[363] **Dr Paranjothy:** We would need the team, so we would need some resource for the expert panel and some additional resource for the enhanced data collection. We could put a costing together for that.

[364] **Mark Drakeford:** Am I interpreting you correctly when you say—and I think that I have heard others say this—that the resource needed is relatively modest, but what is really needed is the remit? What you need is the Welsh Government to say to you, 'We want you to do this' and then you will be able to get on and do it. The resource is maybe not the top issue.

[365] **Dr Paranjothy:** Yes, that is right.

[366] **Lindsay Whittle:** I apologise to the committee for missing this morning's session, so this question may already have been answered. Throughout all the reports that we have received, I have read phrases such as 'supporting pregnant women', 'working with women' and 'educating pregnant women'. Is there any involvement with fathers, expectant fathers or even expectant grandfathers—where I suppose I have to declare an interest? I think that that is really important. This is a family event for many people. Are expectant fathers told of these issues so that they can assist their partners through this exciting time of their lives to prevent any possible tragedy?

[367] **Dr Jones:** Obviously, maternity services do involve fathers throughout the pregnancy. From a public health perspective, we would advise that they be involved considerably in issues where behaviour change is needed. To go back to the example of smoking, we know that it is often more difficult for women to give up if their partner smokes. That issue was discussed at a conference that I was at this week, with the importance not just of supporting the woman to quit but giving that holistic approach to the family, including wider family members such as grandparents. It is about communicating the message to the family, as you said. This probably goes back to some of the comments that I made about our family-focused approaches, such as the Flying Start team around the family, so that you are working with families and communities on these issues. When smoking cessation support is offered, for example, we would like to see it being extended to include the father so that they can also access specialist smoking cessation services and so that they are present at things such as the booking visit to hear all the messages about the importance of diet and carrying on with physical activity, which is not contraindicated in pregnancy. We have evidence to support that, so that message needs to go out clearly and to be heard by the whole family. I agree that they need to be included.

[368] **Lindsay Whittle:** I am visiting my daughter this weekend, Chair, and I am taking this entire file with me. *[Laughter.]*

[369] **Elin Jones:** My first question follows on from the issue raised by Mick Antoniw about the least deprived and most deprived figures getting slightly closer together. I take your point about the numbers being small, and I suspect that that may be the reason you give in answer to my question, but, from a quick glance at the regional data by local authority that you have provided, it seems to me that something is happening in some of the rural areas of Ceredigion, Gwynedd and Powys, with their rates from 2007 appearing very different to their

rates before then. You may not be able to give any kind of detailed answer to that, but it strikes me, from a cursory glance, that there is something different there.

[370] I want to go back to the discussions with mothers on public health. We have heard quite a bit of evidence this morning that, almost culturally, there is a reluctance among health professionals to discuss stillbirth. People are willing to discuss smoking or all kinds of public health issues, but not in the context of stillbirth, and it is almost that they do not want to scare expectant mothers. Do you think that it would be a positive thing for health professionals, and midwives especially, to be trained and for it to be advocated that they have that conversation about stillbirth with expectant mothers?

[371] **Dr Jones:** Do you want to answer the first bit and I will answer the second?

[372] **Dr Paranjothy:** On the rural areas, you are right that it is around their being small numbers, because when you get down to the area-specific level, you have even smaller numbers, so you can expect more fluctuation. Every year, we look at the rates and where anything looks a little odd or where it looks like a trend is coming, we get in touch with the local area to make sure that it is aware of that and that it carries out its own investigation into why that might be. It checks and reviews its numbers and looks at the cases and so on. So, that happens—

[373] **Elin Jones:** The Vale of Glamorgan shouts out, almost, as an area whose numbers are different from what you would expect from some of the patterns that you see. Okay, that is fine. I am glad that you do that.

[374] **Dr Jones:** The second bit of your question was a really valid question.

[375] **Elin Jones:** Was the first bit not valid?

[376] **Dr Jones:** Of course it was. *[Laughter.]* It has been raised a number of times today.

[377] Some of it goes back to training to ensure that staff have the confidence to raise certain issues with families in the right context and the right training to do that. So, we have several specific training programmes, for example on brief intervention for smoking cessation. My view is that they should raise all the risks of some lifestyle behaviours with mothers and families. Cot death has been mentioned a number of times already today and, as part of the cot death scheme, smoking is a really important factor to talk about with families and with mothers to prevent cot deaths. It is important when we talk to women not to induce fear but to have an open and honest and a partnership approach, because they need to make some decisions about their risks and they need to have all the information to make an informed choice about whether to carry on with a specific behaviour and whether to access some of the support that we can offer to address some of their risk factors. So, the training and the confidence need to be there, but they need to have those discussions about what all the risks are. Smoking and obesity or being overweight are difficult issues to raise, because they could be sensitive for all sorts of reasons, so we need to improve confidence to raise those issues. There are all sorts of risks, and stillbirth is one of them. The risk of congenital anomalies is another one that is not raised much, but is a risk. We need to put them all on the table and have that discussion; that would be my view.

[378] **Rebecca Evans:** We have heard evidence that some ethnic groups are more likely to experience stillbirth than others. Does Public Health Wales engage particularly with any ethnic groups on this issue? Do you have any examples of how you do that? Is it something that you do at the moment?

[379] **Dr Jones:** I probably do not have that information to hand. I do not know if Shantini

wants to comment on the data that come out of the all-Wales perinatal survey. I can certainly find out whether there are any specific pieces of work. I do not know of any, but that does not mean that there is not anything happening. I could bring back any specific pieces of work to committee. I know that we do a lot of work with certain areas of the community, as I have discussed. Shantini, do you want to say anything on that?

[380] **Dr Paranjothy:** We have a problem with the data. If you want to look at rates by ethnic group, you need to have good data on ethnicity for all births, and at the moment, that is not good. While we might have ethnicity data for the cases, we do not have it for all births, so we cannot put the rates in the context of the whole population. That is a data issue that we are starting to address now; one of the streams of work that we have in Public Health Wales is looking at the quality of data that are collected on early years across the board. We are trying to take clear steps to improve the quality of those data so that you can have better monitoring. If you do not have good, regular monitoring you cannot do anything about it, because you have nothing to act upon. So, that will come through. Local health board teams will have specific programmes of work with minority groups through the early years programmes, but that is one for specific health boards.

[381] **Rebecca Evans:** If we do not have the data in Wales, are you aware of any UK-wide or international studies that suggest that this is a particular issue?

[382] **Dr Paranjothy:** That is certainly the case. There was a paper in *The Lancet* from a study that had looked systematically at the risk factors for stillbirth. In terms of sociodemographic characteristics, it is definitely advancing maternal age, ethnic minority groups and people who live in more deprived areas, and poverty. Lower educational attainment is also a factor. Those are the things that come out consistently. We have seen that in Australia and Canada as well. What is interesting is that the effect of cigarette smoking is different; for example, it seems to have a stronger effect in more deprived populations. Some of this might be epigenetic—how you respond depends which genes are switched on. Depending on my genetic make-up, the effect of cigarette smoke on me might be slightly different to someone else. These are the areas where strong research is needed to take it forward. That is to the detriment of our profession—we have neglected this area—but we are looking at it now. There are things that we can do now to get up to speed, like the confidential inquiry, to try to implement things, and put them into practice, so that we get to where the evidence says we should be. It is also clear that we need more research, and we can do that as well, contributing to the evidence base so that, 10 years from now, screening for stillbirths will be comparable to screening for other outcomes from pregnancy, much as Professor Smith was saying. We need to invest in that research in order to make that happen.

[383] **Elin Jones:** I have a question just for my own curiosity. We have heard quite a bit this morning about the important role of health professionals listening to the views of the pregnant woman, and her intuition. Are there any data in Wales, or studies anywhere, that show a higher incidence of stillbirth in first-time mothers, as compared with later pregnancies?

2.15 p.m.

[384] **Dr Paranjothy:** Being a first-time mother is a risk factor in itself, but when you combine risk factors—when you are a bit older, it is your first pregnancy and you are also overweight—you have an accumulation of risk factors. As we have heard this morning, that would probably put you in a high-risk group in obstetrics terms; it may or may not, now. There has been a whole population shift, and given that 50% of pregnant women in Wales now are overweight or obese, what do you do? You cannot classify them all as high risk, but, equally, there are issues. The question was around primiparity: yes, it is a known risk factor.

[385] **Vaughan Gething:** I forgot to ask about a comment made earlier by the witness from the Royal College of Obstetricians and Gynaecologists, Bryan Beattie. It was made in a discussion in response to Mick Antoniw's question about late births and the identifiable decline in birth outcomes if women are induced after 10 or 12 days. It was noted that the later it got, the more difficult it was and the more likely it was that there would be a stillbirth. He said that it may be interesting to understand why that is, in terms of whether that is happening because of maternal choice or for another reason. He suggested that there may be instances where there is a problem with the service providing an induced birth early enough. I wonder whether you already have evidence about the reasons for late inductions and the impact of a birth that is induced later than 10 or 12 days and how quickly we can plot the line in terms of the outcomes for the child.

[386] **Dr Paranjothy:** That evidence is covered in the National Institute for Health and Clinical Excellence guidance for induction of labour. The evidence shows that the rate of stillbirths increases as the pregnancy goes on, which has led to the recommendation that there should be induction of labour—I cannot remember the exact figure now—at around 41 weeks. So, the evidence base behind that recommendation is laid out in that guideline. I do not have evidence other than that.

[387] **Mark Drakeford:** I am afraid that the clock has beaten us again, as it has in every session of the inquiry so far. Thank you both for your help today. Siobhan, if there is any work going on within Public Health Wales with minority communities around this issue, please let us know about it.

[388] Symudwn ymlaen yn awr at y panel olaf o dystion. Prynhawn da. Croeso i'r rhai sy'n cynrychioli byrddau iechyd lleol Cymru: Angela Hopkins, cyfarwyddwr nyrsio Bwrdd Iechyd Lleol Cwm Taf, a Fiona Giraud, pennaeth staff cyswllt ar gyfer gwasanaethau i fenywod, Bwrdd Iechyd Lleol Prifysgol Betsi Cadwaladr. Diolch yn fawr i chi'ch dwy am ddod.

We will now move on to the final panel of witnesses. Good afternoon. Welcome to the representatives of Welsh local health boards: Angela Hopkins, director of nursing at Cwm Taf Local Health Board, and Fiona Giraud, associate chief of staff for women's services, Betsi Cadwaladr University Local Health Board. Thank you both for coming.

[389] Fel arfer, rydym yn gofyn i bobl a oes ganddynt unrhyw sylwadau agoriadol byr i'w gwneud. Rydym wedi cael eich tystiolaeth ar bapur, a diolch yn fawr am hynny. Wedi ichi wneud unrhyw sylwadau agoriadol, byddaf yn troi at aelodau'r pwyllgor i ofyn cwestiynau.

Usually, we ask people if they have any brief opening remarks to make. We have received your written evidence, and thank you for that. When you have made any introductory comments, I will turn to committee members to ask questions.

[390] If you have any brief opening remarks to help us, we would be grateful for those. We will then go into questions from around the table. Angela, you look like you might be poised to start. *[Laughter.]*

[391] **Ms Hopkins:** We are grateful for the opportunity to present our evidence here today. We wanted to start by advising the committee that we are both nurses and midwives as well, so we have experience of caring for women during labour. Sadly, we also have experience of caring for women and their families when they have, regrettably, had a stillborn child.

[392] We have heard much of the evidence today, and we concur with a great deal of it. We certainly support the national work that is under way with 1000 Lives Plus, because we think that that will bring forward a more standardised approach that should improve the care of women and hopefully reduce the incidence of stillbirth. We also support the ongoing

education of midwives and obstetricians in providing care, and using the best evidence and application of the available guidelines to improve the care that is available.

[393] From my experience in Cwm Taf, we have heard a great deal of information from the public health sector regarding the health of the nation, the work that we all need to do and the important role that midwives have to play in putting across the public health messages that are so important to improve the outcome of pregnancy.

[394] **Mark Drakeford:** Fiona, is there anything that you would like to add?

[395] **Ms Giraud:** Hoffwn ddiolch am y **Ms Giraud:** I would like to thank you for the cyfle i gyflwyno'r dystiolaeth yma y opportunity to give evidence here this prynhawn yma. afternoon.

[396] From a north Wales perspective, our overall stillbirth rate, as reported in the last perinatal mortality survey, was 3.7 per 1,000 births—it was a question that was asked before—which was one of the lowest in Wales. We have pockets of higher levels in north Wales, which may answer the question that you asked earlier, reflecting local demographics and areas of deprivation.

[397] Like the national trend, our rate in north Wales has plateaued and has not seen an improvement in the last three years. However, the health board acknowledges that services throughout Wales face significant challenges, which may account for this lack of reduction in stillbirth rates. The service has seen an increase in women presenting with social complexities. We have seen an increase in women who smoke, as was previously alluded to, and an increase in obesity and teenage pregnancies. We have also seen the advancement of medical technology in the last 15 to 20 years, which has increased the number of women who present to services with complex comorbidity, which we have not seen before.

[398] In acknowledging these factors, the health board prioritises the public health agenda, recognises the role of the midwife and supports the midwife in actively providing advice in view of the risk of stillbirth. We also recognise the need for compliance with national guidance. We also support the continuity of carer and we recognise the need to standardise the review of all stillbirths in Wales. We welcome the development of a 1000 Lives national stillbirth group.

[399] **Kirsty Williams:** I am interested to know how you on the ground are able to put the resources into tackling this problem, because you are under a huge amount of pressure from having to provide money for all sorts of services, not just services for women, but also for services such as cancer and orthopaedics. Within your own services, we heard earlier that local health boards might choose not to employ a specialist in fetal medicine because they are worried about meeting compliance for general gynaecological waiting times, which the Assembly will jump up and down if you do not meet. As people who have to provide the service, is it easy to get the resources that you need to tackle this problem? If not, what could this committee recommend that would make it easy for people like you to be able to say to others, 'No, I'm sorry, we're going to have to prioritise this and spend money on this, because it is important'? I am just trying to get a sense of what it is like for you from day to day in battling to get the resources that you need.

[400] **Ms Hopkins:** In Cwm Taf, we would say that we use the national tools that are available to us. We have already heard today about the use of the Birthrate Plus tool to appoint the appropriate levels of midwifery staff and midwifery support workers. That is a very useful tool that is applied across Wales. That is one area in which you can be assured that your resources are being appropriately placed. It is not without its challenges. We are well aware of the medical challenges, as is this committee, in terms of available medical staff.

It is always a question of balancing the risks, but I would say that, for my health board, we comply with Birthrate Plus and we see it as a priority.

[401] Also, from a director of nursing perspective, my colleagues across Wales and I would say that we all have maternity services as a priority. We recognise the high risk that exists, because it is not just about the mother; it is also about the baby, which is why we are here today. So, I think that there is a good priority for maternity services, but there is always the balance in trying to get the right resources into the right place, and I would say that it is about the appropriate use of the national tools and application of the national guidance, and, going into the future, the national group will come forward with further recommendations, using the 1000 Lives methodology and approach, which will certainly help us in the health boards to apply the resources well. We all want to deliver good services, and we all want to reduce the rate of stillbirths across all health boards.

[402] **Mark Drakeford:** Fiona, do you have anything to add?

[403] **Ms Giraud:** In view of Midwifery 2020 and the public health role of the midwife, we do invest in the midwife's training, and not just to the mandatory level, but in public health and getting the right public health messages out as well. We recently had a north Wales conference on maternity services, which focused on the public health agenda, looking at smoking, obesity, teenage pregnancies and the risks associated with those public health messages.

[404] **William Graham:** Thank you for your evidence today, particularly your description of some of the actions that you are able to take in your respective boards on this particular subject. One thing we heard this morning was a suggestion that there might be, as it were, a case for review at the end, which I imagine would be beneficial for all. What would be your perspective of that?

[405] **Ms Hopkins:** Certainly, in my health board, there is a full case review of each stillbirth. Every one of those cases is a regrettable loss, and we expect there to be a deep investigation into each one. Again, we use a standardised approach, which has been developed in the 1000 Lives project. So, we use a root-cause analysis of every aspect of the care, not just the period around the stillbirth, but the run-up to it and the care of the woman through pregnancy, to ensure that there is a full investigation. There is also an analysis of whether anything could have been performed differently or better to improve the outcome.

[406] For those stillbirths where there is an identifiable cause, such as a congenital anomaly, we recognise that as a cause. However, for those where the loss is unexplained, which we have heard a lot about today as that tends to be the majority of cases, and where it is difficult to describe why there has been a loss, those cases are presented in Cwm Taf to me as the director of nursing and to the medical director so that we can scrutinise the investigation, to make sure that the actions that have been drawn together are appropriate and to be clear about how those actions will be shared back into the service to ensure that the lessons are learnt.

2.30 p.m.

[407] We heard earlier about variation across Wales, and that is the case. I think that it would be helpful if we were to have a national approach. Certainly, in my earlier career, I was a reviewer with the national confidential inquiry into stillbirths and deaths in infancy and, from a personal perspective, I would say that there is a great deal of learning to be done from those inquiries on an individual basis that you then take back into your service, but also nationally. The recommendations that come out of such an inquiry, or an audit, as we heard it described earlier, would be helpful to achieve a more standardised approach in Wales.

[408] **William Graham:** May I ask you about training? We appreciate that there is a shortage of midwives, therefore, there is a balance, as you have described. Do you think that sufficient time is available for training when they are employed to make up those new developments in their particular speciality?

[409] **Ms Hopkins:** Again, I would say that there is good guidance, particularly in things like the NICE guidelines, and the Centre for Maternal and Child Enquiries, which you have heard about this morning, comes forward with a series of recommendations that we then build our training programmes around. So, we will have mandatory and statutory training programmes. I can only speak for my health board, but we achieve full compliance with that. It is an ongoing challenge, because there will always be other areas where we want to provide further training and further ongoing education so that our clinicians, midwives and obstetricians can remain current in their practice and make the best use of the available evidence.

[410] **Ms Giraud:** When the Welsh risk pool undertakes its annual review of the maternity services as a high-risk area, it also requires compliance by health boards in view of the training that they provide. So, you have to give evidence of the training that you have provided. In our health board in north Wales, on an annual basis, we review our training needs analysis in view of developments and lessons learnt and modify the training in view of that, in addition to the mandatory requirements. This is a challenge, but it is a necessary requirement.

[411] **Mark Drakeford:** Rwy'n mynd at **Mark Drakeford:** I will go to Mick next, Mick nesaf, draw at Elin ac yn ôl at Vaughan. over to Elin and back to Vaughan.

[412] **Mick Antoniw:** I have a couple of questions following on from that. You answered part of my question when you said that it would be helpful to have a national approach. Some of the witnesses that we heard from earlier talked about the analysis of information that is needed to do these perinatal audits, which would be a surveillance-based audit, that is, assessing a lot of the data, the monitoring and so on. Does that mean that midwives would carry out a more sophisticated system of record keeping than happens at the moment? I have seen from my daughter's experience the sort of data being collated at the moment. Would you say that that is effectively what you are doing and that you are getting enough information or are there ways that, if there were a national approach, you would want to change and perhaps improve or adapt the data gathering that you have at the moment?

[413] **Ms Giraud:** We have the all-Wales handheld notes, which were introduced last year. In view of getting the information that you would require on a specific case, a root-cause analysis would be needed, namely a review of the case with more than just the handheld notes—you would need the case notes as well and any other information that was available to give you the robust information and allow scrutiny of the case.

[414] **Mick Antoniw:** May I raise one further thing? Cwm Taf covers my constituency, so I am pleased to see the work that is going on there. What happens to the data that you produce when you have the evaluations and the audits? Do they go anywhere beyond yourselves?

[415] **Ms Hopkins:** Yes, they do. The health boards all submit information to the national perinatal survey, and I think that you heard information about that earlier. So, we now all provide some information to a national database, which is important. At a local level, when there has been a stillbirth, one of the most important things is that you provide some feedback to the family. We would expect to be engaging with families and providing information to them.

[416] **Ms Giraud:** The intrapartum stillbirths are reported to the Welsh Government. That is a requirement—they have to be reported to the Welsh Government. The health board will normally be provided with the level of inquiry that is required to be undertaken. That is a given a time frame, from the time you report to the Welsh Government to the time that you have to provide preliminary information back to the conclusion of the report, if you like—the submission of the report and the action plan required as a result of your full inquiry.

[417] **Elin Jones:** We have had evidence all day about the importance of a conversation being held between a midwife and a pregnant mother about stillbirth, the risk of stillbirth and the actions that can be taken to reduce the risk. We have heard that that should be a requirement. Would you support that?

[418] On the value of the information that can be gleaned from a post-mortem, there do not seem to be enough post-mortems happening for some quite obvious reasons, but how do you support your staff for them to recognise and realise the value of post-mortems of stillborn children, and then train them to have those difficult conversations with parents and families?

[419] **Ms Giraud:** Picking up on your last point, there has been a national drive to train staff within maternity services on how to gain consent for a post-mortem, and trainers have been identified within health boards. Once staff have been trained, it is logged on a national register in Cardiff. So, it is a well-structured, formalised form of training with a live register of those people who can take consent for a post-mortem.

[420] **Ms Hopkins:** Fiona is describing something where we are doing some work at the moment, and that is absolutely important. We know from issues such as organ and tissue donation that by focusing on specific individuals who have a range of skills in having very difficult discussions at the time of death, you can improve the take-up of, in this case, post-mortem, so that you can provide evidence not just for us to learn from on a national basis, but for the family by trying to discover whether there was a reason for the stillbirth. That approach is the one that is being taken in Wales, and we all welcome that.

[421] You asked in the first part about the discussion on stillbirth, and Fiona and I have discussed this throughout the day. We know that midwives are having discussions with women at the time of their pregnancy booking, and throughout their pregnancy, about the risk factors that can lead to a problem with their pregnancy. However, what we have heard today is that there should be much more of an upfront statement that there is a risk in every pregnancy of a stillbirth and these are the things that could predispose a woman to having a stillborn child. Perhaps there needs to be more of that type of discussion. We would say that the discussions between midwives and obstetricians are occurring around the risk factors, but I would say that we do not open it up by saying that every pregnancy has a risk of a stillborn baby. That is something that we can take back in order to look at how we frame those discussions. I would say that that is also something that we should be discussing in our maternity liaison committees, where we have mothers in the groups, and their view on that is important as well. That is a place where we can have further discussions on how we, as professionals, might engage appropriately in those discussions.

[422] **Mark Drakeford:** We heard earlier from a witness about motivational interviewing. It is not a matter of just saying that you have to talk about this; you can talk about things in a way that does harm as well as talking about things in a way that leads to better outcomes. It is not just enough to say, 'We need to talk about it', you have to talk about it in the right way. Motivational interviewing is one technique that some people think helps you to do that.

[423] **Vaughan Gething:** I want to come back to the points that have been made about consistency and post-event scrutiny. I could not help but notice that, in the Cwm Taf Local Health Board paper, the definitions of young mothers and older mothers are different from

those given in some of the papers that we have seen from other health bodies. Some of the points about how you identify risk factors feed into this. I was interested in what you were saying about scrutiny and review after each stillbirth and about how that is run, and how that actually feeds into staff learning. Particularly given the evidence that we had earlier today about how the quality of care and consistency of care is a factor in stillbirths, I am interested how you then respond to any issues uncovered in your scrutiny. I am also interested in whether that has or has not fed into the training and the re-evaluation that you say that you are undergoing for midwives and professional staff.

[424] **Ms Hopkins:** I think that you are absolutely right. In terms of the way that it would feed in, we have perinatal mortality groups within the health boards that would discuss issues such as the outcome of stillbirth inquiry. That would be an area where multidisciplinary teams are coming together to look at areas that we could learn from. Not just in Cwm Taf Local Health Board, but in other areas, we have modified some of our educational tools, for example, the interpretation of fetal heart rates—cardiotocograph—monitoring, has been reviewed across Wales because of learning that we have had earlier. We know that you can monitor the heart rate, but it is then about the action that you take if there is a problem with that heart rate. As we have heard earlier today, you can encourage a mother to record the wellbeing of her fetus by its movements, but it is then about the actions that you take as a result. The learning that we get out of stillbirth inquiries in areas such as the perinatal mortality groups is absolutely important in the learning for that team, but also for the educational tools that you will use in going forward to support learning in the future.

[425] **Vaughan Gething:** To come back to this point about consistency, we have heard from many witnesses about a lack of consistency, because there are different services in the different health boards. Are you telling us that, for your own two health boards and, if you like, more generally, you think that there are probably seven different ways that it is all being done consistently, or are there inconsistencies within health boards, particularly in your own? If you have identified such inconsistencies, what have you then done in response to those inconsistencies, and is there anything that we or the Government could do to help resolve some of those inconsistencies in practice? We have had discussions back and forth with witnesses about the fact that there is a set of guidance that does not appear to be creating the level of consistency in practice that we would want to see and would expect medical professionals to provide.

[426] **Ms Hopkins:** We know that we have such things as NICE guidance. We also have the Royal College of Obstetricians and Gynaecologists' guidelines and in our two health boards in particular we would certainly advocate the full application of those guidelines, and you will see from our evidence that we are compliant. In terms of the variation that we have heard about earlier this morning, the 1000 Lives Plus team has set up the national stillbirth group, which will definitely be a focus for looking at a standardised approach across Wales. There is no doubt that that will support not only the full implementation of such things as guidelines, when they do come through, but it will also look at areas where we can learn from the best and make sure that that is applied consistently across Wales.

[427] **Ms Giraud:** I will give an example. In relation to the Welsh risk pool, the Wales Audit Office review on maternity services—the last report was published in the last few weeks—identified issues about the interpretation of electronic fetal monitoring and the language being used in interpretation. The NICE guidance is clear on the terminology that should be used. The use of appropriate terminology reduces risk within the communication of risk. In our health board, we have looked at producing stickers—each individual in the multidisciplinary team uses the same sticker to interpret electronic fetal monitoring, and that has reduced the risk of variation in the terminology used in monitoring. It is about issuing that kind of alignment and using the NICE guidance.

2.45 p.m.

[428] **Mark Drakeford:** Angela, you have referred a couple of times in your evidence to the new national group. We know a bit about it—we know that it has been set up, we know about its terms of reference and we know a little bit about its membership. Do you have a sense of the timescale it is operating to, which topics it is likely to tackle first and so on, and the priorities for its work programme?

[429] **Ms Hopkins:** It is only just being formed now. Clearly, there is good evidence already available on the areas that we might need to look at, and I think that the information provided to the committee today has been helpful.

[430] In Wales, and across the UK, there has been a great focus on the high-risk mothers and the particular health issues that we know move women into a higher risk group, but we know that a lot of stillbirths still happen in the low-risk groups. Perhaps Fiona has some information on the national group.

[431] **Ms Giraud:** The group has asked each health board to provide evidence—it has produced a document and has sent a copy to each of the health boards requesting information on where they are performing against each of the standards that it has put forward and asking them to present evidence and any documents that they have, including information on the development of documents. That has been sent to all the health boards, and I know that our health board has submitted that information, as has yours, Angela.

[432] **Mark Drakeford:** Thank you. That is probably the end of the questions that we have for you. Where we have had a chance to do so—we just about have a chance to do so now in the time left—we have asked some witnesses whether they might help us by identifying what they think of as the top priority actions to be taken to start making an inroad into the stubbornly high figures for stillbirths in Wales. If you were making recommendations on one thing for us to say what would it be?

[433] **Ms Hopkins:** With regard to this particular inquiry, it is a very complex area, but my own recommendation would be to support the production of a national confidential inquiry team. There is a great deal of information to be learned from that, as not only would it look at all cases across Wales, it would also come forward with a series of recommendations that could support a standardised approach across Wales. That would be very helpful, and it would give some confidence to the public, as well as supporting the professionals who provide this care daily.

[434] The other areas where we know we have an increasing problem in Wales relate to the health of the nation overall. The initiatives that we have in place for smoking cessation and the obesity programmes need our support, because there is no doubt that they have a particular impact on pregnant women as well.

[435] **Ms Giraud:** I would support what Angela has put forward and look to the review of all stillbirths as standard, and not just the ones that are reported to the Welsh Government. Also, I would make it a requirement to educate women about the risks of stillbirths as a priority.

[436] **Mark Drakeford:** Diolch yn fawr am eich help y prynhawn yma; mae wedi bod yn ddefnyddiol iawn i ni. Rydym wedi dod i ddiwedd y sesiwn.

Mark Drakeford: Thank you very much for your help this afternoon; it has been very useful for us. We have now reached the end of the session.

2.49 p.m.

**Papurau i'w Nodi
Papers to Note**

[437] **Mark Drakeford:** Un papur yn unig sydd i'w nodi, sef cofnodion y cyfarfod a gynhaliwyd ar 14 Mehefin. A yw pawb yn hapus i'w nodi? Gwelaf eich bod.

Mark Drakeford: There is only one paper to note, that is, the minutes of the meeting held on 14 June. Is everyone happy to note them? I see that you are.

2.50 p.m.

**Cynnig dan Reol Sefydlog Rhif 17.42(vi) i Benderfynu Atal y Cyhoedd o'r
Cyfarfod
Motion under Standing Order No. 17.42(vi) to Resolve to Exclude the Public
from the Meeting**

[438] **Mark Drakeford:** Cynigiau fod

y pwyllgor yn penderfynu gwahardd y cyhoedd o weddill y cyfarfod ac o eitem 1 yn y cyfarfod ar 4 Gorffennaf yn unol â Rheol Sefydlog Rhif 17.42(vi).

Mark Drakeford: I move that

the committee resolves to exclude the public from the remainder of the meeting and from item 1 of the meeting on 4 July in accordance with Standing Order No. 17.42(vi).

[439] A yw'r Aelodau i gyd yn fodlon? Gwelaf eich bod. Felly, dyna ddiwedd y sesiwn gyhoeddus.

Are all Members content? I see that you are. Therefore, that brings the public session to a close.

*Derbyniwyd y cynnig.
Motion agreed.*

*Daeth rhan gyhoeddus y cyfarfod i ben am 2.50 p.m.
The public part of the meeting ended at 2.50 p.m.*