Pecyn dogfennau cyhoeddus

# Y Pwyllgor Iechyd a Gofal Cymdeithasol

Lleoliad:
**Ystafell Bwyllgora 1 – y Senedd**

Dyddiad:
**Dydd Iau, 28 Mehefin 2012**

Amser:
**09:00**

Cynulliad Cenedlaethol Cymru
National Assembly for Wales

I gael rhagor o wybodaeth, cysylltwch â:

**Polisi: Llinos Dafydd**
Clerc y Pwyllgor
029 2089 8403
HSCCommittee@wales.gov.uk

## Agenda

### 1. Cyflwyniad, ymddiheuriadau a dirprwyon

### 2. Ymchwiliad un-dydd i farw-enedigaethau yng Nghymru – Tystiolaeth lafar (09:00 – 15:00) (Tudalennau 1 – 133)

**09:00 – 09:40**
HSC(4)-19-12 papur 1 – Cronfa ymchwil marw-enedigaeth Holly Martin
Isobel Martin
HSC(4)-19-12 papur 2 – Sands
Janet Scott, Rheolwr Ymchwil ac Atal
Shirley Gittoes, Ymddiriedolwr ac Is-gadeirydd Rhwydwaith Sands yng Nghymru

**09:40 – 10:20**
HSC(4)-19-12 papur 3 – Ymddiriedolaeth Genedlaethol Geni Plant
Elizabeth Duff, Uwch-gynghorydd Polisi
Marilyn Wills, Cynghorydd Polisi
HSC(4)-19-12 papur 4 – Y Gynghrair Marw-enedigaethau Rhyngwladol
Yr Athro Gordon Smith
HSC(4)-19-12 papur 5 – Canolfan gwyddorau iechyd academaidd Manceinion
Dr Alexander Heazell

**10:20 – 10:30 Egwyl**

**10:30 – 11:10**
HSC(4)-19-12 papur 6 – Coleg Brenhinol yr Obstetryddion a'r Gynaecolegwyr
Mr Bryan Beattie
HSC(4)-19-12 papur 7 – Sefydliad amenedigol Gorllewin Canolbarth Lloegr
Yr Athro Jason Gardosi, Cyfarwyddwr

**11:10 – 11:50**
HSC(4)-19-12 papur 8 – Coleg Brenhinol y Bydwragedd
Julia Chandler, Swyddog Cenedlaethol
Stuart Bonar, Swyddog Materion Cyhoeddus
HSC(4)-19-12 papur 9 – BMA Cymru
Dr Mark Temple, Cadeirydd – Pwyllgor Meddygaeth Iechyd y Cyhoedd Cymru
Mr Phil Banfield, aelod o Gyngor BMA Cymru

**11:50 – 13:00 Cinio**

**13:00 – 13:40**
HSC(4)-19-12 papur 10 – Llywodraeth Cymru
Dr Jean White, Prif Swyddog Nyrsio
Polly Ferguson - Iechyd Atgenhedlol Menywod
Dr Heather Payne - Uwch-swyddog Meddygol (Iechyd Mamau a Phlant)

**13:40 – 14:20**
HSC(4)-19-12 papur 11 – Iechyd Cyhoeddus Cymru
Dr Siobhan Jones, Ymgynghorydd mewn Iechyd Cyhoeddus / Cyfarwyddwr Cyswllt Iechyd Cyhoeddus
HSC(4)-19-12 Papur 12 – Arolwg Amenedigol Cymru gyfan
Dr Shantini Paranjothy

**14:20 – 15:00**
HSC(4)-19-12 papur 13 – Bwrdd Iechyd Cwm Taf
Angela Hopkins, Cyfarwyddwr Nyrsio
HSC(4)-19-12 papur 14 – Bwrdd Iechyd Prifysgol Betsi Cadwaladr
Fiona Giraud, Pennaeth Staff Cyswllt ar gyfer Gwasanaethau i Fenywod

## 3. Papurau i'w nodi (Tudalennau 134 - 136)
HSC(4)-18-12 cofnodion – Cofnodion y cyfarfod a gynhaliwyd ar 14 Mehefin

## 4. Cynnig dan Reol Sefydlog 17.42(vi) i benderfynu atal y cyhoedd o'r cyfarfod ar gyfer eitem 5 ac ar gyfer y cyfarfod ar 4 Gorffennaf ar gyfer eitem 1

## 5. Ymchwiliad un-dydd i farw-enedigaethau yng Nghymru - Trafod y dystiolaeth (15:00 - 15:30)

# Health and Social Care Committee

## HSC(4)-19-12 paper 1

## Inquiry into Stillbirths in Wales – Written Evidence from The Holly Martin Stillbirth Research Fund

My evidence is based on my own personal story and the shortcomings which led to my baby Holly being stillborn. I started The Holly Martin Stillbirth Research Fund in 2010 to raise money and awareness for stillbirth. I was shocked that the stillbirth statistics in the UK have remained static for at least 20 years and the stillbirth rate in the UK is one of the 3 worst in Europe out of 35 countries. All the money I raise goes to support the work of Dr. Alexander Heazell at St. Mary's Hospital in Manchester. I have recently joined The National Stillbirth Working Group for Wales, looking at stillbirth as part of the 1000 Lives Campaign .

I was pregnant with my first baby in 1985. It was considered to be a low risk pregnancy. I was 25, a professional physiotherapist, married and living in my own home in an affluent town. I was of normal weight, never smoked, never took drugs and never drank alcohol during my pregnancy. I attended every ante-natal visit. I had no health problems.

Everything was completely normal up to 37 weeks. At that point I noticed reduced movements and immediately informed the midwife. I was started on a kick chart where I had to record the time it took for the baby to move 10 times in a day. At no time was I told the risk with reduced movements or that there was chance that the baby might be stillborn. Quite often it was mid- afternoon before I had felt 10 kicks but no- one was concerned.

I started having regular CTGs(cardiotocographs) to check the baby's heart rate. I went to the hospital every 2 days. The tracing was very flat and I was told to move around more and prod the baby to make it move. Again, no-one seemed to be concerned and I trusted they knew what they were doing.

This went on for nearly 3 weeks. At one tracing done by a junior doctor at the hospital, the heart rate dipped to 60 beats a minute, which is about half what it should be. I was told to go home and get my things and return to the hospital for monitoring later in the day. This was on Friday 23rd August, 1985, the start of a bank holiday weekend. When I returned to the hospital, no doctor came to see me. She had gone off on holiday and had not handed me over to another doctor. I did not see any doctors for the rest of that day.

The next morning I felt the baby moving at 7.30 in the morning. The kick chart counting did not start until 9am so I was waiting for that to start counting. My husband came to visit me at 10am. Shortly after, a midwife came to monitor me. She hunted round for a heartbeat and then left the room. Another midwife came and also hunted for a hear beat. No-one said anything. They left without saying anything. After a while my husband went to find them to see what was happening. They said I needed an ultrasound scan to confirm what they feared, that the baby had died. The scan did indeed confirm that there was no heartbeat and it was the worst moment of my life.

At that point they called in the consultant. This was the first time I had seen him. Up to then I had seen a variety of different midwives and doctors. I was induced. The labour went on for 16 hours. During the pushing stage, the baby refused to come out. I was told that as it was Bank Holiday, there was only one doctor in the hospital and he was busy with a lady whose baby was alive and therefore more urgent than I was. I was pushing for 3 hours and ended up with a forceps delivery and a lot of stitches. My husband was sent to find an oxygen cylinder when I needed some oxygen.

I went home the next morning. There was no bereavement service at the hospital. I saw 2 midwives after that, one who was extremely kind and the other who told me I wouldn't be complaining about the stitches if I had a baby to look after. It was a very isolating experience following Holly's death. People crossed the street to avoid me. Friends who had babies at the same time were concerned that if they saw me I would want their babies. Former colleagues changed the subject instantly if I mentioned my baby had died. I felt as if I was the only person in the world who didn't have their baby.

We spoke to the consultant afterwards and he said the baby was apparently normal and the placenta had a few infarcts. The baby was a bit small compared with subsequent babies. He said he should have delivered the baby 3 weeks early.

I went on to have six more babies. The same thing nearly happened with baby number 6 when the movements reduced at 36 weeks. The scans were flat. I went to the hospital and insisted to the doctor that she got the baby out. To her credit she did, and it was just in time. The baby was small and the placenta grey. However the baby was healthy, didn't need special care and is living a very busy life. It was very nearly a different story. All my babies since Holly were delivered at 37 or 36 weeks by caesarean section.

The fact that I am here fighting for action to prevent stillbirth 27 years later, shows that it is not something that goes away. Just because the baby wasn't born alive doesn't mean she wasn't a person who we loved. Not a day goes by when I don't think about Holly. She has been very much a part of our lives for 27 years. In Wales there are 190 stillborn babies every year. This means there are 190 families grieving for those lost children for the rest of their lives. These are not statistics, these are Welsh people's lives.

Points to Consider

1. A low-risk mother doesn't mean a low-risk baby

2. Stillbirth is rarely mentioned to the mother at any stage during pregnancy for fear of upsetting her. When 1/200 pregnancies ends in stillbirth, the mother has a right to know the facts. She can then play a more informed part in monitoring her pregnancy. The parents are informed in detail about other less common problems such as Down's Syndrome and this is widely accepted.

3. Kick charts are widely used when reduced movements are reported. However, their use is not fully explained. The purpose and relevance of the kick chart should be clear to the mother. There need to be clear criteria for intervention when using kick charts.

4. Stillborn babies are often small. The intra-uterine growth of a baby should be monitored with a more accurate method than a tape measure. Lack of sufficient growth of the baby should initiate a protocol and closer investigation.

5. CTG is used to monitor heart rates. There needs to be a criterion for intervention.

6. There needs to be continuity of care. All of the health professionals should be very well informed on stillbirth and better information should be provided to the parents on all the tests.

7. Clear protocols need to be in place and all the health professional should be aware of them and follow them.

Until further research can be carried out to find definitive causes for stillbirth, we must use the resources we have to the best advantage to save babies' lives. This initiative gives us the opportunity to pilot a different way of working that would make a real difference to families here in Wales.

Isobel Martin
On Behalf of The Holly Martin Stillbirth Research Fund

# Health and Social Care Committee

## HSC(4)-19-12 paper 2

## Inquiry into Stillbirths in Wales – Written Evidence from Sands

**In Wales in 2010 there were 190 stillbirths: one baby in every 200 is stillborn. Across the UK 11 babies are stillborn every day, devastating the lives of over 4,000 families each year. While neonatal and infant mortality rates have improved significantly over the last decade, stillbirth rates have barely changed.**

**Despite how prevalent stillbirths are across Wales they are the deaths no-one wants to talk about – the final taboo. There is a tendency to see the death of a baby before birth as 'just one of those things', and stillbirths have historically attracted little national attention or action. Yet many of these deaths are potentially preventable.**

***"I'm not an expert but I know her death was avoidable, that if she'd been taken out sooner she'd have survived.***
***After Erin died I got a letter from the hospital and it described all the scans I'd have if I got pregnant again.***
***But it's too little too late.***
***I wanted Erin. She wasn't a test run."***
**Louise McGeehan**

***"So often as obstetricians we sit down with a couple who have lost their baby and make plans for how we can work together to carefully monitor and manage the next pregnancy for a better outcome. It's time we all got it right first time round"***
**Bryan Beattie, Consultant in Fetal Medicine, University Hospital of Wales**

## A. BACKGROUND: ABOUT SANDS

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents devastated by the death of their babies, and by the total lack of acknowledgement and understanding of the significance and impact of their loss. Since that time, Sands has supported many thousands of families whose babies have died, offering emotional support, comfort and practical help.

Today Sands operates throughout the UK and focuses on three main areas:

- supporting bereaved families
- working in partnership with health professionals to promote awareness of perinatal mortality and provide professional training in bereavement care.
- raising awareness of the numbers and causes of babies' deaths and promoting prevention work, and funding research that could help to reduce the loss of babies' lives.

In Wales there are currently seven Sands voluntary groups offering support to parents across most regions, and co-ordinated through the Sands Welsh Network. The groups fundraise and have equipped four bereavement suites in maternity units in Wales, as well as a number of cold cots. Trained group members run training sessions for midwives and Supervisors based around Sands' internationally respected *Guidelines for Health Professionals*.

Sands parents in Wales lobby for more action to reduce the numbers of babies dying. In 2009 we presented our *Saving Babies Lives Report* to the Welsh Assembly and our petition calling on the Welsh government to develop a strategy for reducing stillbirths in Wales was signed by 816 people.

Our new *Preventing Babies Deaths: what needs to be done* report was launched in Westminster in March 2012.

**B: OVERVIEW**

1. The stillbirth rate in Wales is no worse or better than the UK generally, but that does not mean that stillbirths in Wales are something to be complacent about. Across the UK the levels of baby loss are unacceptably high.

2. When a baby is stillborn families are devastated by the loss of their precious baby. The impact is heart-breaking, profound and life-long.

***"I left the house thinking I would come home with a car seat with my baby in. Instead I didn't bring my baby home until a few weeks later, and that was in a tiny box."***
***A Welsh mum***

3. There is real potential to prevent a significant proportion of stillbirths in Wales.

4. A devolved Wales with close communication between policy makers and those who deliver care has the opportunity to make a difference. But leadership and a clear commitment from government is needed to tackle this relatively ignored issue.

5. There have been some relevant steps forward in addressing stillbirths around the UK:

    - The Scottish Government established a Stillbirth Working Group in 2010 which is focussing on areas where real and tangible work can be done. Key themes include: failure to identify risk by health professionals and parents; and inequalities in practice in adhering to guidelines and in care after a baby dies.

    - The Department of Health in England and Sands held a Stillbirth Workshop in March 2012, including parents and experts from a wide range of key disciplines. Five working groups are being set up to focus on particular issues:

        - standards for perinatal death review;

        - determining dataset indicators that ought to be collected in order to improve detection of risk of stillbirth;

        - harmonising guidance and training for midwives and doctors;

        - identifying key public health messages for reducing the risk of stillbirth;

        - developing information needed to build stillbirth prevention into the commissioning of maternity services.

    - The Stillbirth Clinical Study Group, set up in 2011 within the National Reproductive Health Research Network and sponsored by Sands, aims to develop new research into stillbirth and to field prospective projects to improve their quality and access to funds.

- Sands is supporting a National Post Mortem Working Group which is aiming to design a more acceptable and workable national template for a post mortem consent form. Wales is represented in this group.

- The Wales Maternity Collaborative has very recently set up a new National Stillbirth Working Group as part of the 1000 Lives Plus programme. The group is starting to shape an action plan to tackle stillbirths in Wales. Sands is delighted to be contributing to this group.

- The Clinical Outcome Review Programme which will gather perinatal outcomes data across the UK is due to resume this year, though final confirmation of the programme's start is still pending.

## SUMMARY OF SANDS RECOMMENDATIONS:

1. **Key public health messages need to be developed so that parents and the pre-pregnant population in Wales are aware of the risks of stillbirth and can make informed choices about their health and pregnancy.**

2. **Stillbirth and associated risks must be more prominently featured in Welsh midwifery and obstetric training curricula.**

3. **Standards of practice in detecting and managing at-risk babies must be raised across Wales: best practice guidance must be shared and implemented as standard, and audited, so that all mothers and babies receive the best antenatal care.**

4. **Funds for research into the causes and prevention of stillbirth must be prioritised.**

5. **Action is needed to ensure minimum staffing levels and the right skills mix in all areas of maternity care in Wales, as outlined by the relevant professional bodies.**

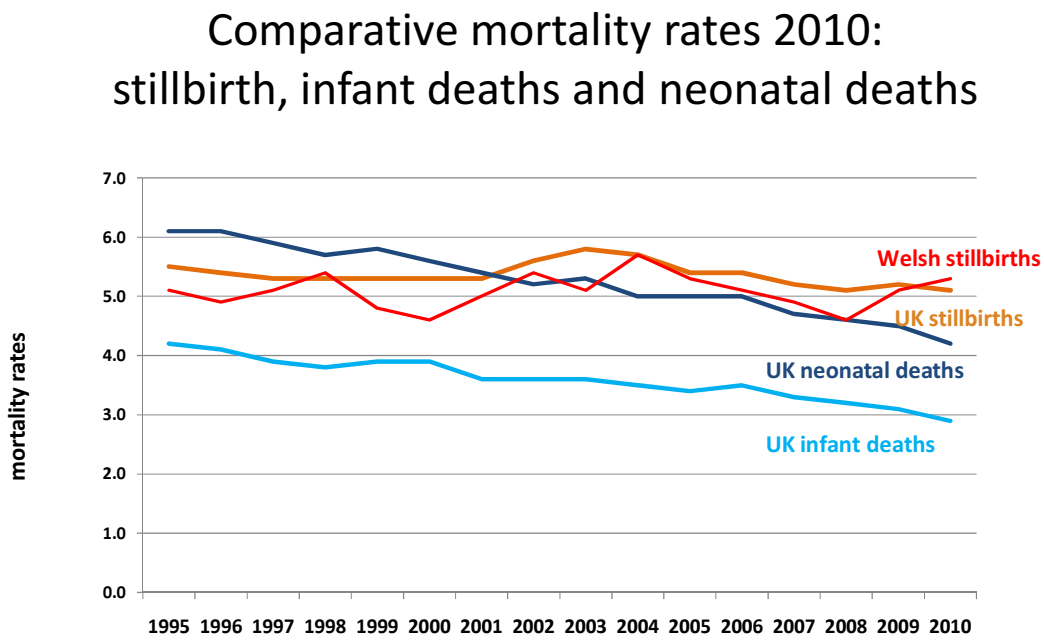
6. **A national standard for reviewing perinatal deaths must be developed and followed across Wales. The quality and effectiveness of hospital level review must be audited.**

7. **At least one more full -time Perinatal Pathologists should be appointed in Wales. Training for consent takers needs to be improved in tandem with improved information for parents.**

8. **Bereavement services across Wales should be organised and resourced in line with standards set out in Sands' *Pregnancy Loss and the death of a Baby: Guidelines for Professionals*.**

**C: STILLBIRTHS IN WALES – THE FACTS**

1. In Wales in 2010, 190 babies were stillborn. The rate of stillbirth has remained at the around the same level for over a decade[1]. This lack of change in stillbirth rates reflects the situation for the UK[2] .




Sources: Welsh Statistics Office; Office of National Statistics; General Register Office for Scotland; Northern Ireland Statistics and Research Agency.

2. Unlike stillbirths, neonatal mortality and infant mortality have fallen significantly in the same time. Stillbirth is in fact the most common form of child mortality[3].

3. As a cause of death for children, stillbirths are 10 times more common than cot death[4]; 40 times more common than child road deaths[5]; 80 times more common than childhood meningitis[6]. While rightly there are strenuous efforts to reduce these deaths, stillbirths, which are far more common, remain relatively ignored.

4. Similar high-income countries have lower stillbirth rates: the UK ranks 33rd out of 35 similar nations in a recent Lancet analysis[7]. What is more worrying still, while other countries are reducing their stillbirth rates, the same is not true in both Wales and England where rates have not changed for more than a decade.

5. 90% of stillborn babies have a no lethal congenital anomaly or any significant fetal condition[8], challenging the perception that these babies are somehow 'meant to die'. The majority of stillbirths are unexplained, in other words the baby was perfectly formed and no maternal condition or problem was found.

6. There is an increased risk of stillbirth associated with certain maternal medical conditions such as hypertension and diabetes, with previous obstetric complications, in multiple pregnancies and in first pregnancies[9]. However most stillbirths happen in pregnancies that were considered 'low risk', until the baby died.

7. A quarter of stillbirths are associated with smoking in pregnancy. Women who smoke more than 10 cigarettes a day double their risk of stillbirth[10]. In Wales 16% of mothers continue to smoke through pregnancy[11].

8. Stillbirth rates are higher amongst mothers who have a BMI over 30, with almost twice the risk of stillbirth than a mother with a BMI under 25. The risk increases with increasing obesity[12].

9. The odds of having a stillbirth increase steadily with age in mothers over the age of 35, doubling for mothers over 40[13].

**D: RECOMMENDATIONS FOR IMPROVEMENT**

### *1. Public health and informed choice*

Time and again parents tell Sands of the devastation they experienced when their baby died, and the subsequent shock when they discovered how relatively common stillbirths are. Many ask why they were never told this could happen. Cot death and Down's syndrome are openly discussed, yet stillbirths which account for many more deaths are rarely mentioned.

Welsh mothers are not informed of the risk factors for stillbirth. The messages about the dangers of smoking and obesity in pregnancy do not mention that stillbirth is also a risk, yet these are factors which mothers can potentially modify. An older mother might want to know her risk of stillbirth is increased, when she makes decisions about her birth plan.

***"You can't make informed decisions if you're not informed"***
***Bereaved dad***

Is it scaremongering to tell prospective parents of the risks, however small, of their baby dying or is it giving them the power to make truly informed choices?

**Key public health messages need to be developed so that parents and the pre-pregnant population in Wales are aware of the risks of stillbirth and can make informed choices about their health and pregnancy.**

### *2. Training for health professionals*

It is not just parents who are surprised to hear that 1 in 200 babies is stillborn. An individual health professional in Wales may never, in their professional career, care for a women who has a stillbirth; many perceive stillbirth as an uncommon event, but it is not rare nationally.

Lack of awareness means too often that women who do exhibit risk factors are not actually picked up. Many trainee midwives tell Sands that they graduated without having learned about stillbirth and the risks; many say they do not feel confident about caring for bereaved parents.

If Welsh health professionals perceive stillbirth to be a rare event there is a danger they will miss warning signs or underestimate the potential risks.

**Stillbirth and associated risks must be more prominently featured in Welsh midwifery and obstetric training curricula**.

***3. Picking up risk***

Routine antenatal care in Wales is failing to spot too many babies who need help. NICE Guidelines for routine assessment of fetal wellbeing after the 24th week is simply,"Symphysis-fundal height should be measured and recorded at each antenatal appointment"[14], in other words, use a tape measure. Screening methods today are not dissimilar to those in use 40 years ago.

Today it is rare to lose a baby in a pregnancy where a risk has been identified. But most stillbirths are in pregnancies where the risk was not spotted: the 'low risk' women who in fact have high risk babies are being missed.

Growth restriction in the baby is strongly associated with stillbirth, yet current antenatal care only picks up 30% of babies in the womb who are growing too slowly[15]. Growth monitoring varies in practice and quality from unit to unit, and is not audited. Too many babies who are failing to thrive and who should be having high risk care are not picked up until it is too late.

A decrease in fetal movements can indicate that a baby is in trouble yet it is common for parents to tell Sands they reported a decrease in their baby's movements but were reassured and sent home, only for their baby to day hours or days later. Parents in Wales are not equipped with good advice about fetal movements, but neither are many health professionals fully aware of the latest guidance from the Royal College of Obstetricians and Gynaecologists (RCOG) on managing decreased fetal movements[16]. In Norway a focus on improving fetal movement advice was accompanied by a significant fall in the numbers of stillbirths[17].

***"I had been telling the midwives for weeks that my bump wasn't moving as he used to but was told that it was normal as there is less space in the womb.***
***I went into labour in morning and the midwife made an appointment for me at the antenatal day clinic for the afternoon, a good six hours away. During the morning my little bump was moving, but on the way to the hospital I knew something wasn't right. I told them when I arrived but felt that they didn't take me seriously and I was made to wait.***
***Now for me looking back those six hours were a long time to wait and if I could have gone in during the morning things could well have been different."*** **A Welsh mum**

A third of stillbirths are term babies, in other words babies who might otherwise be ready to start their lives outside the womb. It is well known that stillbirth risk increases near the end of pregnancy, particularly for women who already have some other risk factor such as advanced age, yet practice about when to induce delivery in prolonged pregnancies varies greatly.

There is the same lack of consistency in detecting and managing maternal conditions associated with stillbirth such as infections, hypertension and diabetes.

**Standards of practice in detecting and managing at-risk babies must be raised across Wales: best practice guidance must be shared and implemented as standard, and audited, so that all mothers and babies receive the best antenatal care.**

***4. New research***

Even if we standardise care, and improve detection of at risk babies with the tools we already have, there is still so much we do not know. Research into stillbirth is where cot death research was 20 or 30 years ago: at the very beginning of its journey. The Lancet's 2011 Stillbirth Series recommends that, "*Further research is needed on underlying mechanisms to aid early detection and effective management of women at increased risk."*[18]

We have made huge advances in other difficult areas such as prematurity but virtually no progress in understanding why a seemingly perfectly healthy baby dies at term. Placental problems underlie most unexplained stillbirths but research into what is going wrong is lacking and there is no accurate way of predicting a failing placenta.

***"If we had tests that could identify babies at risk of death in late pregnancy, induction of labour would have a very high chance of preventing stillbirth."***
**Professor Gordon Smith, Head of Department of Obstetrics and Gynaecology, University of Cambridge.**

Sands parents and other parent charities are passionate in their commitment to fundraise for the research that is so desperately needed. The numbers of babies dying from cot death has fallen by 70% as a direct result of research, and we believe the same could be done for stillbirth. But for this to happen the generosity of parents must be matched by a commitment from government.

**Funds for research into the causes and prevention of stillbirth must be prioritised.**

***5. Resourcing for quality and safety***

Safety and quality of care are threatened by understaffing throughout maternity care in Wales.

High quality antenatal care depends on continuity of midwifery care. Routine antenatal monitoring relies on the instincts of health professionals, their sense that 'this doesn't seem right'. When a mother is seen by a different midwife at every antenatal appointment, and has a relationship with none, is it surprising that warning signs are missed?

Births are rising in number at the same time as becoming increasingly complex. The Royal College of Midwives is calling for 136 more midwives in Wales to meet rising demands[19], and the Royal College

of Obstetricians and Gynaecologists has expressed concern about the continuing lack of obstetric cover on labour wards[20],[21].

The death in labour of a term baby is a tragedy that should never happen. Yet the numbers of avoidable intrapartum death rates remain stubbornly unchanged, the same failures being repeated.

Under-resourcing and under-staffing can have tragic consequences. This was confirmed in recent research which found the chance of a baby dying from labour related causes increased by 45% at nights and at weekends, when staffing levels were lower[22]. Although 70% of babies are born at night maternity services are not run as a 24/7 service.

High quality maternity care requires that we have the right numbers of staff with the right skills mix in the right place, at the right time. There are too many maternity units with inadequate numbers of midwives and doctors, putting pressure on team working, communication and risk allocation.

**Action is needed to ensure minimum staffing levels and the right skills mix in all areas of maternity care in Wales, as outlined by the relevant professional bodies.**

***6. Learning lessons through perinatal review***

When their baby dies, most parents want to know why. Especially if the death was 'unexplained', it is often presented to them as a rare and regrettable, but unavoidable, tragedy. Yet we know that substandard care plays a role in many stillbirths.

Confidential enquiries into stillbirths have consistently found that sub-optimal care factors contributed to the baby's death in at least 45% of cases[23],[24] . These enquires also find that lessons are too often lost because deaths are not adequately investigated and recommendations for change are not implemented.

When a case of sub-standard care is so extreme that parents sue for negligence it costs the NHS dearly: in Wales obstetrics is the largest single contributor to clinical negligence costs. Claims over £1million in 2010/2011 in obstetrics amounted to £9.5 million out of total costs of £17.2million: well over 50% of payments[25].

Experts agree that rigorous and independent perinatal review is vital if sub-optimal care is to be identified[26]. But the quality of review in Wales varies widely: each unit conducts reviews differently and it is unclear who attends the meetings or what the outcomes are. We believe the process requires scrutiny and analysis to establish minimum standards of review with minimum time frames.

Parents need honest answers about why their baby died. They also need their own perspective of their care to be acknowledged and included in the review when appropriate. A review process which is rigorous, fair and open will answer questions for parents. It is not to apportion blame for blame's sake, but to gain some measure of 'truth and reconciliation', to learn lessons and improve quality and safety of care for the future.

**A national standard for reviewing perinatal deaths must be developed and followed across Wales. The quality and effectiveness of hospital level review must be audited.**

### 7. *Perinatal Post mortem*

Perinatal post mortem rates are low. The most recent data shows only 45% of parents consent to a post mortem in Wales[27].

Parents are asked , in the disorienting hours after they find out their baby is dead, to fill in a long and complex consent form with distressing details and choices about having a post mortem. It is essential that the staff caring for them have the information and skills to support them through this painful process. Yet recent research[28] has found that the health professionals who most often carry out this task often feel ill equipped or trained and voice their lack of confidence to do so.

Resourcing of perinatal pathology services in the Wales is inadequate: the whole country is serviced only by the equivalent of a 1.2 whole time perinatal pathologist. This situation has not improved over several years and parents continue to have to wait too long for post mortem reports.

Add to that the prospect of their baby being transported across the country to a specialist perinatal pathologist, it is little wonder so many parents opt to avoid post mortem altogether.

**At least one more full -time Perinatal Pathologists should be appointed in Wales. Training for consent takers needs to be improved in tandem with improved information for parents.**

### 8. *Care after a death*

The care that bereaved families receive around the time of their baby's death is extremely important. Good care cannot remove the pain of loss, but care that is inadequate or poor makes things worse and affects a family's wellbeing both in the short and long term.

Sands parents in Wales have experienced very variable standards of care after their baby died, with examples of truly excellent care alongside stories of desperately insensitive treatment and inadequate facilities.

A Sands survey of UK maternity units in 2009[29] found bereavement care is patchy. Basic facilities, such as a room away from the labour and postnatal wards where bereaved parents can be cared for without hearing the sounds of other mothers and their live babies, is still not standard in all units. Similarly, many units have no designated bereavement midwife.

**Bereavement services across Wales should be organised and resourced in line with standards set out in Sands' *Pregnancy Loss and the death of a Baby: Guidelines for Professionals*.**

## E: WELSH CASE STUDIES/PERSONAL EXPERIENCES

**BABY K**

Baby K was stillborn on 8th November 2008 at 39 weeks and 4 days, weighing only 5lbs. At 34 weeks tests undertaken in response to abdominal pain and bleeding showed his mother had high blood pressure and traces of protein in her urine. A series of subsequent tests continued to show the same problems for hypertension.

At 38 weeks a community midwife was due to visit her at home to check her blood pressure but didn't show up. Baby K's mother had to call the hospital to have the visit re-arranged. She still had high blood pressure and the midwife attending this visit recommended a 'plan for delivery' but none was made. The midwife said she would be returning in a few days. She didn't and six days later the mother called to get an appointment. A community midwife eventually arrived and with a hand held monitor confirmed that Baby K had died.

Subsequent to Baby K's stillbirth, his mother found that no record of his growth had been charted in her notes for the last five weeks of her pregnancy, during which time she was seen 9 times in an emergency assessment unit. His post mortem indicated he was growth restricted and had died from lack of oxygen.

**"My partner and I were totally devastated by our son's death. Some people say 'it's a shame but you're still young, you will have more children'. What do they know? Losing a baby is one of the worst things that can happen and we will never be the same."**

Baby's K's mother always felt that she was labelled during the pregnancy as an anxious young mother. Two of her own siblings had died; one a stillbirth (seven years previously) and another a cot death (13 years previously). She was 21 year old when pregnant with Baby K and in her notes one of the many consultants she saw had recorded her as being "identified anxious, no risk factors".

**"One of the most important things we would like to see changed is the communication between the team at the hospital and in the community. Communication is poor, the left hand doesn't know what the right hand is doing. We saw different midwives and consultants every time and they were often not familiar with my notes so we would have to remind them what my symptoms were. We truly believe our son was one of the babies that could have been saved if jobs where done properly. We now have no faith whatsoever in the NHS maternity services. Words can't really express how let down we are by them, to them we were just a number."**

Baby K's parents are now involved in ligation with the hospital where she had her antenatal care.

**BABY X**

Baby X was stillborn on June 14th 2010 at 36 weeks. But the pregnancy had not been a normal pregnancy.

It was instead characterised by repeated water infections, the identification of Group B Strep and growth restriction – issues which Baby X's mother believed she had had to continually fight to be taken seriously. At one point staff caring for her were unaware that the mother had tested positive for Group B Strep and no protocol for what might happen in labour was planned for, either in her notes or explained to her in person. Instead she was encouraged by midwives to go ahead with a planned water birth.

In her final week of pregnancy, Baby X's mother complained daily of abdominal pain, leaking water and reduced fetal movements. She had no further scans but was checked on a day assessment unit with a heart monitor, a device that arguably only indicates a baby is alive at the time when you use it, but does not indicate anything more in depth about its wellbeing.

It was as if staff were simply watching Baby X gradually deteriorate, taking no action except to listen to her heart beat to assure themselves that she wasn't yet dead.

***"Devastated and life shattering doesn't begin to cover how I felt. When they confirmed that she was dead, I screamed telling staff how I'd told them all week things weren't right and they refused to listen."***

Baby's Xs mother had in fact been leaking amniotic fluid during the final week of Baby X's life. An investigation of the placenta indicated that that she had a rare clotting disorder which had caused the placenta to slowly fail. Baby X also tested positive for Group B Strep; had she been born alive, there is a strong possibility she would have died neonatally.

The mother was told by staff at the hospital that a post mortem was 'pointless' and she didn't therefore consent to one, a decision she now regrets.

Baby X's mother went onto have another daughter and experienced the same symptoms (a drop in movements and abdominal pain) in that pregnancy. A scan revealed that this baby had also stopped growing and she was induced at 35 weeks. She now has a healthy little girl.

The story of Baby X reflects what Sands sees time and time again which is the experience of a mother who has to have a baby die in order to receive adequate care in a subsequent pregnancy.

***"If I was able to receive immediate attention with my second daughter and an adequate level of care why didn't I get that with my first daughter? You should never ever have to lose a child to gain one."***

The family feel Baby X's death could have been avoided with better care, and having been rebuffed by the trust they are now seeking legal redress.

***"I believe strongly my daughter's death could have been avoided had I received appropriate care and attention. I hope to get justice for her."***

**BABY G**

Baby G was stillborn on his due date on 30th January 2010. His mother had reported reduced fetal movements from 38 weeks to midwives. She attended a day assessment unit four times, when midwives checked the baby's heart beat.

She was advised to keep drinking cold water and be aware of her baby's movements although reduced movements were 'normal because there was less space in the womb'.

When she went into labour on 29th January Baby G's mother called into the hospital and was given an appointment to be admitted six hours later. While the baby had moved in the morning, on the way to hospital she knew something was wrong because he hadn't moved for several hours. After two scans it was confirmed that Baby G had died. He was 8lbs when born.

Baby G's mother was put in a private room on the labour ward and her family told to go home. The next morning she could hear a woman laboring in the next door room. Despite putting on the television and radio, as well as wearing I-pod headphones, she could still hear the cries of a new baby.

***"I sat in the corner going out of my mind. Thankfully my partner came in at the point when I was just about to walk out. They wanted me to stay but I refused saying this isn't the right environment."***

The family were given Sands information but offered no counseling and given no information from the hospital about holding a funeral for their son. They had to look the information up on the internet.

When they went to register their son's death, there was confusion over his stillbirth certificate. The registrar had never recorded a stillbirth before and despite having an allocated slot, the process took a long time, with the cries of babies in the waiting room audible throughout.

A post mortem found no explanation for Baby G's death.

***"When I fell pregnant with second pregnancy I was naturally worried. Throughout the pregnancy I felt like I was on my own. I tried to talk about my anxiety and feelings to my midwife but got the feeling that she just didn't know what to say. I wish there was a specialist midwife that I and others in my situation could talk to with the feeling of being listen to and being supported."***

**BABY H**

Baby H was stillborn at 42+ weeks on 14th January 2001. Her mother went into hospital three days before Baby H was born, complaining of acute abdominal pain. She was monitored overnight but not seen by a doctor despite staff saying she would be before she was sent home.

She went home only to return to hospital the following day with strong contractions. But labour was slow to progress and when the baby's heart rate dropped, her waters were broken to speed up delivery.

Staff found meconium in her waters and she was sent for an emergency C-section. When she woke from the general anaesthetic, she was told her baby had died.

***"The only way I can describe it is to say it was like an out of body experience. I could hear this howling and I didn't realise it was me."***

Baby H was 10lbs 1oz and while a post mortem was inconclusive and the hospital did not send her placenta for post mortem, doctors delivering her say the placenta was very degraded.

The story of Baby H reflects what Sands hears time and time again. A low-risk mother in a supposedly low-risk pregnancy, whose pregnancy goes well beyond term, only for her baby to die.

Baby H's mother has gone on to have two healthy boys, both delivered at 38 weeks by elective C-section.

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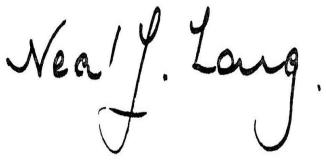
**IN CONCLUSION:**

We believe there is real potential to tackle unacceptably high stillbirth rates in Wales. Other countries have shown that this can be done. A clear commitment from the Welsh Government to prioritise this issue and to lead a national prevention strategy, could lead to many babies' lives being saved.

We would welcome working with the Welsh Government and contributing to achieving this.



**25th May 2012**

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# NCT submission to the National Assembly for Wales' Health and Social Care Committee Inquiry into stillbirths in Wales

Prepared by Elizabeth Duff, Senior Policy Adviser, NCT, May 31, 2012  Alexandra House, Oldham Terrace, London W3 6NH Reg. Charity No. 801395

# NCT

### Who we are

NCT is the UK's largest charity for parents. Since 1956 we have been a trusted voice and provided essential support for millions of parents.

### What we do

We offer services across the UK, from antenatal and parent preparation courses through to day-to-day peer support based in our local branches. We guide people through the transition to parenthood, from pregnancy up to their children's second birthday. We believe our role is to help parents through what will be one of the most challenging changes in their lives.

Our online support, events and helpline reaches millions of people each year.

### How we do it

We help parents both through our own activities and by working externally with health professionals and maternity and family service providers as well as policymakers, opinion formers and employers.

We have 10,000 volunteers on hand to help with local branch support and 1,000 NCT Practitioners to deliver courses. Alongside our traditional classes we also provide antenatal and breastfeeding support through the NHS and Children's Centres in England as well as providing parent focussed training for health professionals.

#### NCT Shared Experiences Helpline

Our Shared Experiences Helpline supports parents who are experiencing specific difficulties, problems, worries or other issues during pregnancy, birth and early parenthood by putting them in touch with someone who personally understands.

It is staffed by volunteers who have gone through the same experience and are able to offer understanding and a listening ear. Callers are also given details of other relevant charities or support organisations who may be able to help them.

In the case of a woman or her partner who had experienced the stillbirth of their baby, we would suggest contact with SANDS, the stillbirth and neonatal death charity.

# The National Assembly for Wales' Health and Social Care Committee Inquiry into stillbirths in Wales

We understand that the purpose of this session is to examine the awareness, implementation and effectiveness of current guidance and recommendations across the different sectors with regard to stillbirth prevention, especially in relation to poor fetal growth and reduced fetal movements, and where potential improvements can be made.

We appreciate that, as outlined in the terms of reference for this Inquiry, that stillbirths are more frequent among women:

- with twin or multiple pregnancies
- who are over the age of 35 or under 20
- have specific medical conditions, especially diabetes, hypertension and thrombophilia, or a past obstetric history of complications
- who smoke
- who are obese
- who live in areas of social deprivation
- who are members of certain ethnic minority groups.

There also appears to be some evidence that women pregnant following a previous birth by caesarean section are more likely to experience stillbirth.[1]

We note the point made in the All Wales Perinatal Survey[2] that 'for 41.7% of stillbirths the cause is unexplained. This represents a large proportion and warrants research into the risk factors and causes of stillbirth'. NCT agrees that such efforts are needed, alongside an assurance of high quality midwifery care, timely referral systems and a network of support and information for parents that both offers helpful messages in advance of the birth of a baby and social support for the family.

## NCT services to parents: information

NCT aims to provide information and support to all parents and the charity's 2010-2020 strategy specifically emphasises increasing our reach to groups who are less well represented among those we are currently in touch with. Our contacts among younger parents, those with lower educational attainment and parents in ethnic minority groups are expanding. In some parts of the UK, NCT also has services specifically for women in prison, those seeking asylum and others in particularly disadvantaged circumstances.

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Our web-based ‘info centre’ offers impartial and evidence-based information on a wide range of topics relevant to pregnancy and childbirth, including all those listed above that may affect the wellbeing of mother or baby. The over-arching principle of our information is that pregnancy and childbirth are in general normal, physiological events for women who are in good health, and that medical or surgical interventions are not needed unless illness or serious complications arise. However, there is encouragement for women and their partners to follow healthy lifestyle choices, to learn about the possibility of complications and to obtain advice from a midwife or doctor promptly if there are anxieties or concerns. This includes awareness of fetal movements towards the end of pregnancy.

NCT offers a well-known and widespread service of antenatal preparation courses for expectant parents, many of which are now provided at minimal or zero cost to those attending. NCT antenatal teachers are educated to at least diploma standard with university-accredited qualifications. They are required during the training to follow a module on the subject of ‘loss’, which covers the experiences of late miscarriage, stillbirth and neonatal death. As the ethos of the courses is parent-centred learning, there may be variation as to how much emphasis is put on stillbirth, but those attending will always be asked if they would like to hear more about the risks and frequency of this event.

## NCT services to parents: support

NCT was founded on the belief that parents and parents-to-be welcome social contact with people in the same situation as themselves and that making friends with other parents in the neighbourhood is an ideal approach to avoiding isolation, finding appropriate services and forming a network for leisure and learning activities that can last until well into the child’s growing years or longer.

While the majority of such support inevitably takes place in the context of a family with a live and healthy baby, there have been numerous instances when parents bereaved by the stillbirth of their baby have derived comfort in the short or longer term from the other parents they have met during the present or previous pregnancies.

Parents who have experienced a past stillbirth and are expecting a baby again may be in particular need of a friendly group who can offer empathic support and encouragement.

## NCT maternity policies

The charity has since its inception had a role in lobbying and influencing both government and other health bodies around policies in maternity and family services. Its successes in ensuring that services are more parent-centred (for both mothers and fathers) and avoid routine, non-evidence-based interventions are well documented (http://www.nct.org.uk/about-nct/our-history).

Last year, NCT responded to the consultation held by the Welsh Assembly Government on their Strategic Vision for Maternity Services in Wales. We wrote: "We wholeheartedly support the philosophy, aspirations and values enshrined in the strategic vision, and believe the development of a new strategy provides a welcome opportunity to dismantle barriers to effective delivery. We particularly endorse the emphasis on pregnancy and birth as events 'of social and emotional significance' and the explicit statement that a safe, healthy and satisfying experience of birth is important for new parents to feel 'confident, capable and well supported in giving their child a secure start in life'".

We recommended, in addition, that the Government 'working through a Maternity and Early Years Board, seeks to enable strong co-ordinated leadership for local services, centred around the mother and her family rather than professional divisions, as well as multidisciplinary training and working'.

It was noted that the Strategic Vision had a strong emphasis on public health with maternity episodes seen as an opportunity for good health and lifestyle messages to be conveyed, and the arrival of a baby welcomed as an opportunity for the family to be motivated to improve healthy habits and reduce activities such as smoking and poor dietary intake which can affect the chances of stillbirth or other adverse outcomes of pregnancy. NCT supported this principle but was aware that a major burden can rest on midwives who may be expected to implement the programme at a time of staff shortage, unit closures, rising birth rate and greater social and medical complexities of pregnancy.[3]

Later in the response, we noted that in Wales 'caesarean section rates increased from 12% in 1990 to 24% in 2008 with no improvement in outcomes': we feel this is a significant fact to bear in mind for the current Inquiry, as it serves to confirm our view that the answer to reducing the number of births with an adverse outcome is *not* increased medicalisation of care nor more births taking place in hospital, but an improvement in the quality of care throughout pregnancy, labour and the postnatal period.

## NCT and midwifery services

NCT was represented by the charity's CEO on the UK Programme Board of *Midwifery 2020*.[4] This unique collaborative project across the four countries of the UK was a key piece of work in bringing up to date the elements of the midwife's role in a changing context of birth. Here too was a strong focus on the midwifery role in public health and in particular addressing inequalities. As set out above, women who are in circumstances of social deprivation are more likely to experience stillbirth, and these groups often overlap with very young pregnant women and also women from some ethnic minority backgrounds.

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A further key message from *Midwifery 2020* was that 'midwives should have a visible place in a community setting' and this flags up the immense importance of midwives making their services available in the community including attendance at births in freestanding midwifery units (FMUs) and in the family home. The recent major study *Birthplace in England*[5], while not specifically covering units in Wales, confirmed that – in comparison to an obstetric unit setting - for all low-risk women planning a birth in an FMU is safe and for all women expecting a second or subsequent baby planning a birth at home is safe. When considering if changes are needed to the maternity services to help reduce the rate of stillbirths, it should be remembered that the very large and well-conducted *Birthplace* study did not show any advantage for obstetric unit births in terms of poor outcomes, so long as the women was in a low risk category and not expecting her first baby.

In further support of women receiving midwife-led care, the Cochrane Collaboration has published a review[6] showing multiple benefits of this style of care, including women receiving midwife-led care being 'less likely to experience fetal loss before 24 weeks' gestation', although there were no statistically significant differences in fetal loss/neonatal death of at least 24 weeks.

The elements of midwife-led care that appear to offer the numerous benefits evidenced in both safety and quality of the woman's experience are:

- continuity of care during pregnancy that helps to build a trusting relationship between the midwife and the woman and her partner – this can enable the successful conveying of healthy lifestyle messages that are useful both in pregnancy and beyond
- continuance of this relationship during late pregnancy when the midwife may be able to observe fetal growth restriction, if occurring, and it is essential that each woman feels she can contact her midwife at any time if she is concerned about reduced fetal movements[7]
- Continuous one-to-one midwifery care during established labour which has been shown not only to improve outcomes generally in reducing unnecessary intervention, but also to enable detection of deviations from the norm that could lead to antepartum stillbirth.

NCT strongly supports the present calls for an adequately-staffed midwifery service that ensures women receive quality care, as above, through a trusting relationship with their midwife, and if necessary timely referral to a multi-disciplinary team.

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**Submission to National Assembly for Wales' Health and Social Care Committee is undertaking a one-day inquiry into stillbirths in Wales**

**Gordon CS Smith, MD PhD DSc FMedSci**

*Professor of Obstetrics & Gynecology*
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Member of the Board of the International Stillbirth Alliance, a non-profit coalition of organizations dedicated to understanding the causes and prevention of stillbirth 2009 – present.

Member of the Scientific Advisory Committee of the International Stillbirth Alliance, 2009 – present.

Chair of the SANDS/RCOG Clinical Study Group for Stillbirth.
2011 to present.

1. SANDS are providing written evidence around the burden (social, societal, economic, health) of stillbirth. My major focus of professional activity around stillbirth is in the area of research. Hence the focus of my submission will relate to research.

2. A key approach to reducing the number of stillbirths is to reduce the rates in women who lack strong risk factors. The majority of stillbirth babies do not have a lethal congenital or genetic anomaly. The majority of mothers experiencing stillbirth do not have a major pre-existing medical condition (e.g. diabetes, connective tissue disease etc). Therefore, in order to reduce the overall burden of stillbirth, it will be necessary to focus efforts on women who might ordinarily be regarded as "low risk".

3. In the absence of a major pre-existing medical condition, most maternal characteristics associated with stillbirth are not sufficiently important or discriminating to allow clinically

useful intervention. For example, it is known that advanced maternal age is associated with an increased risk of stillbirth. One of the papers from the recent Lancet series pooled existing studies and concluded that women >35 years of age had a 65% increased risk of stillbirth. This may be taken as an argument for focusing on these women. However, the background rate of stillbirth is approximately 0.5%. Hence, women aged >35 have a <1% chance of having a stillbirth or, put another way, have a >99% chance of not having a stillbirth. Between 6% and 8% of all stillbirths were attributed to the increased risk among women aged >35. Hence, even if a programme of intervention reduced the rate of losses among this group by 50%, the overall rate of stillbirth would be minimally reduced.

4. The current methods of screening women are virtually unchanged in recent years. The National Institute of Clinical Excellence Antenatal Care guideline suggested serial measurement of a woman's bump with a tape measure (technically called the symphysis-fundal height) as the sole method of assessing fetal well being among low risk women. A number of other methods, such as serial ultrasound scanning, were evaluated. They were not recommended as there is no evidence that the routine use of ultrasound reduced the number of losses. The evidence is from pooled analyses of randomised trials including tens of thousands of women.

5. The current methods of screening the low risk population for stillbirth are extremely crude compared with the methods used screening for Down's syndrome. In contrast to the point above, the protocol for screening for Down's is as follows:
*Screening for Down's syndrome should be performed by the end of the first trimester (13 weeks 6 days), but provision should be made to allow later screening (which could be as late as 20 weeks 0 days) for women booking later in pregnancy. The 'combined test' (nuchal translucency, beta-human chorionic gonadotrophin, pregnancy-associated plasma protein-A) should be offered to screen for Down's syndrome between 11 weeks 0 days and 13 weeks 6 days. For women who book later in pregnancy the most clinically and cost-effective serum screening test (triple or quadruple test) should be offered between 15 weeks 0 days and 20 weeks 0 days. When it is not possible to measure nuchal translucency, owing to fetal position or raised body mass index, women should be offered serum screening (triple or quadruple test) between 15 weeks 0 days and 20 weeks 0 days.*

i.e. there is a panel of 6 possible biomarkers (blood tests) to assess Down's syndrome risk, but no recommended biomarker screening for stillbirth risk.

6. The relative lack of emphasis on screening for stillbirth occurs despite the fact that it is one of the most common of the serious complications of pregnancy. Death of babies due to prematurity affects about 1 in 1000, Down's syndrome affects about 1 in 700-800, whereas stillbirth affects about 1 in 200. This is equivalent to all infant deaths (i.e. deaths of liveborn infants in the first year of life) put together, a category which includes areas of intense research and public health interest (e.g. sudden infant death syndrome, congenital anomaly, prematurity, infection, trauma and abuse).

7. There is a relative lack of focus of research funding to address the problem of stillbirth. Although SANDS are starting to raise and distribute funds for research, there is no major charitable funding devoted to stillbirth which is comparable in scope to Cancer Research UK or the British Heart Foundation. The UK government's Medical Research Council (MRC) has funded specific projects relevant to stillbirth research. However, there is no MRC Unit or Centre in the country which is devoted to stillbirth or has stillbirth as a major focus of research.

8. It is plausible that good biomarkers could impact on the burden of the disease. Although routine ultrasound scanning does not reduce perinatal mortality among low risk women, it does reduce losses in high risk pregnancies. Hence, identification of high risk pregnancies using, for example, blood tests, could lead to interventions to improve outcome. Moreover, of the >4000 stillbirths in the UK in the last national report, almost one third (~1200) occurred at or after 37 weeks of pregnancy. Induction of labour carries a low risk of short or long term problems when performed at 37 weeks. If babies at high risk of stillbirth at term could be identified, induction of labour would be a plausibly effective intervention.

9. Conclusion: Stillbirth is a relatively ignored problem which accounts for the potentially preventable loss of large numbers of babies. There are aspects of stillbirth which indicate that the relatively high levels could be reduced by novel methods of screening coupled with safe and effective intervention.

# Health and Social Care Committee

## HSC(4)-19-12 paper 5

## Inquiry into Stillbirths in Wales – Written Evidence from Dr Alexander Heazell

*Dr Alexander Heazell MBChB(Hons) PhD MRCOG, Clinical Lecturer in Obstetrics, University of Manchester, UK.*

This submission is intended to provide written evidence to the inquiry regarding the awareness, implementation and effectiveness of current guidance and recommendations with regard to stillbirth prevention, especially in relation to reduced fetal movements.

In Wales, approximately 1 in 200 babies born after 24 weeks of pregnancy are stillborn; accounting for 180 births in the country per year. In common with the UK, this rate has not significantly decreased for 20 years. When the Welsh stillbirth rate is compared, with similar-sized European countries, it is higher than Estonia, Finland, Slovakia, Denmark and Norway.

One of my research interests is the potential use of reduced fetal movements to identify babies at increased risk of stillbirth. The use of maternal perception of fetal activity to identify babies at risk of stillbirth is not a new concept; it has been of interest since the 1970s when various studies, including those from Cardiff, found a link between a reduction in fetal movements and subsequent stillbirth.[1]

There have been three significant barriers to progress in managing reduced fetal movements. Firstly, due to the large variation in fetal movements between different women and different pregnancies it has not been possible to come to a useful definition of reduced fetal movements. No definition of reduced fetal movements has ever performed better than a mother's own concern of reduced fetal movement. Our 2008 survey of obstetricians' and midwives' knowledge and views regarding reduced fetal movement found that there was significant variation in what clinicians defined as reduced fetal movements, with up to 19% of respondents unsure of what constituted reduced fetal movements.[2]

Importantly, many studies have now found that a reduction in fetal movements, irrespective of the definition, is related to an increased risk of subsequent stillbirth and fetal growth restriction.[3] Our recent studies suggest that maternal perception of reduced fetal movements is associated with a 2-3 times increased risk of stillbirth and fetal growth restriction.[4 5]

Secondly, the relationship between a mothers' perception of reduced fetal movements and underlying cause has not been fully understood. It is thought that for some infants, a reduction in movements constitutes a response to a problem with nutrient or oxygen delivery from the placenta (afterbirth).[6] This is consistent with the link between stillbirth and fetal growth restriction. One study showed a close link between the amount of fetal movements the day before birth and the levels of oxygen in umbilical cord blood.[7] We have recently shown abnormalities in placental size, shape, microscopic appearance and function in women who attend with reduced fetal movements.[8] This evidence suggests that for some women reduced fetal movements is an important indication of fetal compromise.

Lastly, there is uncertainty about which investigations should be carried out after a mother attends a maternity unit with reduced fetal movements. We found that practice varied widely throughout the UK, with almost all respondents performing a fetal heart rate trace, but only

20% carrying out an ultrasound scan for fetal growth, liquor volume (the amount of water around the baby which indicates placental function).[2] A quality improvement programme in Norway, found that encouraging women to attend for reduced fetal movements, and performing a fetal heart rate trace followed by an ultrasound scan to assess fetal growth, liquor volume and blood flow through the placenta was associated with a significant reduction in stillbirths.[9] [10] We have recently confirmed in 303 women with reduced movements that the most useful investigations to predict poor pregnancy outcome are a fetal heart rate trace, ultrasound measurement of growth and liquor volume and potentially a new marker of placental function.[5]

Recognising and acting appropriately on reduced fetal movements has been highlighted as a potential way of reducing stillbirths. A confidential enquiry into antepartum stillbirths found that 45% had suboptimal care; the two most frequent problems identified were in the recognition and management of fetal growth restriction and reduced fetal movements.[11]

The challenges in the definition and management of reduced fetal movements were recognised by the British Maternal and Fetal Medicine Society who recommended to the Royal College of Obstetricians and Gynaecologists that a national guideline be produced. This was produced, peer-reviewed and published in 2011.[12] We are currently conducting a national survey to determine whether this national guideline has influenced local practice.

In summary, there are national guidelines that can inform UK practice in the management of RFM. Recent evidence from other European countries suggests that if all women with reduced fetal movements had fetal wellbeing confirmed by a fetal heart rate trace and ultrasound assessment of fetal growth and liquor volume, this may identify babies at greatest risk of stillbirth who can then be safely delivered.

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# Health and Social Care Committee

## HSC(4)-19-12 paper 6

## Inquiry into Stillbirths in Wales – Royal College of Obstetricians and Gynaecologists

There are approximately four stillbirths in Wales every week. Unlike many other high-income countries, Wales has not seen a fall in the number of stillbirths per year over the past 20 years. This is similar situation to the rest of the UK, who lie 33rd out of 35 high income countries in terms of a high stillbirth rate.

The causes of stillbirths are complex - there are probably no quick solutions and action to reduce the stillbirth rate in Wales will be required across a number of areas, including understanding the underlying causes, identification of high-risk pregnancies and ensuring lessons are learned. Generally, the discriminating factors for stillbirth risk are poorly understood. Many women are unaware that between 24 and 43 weeks of gestation the risk of stillbirth is approximately 1 in 200. Stillbirth is more common than SIDS (cot death) and Down syndrome, yet education is poor - for example in women understanding the importance of poor fetal growth, responding to decreased fetal movements, recognising risks such as obesity or age. This is not surprising given that there is a lack of information on stillbirth from official sources and many health professionals are reluctant to give information for fear of scaremongering. There is a challenge to create a clinical environment where discussion about stillbirth can be normalised, as it is for cot death and Down syndrome.

Although a number of risk factors are known, 98% of pregnancies in the top 5% at risk do not end in stillbirth yet 95% of stillbirths occur in pregnancies not predicted to be at risk at all. A greater understanding is needed of the discriminating risk factors for stillbirth and better tools are needed to stratify risk - for example, a tape measure is still used to measure fundal height (SFH) as a surrogate of fetal growth, with a detection rate of less than a third for poorly grown babies. Indeed this practice has been dropped in Norway where there is a much lower stillbirth rate, as SFH measurement is not clinically effective.

The 1000 Lives Plus Transforming Maternity Services formally adopted a stillbirth work stream from April 2012 and there is a national Stillbirth Working Group now within this framework. This is supported by the Welsh Executive Committee of the RCOG. It is proposed that action to reduce stillbirths in Wales can be classified under the following four headings

1. Identification of risk factors.

Risk assessment for stillbirth is not very advanced. It may be helpful to look at what test and interventions currently provided for pregnancies assessed as high risk could be provided to all women - for example, a third trimester scan. However, any additional tests or interventions would need to be supported by evidence of their effectiveness. Growth restriction has a known association with stillbirth, but its identification in pregnancy is currently very poor. There is also a lack of knowledge of pathology – for example, a small baby within normal limits may still not be reaching its growth potential. In Wales, we suggest it may be reasonable to start by focusing on unexpected stillbirths a term. Most term stillbirths are of otherwise healthy babies and should be preventable, given induction at term is relatively safe and has been shown not to increase caesarean section rates whilst reducing perinatal mortality.

Intrapartum deaths should also be preventable and all intrapartum stillbirths should be regarded as sentinel events.

2. Increased awareness

The need for greater awareness of the risk of stillbirth by pregnant women and health professionals is not disputed. Risks such as inequalities in care and social background, awareness of what is normal fetal movement, risks associated with obesity, maternal age and smoking should be discussed.

There is a need to ensure health professionals are made fully aware of the risk of stillbirth as part of their education. Although providing bereavement support is recognised, we are not so good at talking to parents about stillbirth as part of antenatal education and this is the key to increasing awareness.

Many high risk women do not attend antenatal education classes, so more needs to be done to increase wider society's awareness of stillbirth, for example by including stillbirth in the curriculum taught by schools, featuring information about stillbirth on television and other media.

3. Clinical Networks and Commissioning

We would recommend that Health Boards consider stillbirth as part of their quality indicators for commissioning for maternity services. It may be appropriate for antenatal care to include an assessment of risk throughout a pregnancy in much the same way as for venous thromboembolism and and improved perinatal pathology services in those pregnancies that end in stillbirth.

Obstetricians in Wales are keen to see the development of a maternity network. Other examples of such a clinical network, in maternity care and beyond, have been effective at improving coordination and standardisation of care through the sharing of best practice. We believe that a maternity network, similar to the Neonatal network in Wales, would add value to co-ordination, standardise practices and implement clinical and management changes, all of which may be important factors in any attempt to reduce the number of stillbirths in Wales.

4. Improving perinatal review

We believe that perinatal mortality reviews in Wales are currently variable, leading to failures to learn lessons from potentially avoidable deaths. There are examples of Standardised Clinical Outcome Reviews to improve the understanding of causes and factors leading to stillbirths, and other adverse incidents. Such standardised review would improve action plans and strategies for stillbirth prevention. We recommend that a Welsh Stillbirth Register, improvements in Post Mortem Uptake and Consent Post Mortem Reporting be part of future plans to review all perinatal deaths, including stillbirths.

# Stillbirths: causes and prevention

Consultation response to Health and Social Care Committee,
National Assembly of Wales

Professor Jason Gardosi MD FRCSED FRCOG - Director, West Midlands Perinatal Institute

## Introduction

The purpose of this submission is to summarise our experience in addressing stillbirths in the West Midlands, and allow consideration whether it might be relevant when looking at the high stillbirth rate identified in Wales.

## Background

The Perinatal Institute is a West Midlands based NHS organisation which seeks to enhance the quality and safety of maternal and perinatal care, and to reduce adverse outcome by investigating causes and developing strategies for prevention.

Rather than relying on potential solutions from future research, we recognise that relevant evidence and recommendations already exists, but often need concerted and sustained effort for proper implementation. This approach has led to improvements in key performance indicators in maternity services, and significant reductions in avoidable perinatal deaths, as well as recent national recognition in the 2012 BMJ Health Innovation Awards for Patients Safety.

## Evidence

1. There has been little if any change in stillbirth rates in the UK over the last 2 decades, despite public health initiatives, reports from CESDI, CEMACH and CMACE, NICE guidelines, and various research initiatives into establishing underlying causes.

2. Conventional classification systems have resulted in up to two thirds of stillbirths being categorised as unexplained, which may be seen as suggesting that they are also unavoidable [1]. We developed a novel classification (ReCoDe) which looked at all relevant clinical conditions, and applied it to a database of 2625 stillbirths in our region. We found that the proportion of 'unexplained' cases was reduced to 15%, with the largest category (43%) being intrauterine growth restriction (IUGR), diagnosed according to the baby's customised weight percentile at the time of death [2].

3. A programme of confidential enquiries in the West Midlands also found that many normally formed stillbirths considered 'unexplained' had IUGR, mostly unrecognised antenatally. The peer review panels found that 86% of antepartum stillbirths with IUGR would have been potentially avoidable (CESDI Grades 2 & 3) with better care [3].

4. The results of the individual case reviews were fed back to the respective units/ Trusts and compared with the results of their own in-house assessments. In many cases, units had failed to identify problems and derive useful learning points from their own assessments. This stimulated the recent, SHA supported development of Standardised Clinical Outcome Reviews (SCOR), which we are currently piloting in the West Midlands as well as in units in the North West, Scotland and Canada [4].

5. Case note audits of live births confirmed that most instances of IUGR are not detected antenatally. This applied to both low risk and high risk pregnancies. Furthermore, mothers at increased risk often fail to receive sufficient scans for serial monitoring of fetal growth [5]

6. Recent, unpublished multivariable analysis of our linked databases of live births and stillbirths confirms maternal obesity and smoking (active and passive) as modifiable risk factors for stillbirth. However IUGR is the strongest potentially avoidable factor, with the highest etiological fraction. Pregnancies with IUGR have a 7 fold increased risk of stillbirth, and the risk is significantly reduced when IUGR is detected antenatally.

## Actions

1. With the collaboration of all stakeholders including provider units, PCTs and the SHA, we established *'antenatal detection of intrauterine growth restriction'* as a key performance indicator. This as well as other indicators such as early booking and smoking cessation are monitored as part of a core dataset, and recorded on the regional perinatal episode electronic record (PEER) [6].

2. We set up a fetal growth training & accreditation programme for midwives, doctors and ultrasonographers, with workshops including standardised fundal height measurement, the use of customised growth charts, and protocols and referral pathways for ultrasound and Doppler. Customised charts, recommended by RCOG guidelines [7], adjust the fetal growth curve in each pregnancy according to the mother's characteristics, resulting in reduced false positives and unnecessary investigations as well as improved detection of pathological growth [8].

3. In Birmingham, an area with high rates of stillbirth and fetal growth restriction, we also implemented the community growth scanning (CoGS) programme, delivered by midwives trained in growth scanning, to help increase availability and access to third trimester ultrasound [9].

## Progress

1. There is an increased awareness of the overall significance of IUGR as a risk factor, which we attribute to the rolling programme of KPI audit, case review and training.

2. Despite continuing ultrasound shortages, antenatal IUGR detection rates have increased from <30% in 2009 up to 37% in 2011. However there is wide variation between units, and a direct relationship between performance and uptake of growth training and protocols, with rates of 50% being reached in the more advanced units [6]. Detection rates are higher in high risk pregnancy, and once referred for scan on the basis of fundal height surveillance, it reaches 60-80%.

3. The latest perinatal mortality rates for Birmingham & Solihull indicate a significant downward trend in normally formed stillbirths with IUGR. This reduction was most marked for stillbirths from 30+ weeks gestation, while there was no corresponding increase in the rate of early neonatal deaths [10].

## Wales

The potential relevance, if any, of the West Midlands experience for the high stillbirth rates identified in Wales could be quickly established.

1. The latest reports from Wales suggest that over 40 % have 'no antecedent or obstetric factors'. It is our contention that many of these cases will be growth restricted, as we have observed in the West Midlands, and are hence potentially avoidable. We are currently assessing the Northern Ireland perinatal mortality database and are obtaining similar results.

2. A confidential enquiry into a selected stillbirth cohort (e.g. normally formed stillbirths from 34 weeks gestation), applying the SCOR process with Welsh multi-professional peer review panels, would be able to quickly establish whether similar factors apply in Wales as in the West Midlands, and would also help highlight other relevant factors of relevnce.

We would be pleased to assist the Welsh national programme if our West Midlands experience is deemed potentially useful, and would also be happy to help implement any of the fore-mentioned tested tools and processes, as desired.

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The Royal College of Midwives

Response

# Written Submission to

# National Assembly for Wales Health & Social Care Committee

# One day inquiry into stillbirths in Wales

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**The Royal College of Midwive's written submission to the National Assembly for Wales Health & Social Care Committee one-day inquiry into stillbirths in Wales.**

The Royal College of Midwives (RCM) is the trade union and professional organisation that represents the vast majority of practising midwives in the UK. It is the only such organisation run by midwives and for midwives. The RCM is the voice of midwifery, providing excellence in representation, professional leadership, education and influence for and on behalf of midwives. We actively support and campaign for improvements to maternity services and we also provide professional leadership for one of the most established of all clinical disciplines.

The RCM welcomes the opportunity to provide oral evidence to the Health and Social Care Committee for the one day inquiry into stillbirths in Wales. Our comments are set out below;

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**Context**

Since 1996 stillbirth rates in Wales have fluctuated between 4.6 and 5.7 per 1000 births. As expected amongst a smaller population the rate has fluctuated more than that in England, but the rate for Wales as a whole has generally been lower. Though neonatal and infant death rates in the UK have fallen over the last decade, rates of stillbirths have not improved significantly. In 2010, the rate in Wales was 5.3, compared to 4.9 in Scotland and 5.1 in England.

There is no question that stillbirth rates in the UK need to improve. Of 35 high-income countries, the UK has the 33rd highest stillbirth rate. Unfortunately, we may have to accept that there will always be some stillbirths and that the cause for some of these will remain unknown. And there will be occaisions when, despite extensive intervention and monitoring women will still have a stillbirth. Sweden has the lowest stillbirth rate in Europe, which is still as high as 3.5 stillbirths per 1000 births. The objective should be to identify specific

opportunities to reduce stillbirths by tackling known-causes and improving the care available to women.

**Appropriateness of current guidelines**

The Royal College of Midwives supports the existing guidance as outlined in the Inquiry's terms of reference. In particular, we support the National Institute for Clinical Excellence's clinical guidance on antenatal care which states that fetal growth should be measured by fundal height and that routine formal fetal-movement monitoring should not be offered. There is also evidence from the West Midlands Perinatal Institute that the use of symphysis fundal measurements and customised growth charts were valuable in increasing the recognition of Intra Uterine Growth Retardation. It is of concern however, that there are inconsistencies in how professionals actually measure despite training. We recognise that there are opportunities to improve existing practices to ensure that guidelines are followed more consistently, and to enable midwives to more easily detect risk factors associated with stillbirths.

Though the causes of stillbirths are not fully understood, factors such as smoking, obesity, social deprivation are linked to higher stillbirth rates. The prevalence of these factors amongst child-bearing women is therefore something to be addressed. The role of the midwife in delivering the Public Health agenda is recognised in the Strategic Vision for Maternity Services in Wales (2012). We support this strategy and would like to emphasise how key the midwife is in raising public health issues. In order to address these factors, midwives need to develop relationships with the women that they care for and have enough time and understanding to deliver effective lifestyle support to women.

A key factor in addressing the recognition of reduced fetal movements, IUGR and their relationship to stillbirths is to concentrate on the role of the named midwife for every woman in the community setting providing continuity and consistency. This is in-line with Midwifery 2020 where this named midwife should be the coordinator of the woman's care and her lead professional if all is straight-forward. We also should consider the need for a "buddy" system, where pairs of midwives cover each other and take responsibility and accountability for a designated caseload, where they know their women well, follow them up and where women know their midwife. During pregnancy women feel comfortable about raising issues and midwives can detect any changes that are unusual or unexpected for a particular woman.

Midwives can also discuss with and educate women so that they can identify when their baby's movements change or stop. It is particularly important that women know of the relationship between fetal movements and fetal wellbeing. Where problems are detected, there needs to be rapid and appropriate referral processes in place so that the appropriate action can be taken.

## Implementation of guidelines

The RCM is aware that many of the relevant guidelines have not been implemented consistently throughout Wales. To improve this, health boards, universities and other organisations need to ensure that these guidelines are adequately embedded in up-to-date training offered to practicing midwives and others involved in caring for pregnant women.

## Student Midwife Training

It is important that we do not underestimate the importance of midwifery education in relation to stillbirths. And the RCM would like to highlight the following examples of how students are supported to learn.

The MINT project (2011) demonstrates how midwifery teachers may make a difference through supporting student midwives in the workplace - reducing the theory practice gap, facilitating evidence based practice, supporting mentors, mentorship training and encouraging student midwives to join evaluation of care meetings when there has been a near miss or poor outcome.

In all Welsh Universities the public health role of the midwife is core to the curricula. All midwifery pre-registration students are taught about the role of the midwife in monitoring fetal growth and wellbeing and Universities ensure that they utilise the following (along with updates as they are published):

- All relevant NICE guidelines: Antenatal Care CG62, Multiple pregnancy CG129, Diabetes in pregnancy CG63, Hypertension in pregnancy CG107, Induction of labour CG70.
- The National Service Framework for Children, Young People and Maternity Services.
- Midwifery 2020
- A Strategic Vision for Maternity Services in Wales (2012)
- NOFAS information for midwives http://www.nofas-uk.org/
- RCOG Guidelines: Greentop Guideline 57 and Greentop Guideline 31

Research-based socio-cultural and bio-scientific knowledge is used to raise students' awareness of the underpinning knowledge about fetal growth and wellbeing that supports safe and effective practice.

In practice settings students work with Sign Off mentors towards the NMC competencies as outlined in Standard 17 of the *Standards for Pre-registration Midwifery Education* (2009). Several of these competencies include developing skills in monitoring fetal growth wellbeing as well as in appropriate referral practices.

Assessment of these competencies is summative (core and compulsory for progress in the programme) and in some cases graded (contributing to the degree award).

### Improving understanding of what causes stillbirths

The lack of understanding of the causes of stillbirths remains a problem. One option to improve understanding is to increase the rates of post mortems carried out following a stillbirth. Recent research by the RCOG has shown that emotional distress is the main reason for parents withholding their consent to a post-mortem. This suggests that a greater investment in supporting parents following a stillbirth could help to improve research in the area. In particular, midwives need to be trained to offer bereavement support to women and their families following a stillbirth. The number of midwives who are currently trained and in place to support bereaved parents is variable across Wales and this is an area where improvements could be made.

### The National Stillbirths Working Group

The National Stillbirths Working Group, a subset of the 1000 Lives Plus Transforming Maternity Services Mini-Collaborative, is currently reviewing the relevant evidence and practice surrounding stillbirths in Wales. The working group brings together a wide range of stakeholders, including the RCM, and we are confident that its efforts will help to improve stillbirth rates in Wales.

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# Health and Social Care Committee

## HSC(4)-19-12 paper 9

## Inquiry into Stillbirths in Wales – Written Evidence from BMA Wales

**British Medical Association Cymru / Wales** **June 2012**

**Response to Health and Social Care Committees inquiry into stillbirths in Wales.**

INTRODUCTION

BMA Cymru Wales is pleased to provide a response to the Health and Social care Committees one-day inquiry into stillbirths in Wales.

The British Medical Association represents doctors from all branches of medicine all over the UK. It has a total membership of nearly 150,000 including more than 3,000 members overseas and over 19,000 medical student members.

The BMA is an independent trade union and the largest voluntary professional association of doctors in the UK.

BMA Cymru Wales represents some 7,500 members in Wales from every branch of the medical profession.

BMA EVIDENCE ON STILLBIRTHS IN WALES: JUNE 2012

**Aims and Introduction**

This paper gives an overview of the current situation and problems and the plans to address the finding that the stillbirth rate in Wales has not fallen for the last 10 years, whilst the rate in many other countries is much lower.

It considers, specifically, stillbirths in relation to reduced fetal movements and fetal growth restriction.

It is not intended that this is a comprehensive review of stillbirth prevention and management, but it necessarily mentions the current situation in regards to research into intrapartum fetal monitoring in Wales and the new stillbirth work-stream of the 1000 Lives Plus Transforming Maternity Services mini-collaborative as this may be useful to the Committee's deliberations.

The following areas are addressed in this paper, aiming to provide clarity in some areas of potential confusion:

- Stillbirth rates
- Local and national enquiries
- Classifications of stillbirths
- 'High risk' pregnancy
- Mechanism of fetal compromise and demise

- Fetal movements
- Fetal growth
- Electronic fetal monitoring
- The challenge in 'low risk' women
- Finding evidence
- Data in Wales
- The 1000 Lives Plus Transforming Maternity Services mini-collaborative

**Stillbirth rates**

Technically, stillbirth is defined as fetal death prior to delivery of a potentially viable baby. Prior to viability, fetal death is termed as a miscarriage.

In the UK, this means that the definition for statistical purposes is a baby "issued forth" at or after 24 weeks, showing no signs of life. Many countries regard viability as being 28 completed weeks of pregnancy and thus record fewer stillbirths than in the UK. A baby born prior to 24 weeks is unlikely to survive, and if they do, the rate of serious handicap is high.

Many countries do not routinely collect data on all pregnancies. In addition, routine ultrasound scanning to confirm or estimate gestation is not universally available, nor do many women know how pregnant they are in many countries hence the WHO recommendation for the collection of data on pregnancies at more than 22 weeks. This can explain some of the difference between quoted stillbirth rates and some of the variation.

The stillbirth rate in Wales in 2010 was 5.3 per 1000 births - that equated to 190 babies. Scandinavian countries have far lower stillbirth rates at 2 - 3.5 per 1000 births. If Wales was to reduce its stillbirth rate to these figures, there would be at least an extra 64 babies alive each year. This is not directly transferable to Wales because of different population demographics (for example, there is an association between deprivation and increased stillbirth rates) but nevertheless this produces a figure that Wales can and should aspire to.

Stillbirth rates in the UK have fallen over recent decades, but have been steady for the last 10 years. There is a natural variation in rate because stillbirth is relatively uncommon (1:200 pregnancies) which makes comparisons between individual practice and maternity units difficult as the confidence in a rate in terms of statistically significant differences is often very wide. It is not possible to be exact about numbers of stillbirths for several reasons such as, for example, uncertainty about gestation at delivery for some women. Combined with differences in notification, this explains why there is often a discrepancy in different data sets – such as the All Wales Perinatal Survey and the Office for National Statistics.

As discussed above, in many other industrialised countries stillbirth rates have dropped to be consistently lower than those in the UK. Although this may be due to increased medicalisation of pregnancy and childbirth compared to the UK – there are fewer home births, continuous electronic fetal monitoring in labour is more common and new technologies are more often employed – the situation in the UK remains confusing because of a lack of accurate routine high quality clinical data.

Stillbirth rates vary most notably when consideration is made of the effects of antenatal programmes screening for congenital abnormalities and it is common to see stillbirth rates quoted that exclude such cases. The effectiveness or otherwise of antenatal screening is not part of this paper.

**Local and national inquiries**

Obstetricians have long been held to be the originators of maternal and perinatal audit, firstly with the establishment of the Confidential Inquiries into Maternal Death for England and Wales in 1957, which was extended to all four UK countries in 1985. The confidential inquiries into stillbirths and deaths in infancy (CESDI) published several annual reports and highlighted important deficits in care, discussed

below. This joined with the maternal inquiry mechanism in 2003 to become CEMACH (Confidential inquiry into Maternal and Child Health) which was part of the Royal College of Obstetricians and Gynaecologists (RCOG), but which became an independent body (Centre for Maternal and Child Enquiries - CMACE) in 2009.

There is currently a gap in confidential inquiries, but the contract to run these in the future has been won by the National Perinatal Epidemiology Unit in Oxford. They are in the process of organising a national advisory group to review the classification of stillbirths in the UK.

The importance of such national inquiries is clear because they have established several clear messages:

1. The 6th Annual CESDI report 1996-97 examined a random 1:10 sample of the deaths reported to CESDI excluding babies weighing less than 1000g, major congenital abnormalities and post neonatal deaths. About ¾ of these, nearly 600 deaths, were stillbirths. The expert panel reviews found that 45% of these stillbirths were associated with care that was 'suboptimal' to a degree that the outcome might or would have been more favourable if this was not the case.

2. In the 8th report, the majority of stillbirths are classed as "unexplained" by the conventional classification system. This is considered further below, but the combination of these two observations would suggest that 'unexplained' does not necessarily mean that such deaths were unavoidable.

3. The five most frequent areas of suboptimal care relevant to this paper are:
    i. Assessment and communication of risk by and between primary care, midwives and obstetricians;
    ii. A failure to take into account a previous pregnancy with intrauterine growth restriction or to suspect or detect it, or a failure to manage this appropriately;
    iii. A failure of women to appreciate the significance of reduced movements of their baby, to report this in a timely manner or of the clinical team to respond appropriately;
    iv. A failure of women to engage with advice on smoking cessation or for services to support this to be provided or for health professionals to refer to such programmes;
    v. A failure to suggest, or for consent not to be given for, postmortum or specialist histological analysis of the placenta. Postmortum rates have fallen since the events at Alder Hey. Specialist pathological services are provided in Cardiff.

The All-Wales Perinatal Survey was established in Cardiff in 1993 and has now published its 18th report. It has the advantage of reporting stillbirths and neonatal outcomes in simple and aggregated triennia, together with statistical 95% confidence limits. It is important because it publishes information about babies actual and intended place of birth which enables some interpretation to assess outcomes in women or babies transferred from one place of birth to another. Because it also gives details by place of residence, there is the possibility of tracking care for some of the demographics known to influence perinatal mortality rates – such as deprivation for example.

The 2010 report confirmed that maternal cigarette smoking, obesity and advancing maternal age are major risk factors for stillbirth, and stated that public health initiatives to address these should be a priority. This report also found a large number of unexplained stillbirths by conventional classification (41.7%) and recommended further research in this area. This is partially linked to the declining autopsy rates in Wales.

*Local perinatal reviews*

Although local reviews of stillbirths are held in all hospitals on a regular basis, stillbirths are too rare for trends to be deduced, although the process usually feeds into the All Wales Perinatal Service and the Congenital Anomaly Register Information Service (CARIS), based in Swansea. There have been formal

structured processes developed, which could be implemented to improve the standard and usefulness of local perinatal audit.

**Classifications of stillbirths**

The two most common classification systems for stillbirth in the UK attempt to provide a clinical correlation with pathological findings at postmortum. They are hierarchical in that there is an order of listing, with major (lethal) congenital anomalies at the top. Both systems have been considered the best we have, but fail to find a specific named cause in over 50% of cases – for example, the 8th CESDI report found 70% were "unexplained" by the Wigglesworth and "unclassified" by the Aberdeen classifications (no congenital abnormality, antepartum haemorrhage, intrapartum anoxia etc). This has been a consistent finding in the UK.

Other classification systems have been developed in Scandinavia and Australia / New Zealand, but there is also great interest in the work from the West Midlands Perinatal Institute led by Professor Jason Gardosi, who developed the Re/Co/De classification that searches for and recognises abnormal fetal growth from dysfunction of the utero-placental unit, through the use of 'customised fetal growth charts' and detailed pathological examination of the placenta and fetal organs to look for specific evidence of this. He reports that, using this classification, the number of unexplained or unclassified stillbirths falls to 15%.

**'High risk' pregnancy**

A most useful definition of 'high risk' was given by Professor David James in his 2010 Eponymous William Fletcher Shaw lecture at the Royal College of Obstetricians and Gynaecologists (RCOG): "*A pregnancy is high risk when the likelihood of an adverse outcome (mortality or morbidity) in the mother and / or the baby is greater than in the general population*".

The stillbirth rates for women identified with risk factors have fallen – and the management of 'high risk' pregnancy has slowly and consistently led to better mortality figures in this group. This is partly because of improved therapies and surveillance, but also because the obstetrician has the ultimate intervention – delivery of the baby – at their disposal. This can, of course, mean that mortality is shifted from the antenatal or intrapartum to the neonatal period – early delivery may expose the newborn to the risks of prematurity, for example, but perinatal mortality rates (stillbirths and neonatal deaths to 28 days) are slowly and consistently falling.

*First of all – 'do no harm'*

Gestation, however, is an important factor, when considering whether identification of an increased risk should result in immediate delivery as this has implications on the provision and configuration of obstetric and neonatal services – even a baby delivered by elective caesarean section at 37 weeks, generally considered to be 'term' – has a ten-fold increased risk of dying or developing respiratory complications compared to the equivalent baby experiencing labour. This is because the 'stress' of labour helps finish fetal lung maturity through the production of stress hormones – the adverse effect of an 'early' caesarean section can be halved through giving two doses of steroid intramuscularly to the mother before delivery, but it does not eliminate this risk.

The decision to deliver a baby with extreme prematurity is one of the most difficult that many obstetricians face as the baby's outcome after delivery is predictable from a population point of view – we have good data on the survival and morbidity of babies at different weights at various gestations – versus the uncertainty of how an individual baby will fare if left in-utero. Sometimes the decision is straightforward – a woman is haemorrhaging at 26 weeks and delivery is necessary to save the mother's life, for example – but more often than not there is a discussion of what is known and unknown between the clinical team and the parents in order to seek an individual plan of management.

Currently, most stillbirths occur in conditions where no excessive maternal risk has been identified – the women are considered 'normal' or 'low risk'. The rates of stillbirth have been shown in several reports to be higher in 'low risk' than in 'high risk' women. This begs the question, "can the gap be narrowed to predict better the outcome of normal pregnancy?"

**Mechanism of fetal compromise and demise**

It is useful to consider what the sequence of events may be as a fetus becomes compromised because this helps in the discussion of potential screening processes and interventions. Importantly, it explains limitations of our current strategies. Again, it is easiest to refer to Professor James:

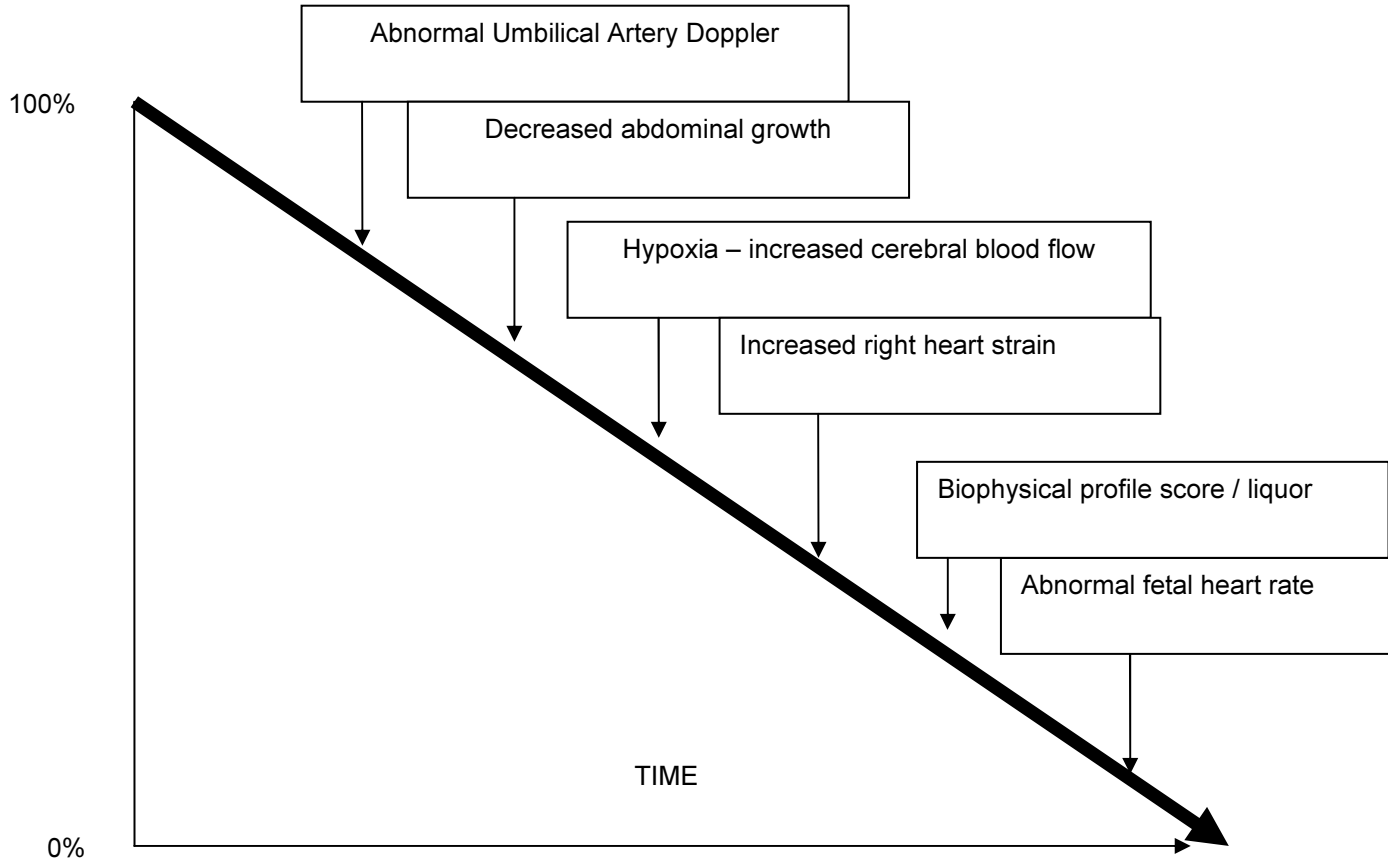


Figure 1: Schematic of optimal placental function against time and the approximate order in which clinical abnormalities could be found. The rate of slope (rate of deterioration) varies between individuals. (Modified from Prof James).

If the optimal placental function starts at 100%, but there is a deterioration in function (from whatever pathological cause) there is debate about whether the uterine artery Doppler or abdominal growth tail off first – as the liver forms a large part of the fetus, alterations in metabolism and therefore glycogen stores result in a reduction in abdominal circumference. As oxygen falls – hypoxia – there is a protective redistribution of blood to the fetal brain, which can be detected by altered blood flow in the middle

cerebral artery. Strain on the right side of the heart follows and this leads to reduced blood flow through the ductus venosus – the blood vessel that shunts oxygenated blood from the umbilical vein directly to the inferior vena cava (bypassing the fetal liver) to increase blood flow to the fetal brain. This can be measured on ultrasound and correlates reasonably with a build up of acid (acidaemia) – the product of needing to produce energy without oxygen (anaerobic glycolysis – which depletes glycogen stores from the fetal liver).

Alteration in fetal heart rate occurs relatively late in the process, even when it forms part of a biophysical score that includes liquor volume. The fetal heart can show reductions in variability that cannot be picked up easily on auscultation and computerised analysis appears to be more sensitive in this respect. By the time there is a pathological CTG, there may be a maximum of 72 hours before a baby dies. It is interesting to note that maternal perception of reduced fetal movements is often earlier in the process than abnormalities of the fetal heart rate.

Conversely, if a baby is small but dopplers are normal, then the outlook is usually very good – the test is reasonably sensitive in high risk pregnancies.

**Fetal movements**

It is perhaps somewhat surprising that only 50% of women complain of reduced fetal movements prior to presenting with an antepartum stillbirth. However, this association does exist and 1:6 still births from the 8th CESDI report were associated with suboptimal care in response to accepted current practice.

Randomised trials of formal fetal movement ‘kick charts’ did not have the anticipated effect – there was no improvement in neonatal outcomes and maternal anxiety was increased. This is reinforced by the Cochrane Review and NICE guidance on antepartum care. However, there is a sense that a change in character or relative number of movements may indeed be clinically significant, and there are studies underway to investigate this further.

From the schematic presented, it is not surprising that reduced fetal movements are not an accurate predictor of fetal well-being as they are affected relatively late in processes increasing placental dysfunction. However, there may be an association between placental abnormalities and reduced movements when the placenta is looked at in meticulous detail (Warrander et al 2012).

**Fetal growth**

In a perfect world, a fetus reaches its genetic growth potential in an optimum uterine environment with a perfectly functioning interface with the outside world (the placenta). Scientifically object assessment of this growth process is poor – we use a tape measure to assess growth believing this to be accurate because it has numbers on it, when we are measuring the baby, liquor, uterus and a varying degree of maternal body as well. As a rough screening tool it is relatively poor, but allows entry into more formalised fetal growth assessment using ultrasound. 50% of babies who do not reach their growth potential are missed by this approach and wrongly classified as being ‘low risk’. Stillbirths contain a disproportionate number of growth restricted babies and even more so when one considers more accurate means of ascertaining growth potential.

The crude population growth charts used to plot growth parameters for fetal ultrasound are derived from different populations and therefore there are several variations available. Male and female fetuses are expected to have different birth weights, first babies are generally lighter than subsequent babies, the birthweight norms for different ethnic populations vary and twins are generally lighter week for week than their singleton counterparts – yet all may have their growth plotted on a single standard chart. Jason Gardosi has developed ‘customised growth charts’ in the West Midlands which appear not only to highlight growth problems in-utero, but which significantly reduce the number of ‘unexplained’ stillbirths when applied to such babies.

The use of customised growth charts is unproven, but shows huge potential and the need to fund further research in this area nationally is essential. The effect of customised growth charts in categorising 'unexplained' stillbirths is seen also from data from Liverpool (figure 2) below:

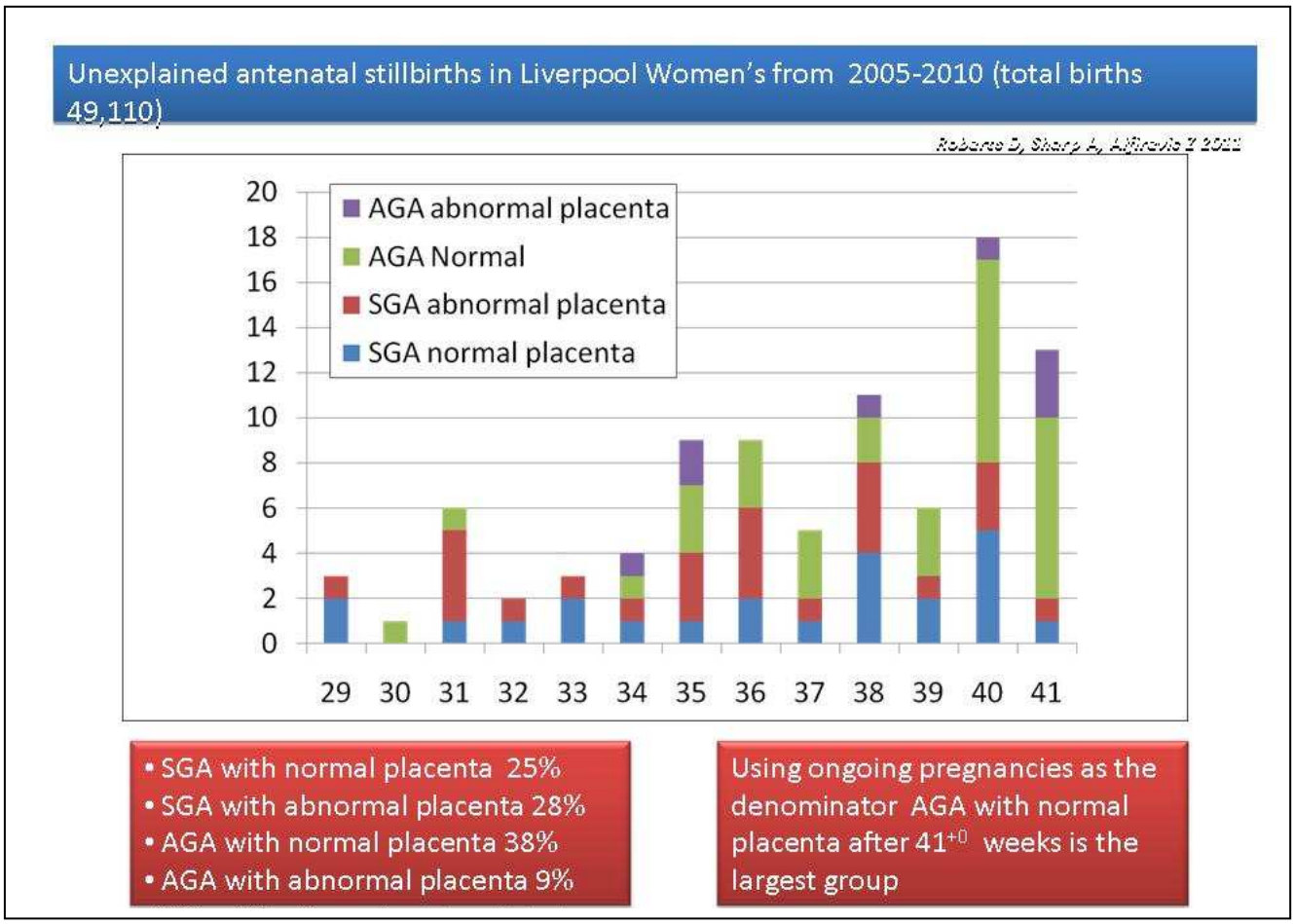


Figure 2: 'Unexplained' stillbirths with regards to being Small for Gestational Age (SGA) or Appropriate for Gestational Age (AGA) and accounting for specialist placental histopathological examination (courtesy of Professor Alfirevic).

Thus, for both reduced fetal movements and the identification of fetal growth restriction, the evidence for a standardised routine application for all women is incomplete (appendix 1). Wales needs to find a pragmatic approach to dealing with this.

**Electronic fetal monitoring**

Intrapartum fetal hypoxia remains an important cause of death and permanent handicap and there are many studies reporting a significant proportion of cases with evidence of suboptimal care related to fetal surveillance. Cardiotocographic (CTG) monitoring remains the basis of fetal surveillance during labour, but its interpretation by healthcare professionals is subject to great variation between observers and between the same clinician at different times – especially where a good or poor neonatal outcome is known (hindsight bias). Thus, there is often poor agreement on the features of a CTG – the presence and significance of slowing of the heart beat, for example and the overall classification of whether the trace is normal or needs intervention – and then what that intervention might be.

The RCOG has developed and launched an e-learning tool that is freely available to all NHS staff. It is both educational and assessed and is a key potential element in improving clinical staff skills in intrapartum fetal monitoring.

Several countries with lower stillbirth and neonatal death rates have introduced developments of the conventional CTG. ST Analysis (STAN) looks at the part of the fetal ECG that changes in the presence of hypoxia – a bit like changes in an adult ECG during angina or a heart attack. These changes are much more frequent than one might expect and thus interpretation depends on the likelihood that any event is significant – which means that it is used in conjunction with the need to interpret the conventional CTG reliably. The consequence to this is a huge training commitment and some people find the technology cumbersome and invasive. The STAN machines cost about five times that of a CTG machine, although it is not clear why this should really be the case. The addition of fetal electrocardiogram analysis has increased the potential to avoid adverse outcomes, but CTG interpretation remains its main weakness.

A program for computerised analysis of intrapartum fetal signals, incorporating real-time alerts for healthcare professionals has recently been developed by the University of Porto and Welsh patients participated in the validation study of this system in the 1990s (Glan Clwyd Hospital). There is a need to determine whether this technology can result in better perinatal outcomes and thus two hospitals in Wales (Cardiff and Glan Clwyd) form part of the four hospitals currently involved in a multicentre randomised clinical trial aiming to provide evidence of the impact of computer analysis for intrapartum monitoring with real-time alerts on the incidence of adverse perinatal outcomes, intrapartum interventions and signal quality. (Current controlled trials ISRCTN42314164).

**The challenge in ‘low risk’ women**

There are inherent problems in dealing with women judged to be at ‘low risk’ of adverse perinatal outcome, because there is a temptation not to tell women about things that can go dreadfully wrong. There is a paradox between the way we assess women as being normal and the science that may detect abnormality. In addition, there is a potential conflict between causing unnecessary anxiety for women and their families or harm from unproven interventions in women striving for the normality that occurs in the vast majority of low risk women otherwise.

From the previous discussion, it is apparent that there are inherent flaws in the way we assess ‘normality’ in terms of being ‘low risk’.

David James highlighted this discrepancy – we ask non-specifically whether a woman feels her baby is moving, without an ability to provide evidence of the significance from randomised trials about what our response should be.

We attempt to make an estimate of appropriate growth, with no knowledge of what might be appropriate for that pregnancy, in measuring symphysis-fundal height and make it slightly more reproducible by using a tape measure, which we turn back over and re-measure when we don’t match the number of

expected weeks with our centimetres. We are measuring the fetus, uterus, amniotic fluid and maternal abdomen, with at best a 50% positive predictive value for fetal growth restriction.

Fetal heart rate is recorded merely as being present and vaguely an acceptable rate with no information on the parameter most sensitive to hypoxia – the baseline variability – and no randomised controlled trial of this as an effective manoeuvre. When we do a CTG it should not really reassure us, because it deteriorates late in the process of placental dysfunction and fetal compromise.

We are left with the only randomised trials of procedures in fetal surveillance being those surrounding doppler in high risk pregnancy, but a Cochrane Review by Zarko Alfirevic concluded that there was insufficient evidence to recommend this as a screening tool in low risk pregnancy.

The challenge, therefore, is two fold: firstly, to know when 'normal' really does translate into 'low risk' in terms of outcomes, by either deciding on appropriate extra surveillance to alter risk status and secondly to instigate optimal monitoring or delivery.

It is tempting to say that, if 'term' is regarded as 37 – 40 weeks, then elective delivery at 37 weeks would reduce the risk of stillbirth. Whilst this is intuitively true, induction of labour is an invasive procedure and elective caesarean section under 39 weeks is associated with increased risks of neonatal respiratory distress and perinatal mortality.

The average length of pregnancy estimated from a woman's last menstrual period, where this is known with certainty (28 day cycle) is about 3 days shorter than when calculated from an ultrasound scan in early pregnancy, making the mean date of delivery about Term +3 and 50% of women would naturally labour on or prior to this date.

For a woman to give birth, the cervix must soften, shorten and dilate (from being closed to 10cm – or full dilatation). The shorter, softer and more open the cervix is, and the lower the fetal head is within the pelvis at the point of induction of labour, the more straightforward and quicker the induction and subsequent labour tend to be. The commonest reason that a woman is 'overdue' (when the dates are confirmed by early scan) is because the baby's back lies to the mother's back. The head extends a little and is therefore not tucked in so does not press so firmly on the cervix. This quarter turn that occurs in the baby, from facing sideways as the pelvis is entered, means that either the baby is born face upwards or a further 180 degree rotation happens, which is usually associated with a slower and more painful labour – with much more back pain.

Thus, women who go 'overdue' may not be representative of the women who have laboured spontaneously and the extra 'ripening' of the cervix from the longer pregnancy may be offset by a naturally more difficult labour.

Although it is usually held that induction of labour is associated with higher intervention rates in terms of vaginal operative delivery (forceps or ventouse) or caesarean section, the latest Scottish data suggest the growth velocity of a baby slows down towards term. Elective induction of labour for a large fetal size is not associated with improved delivery rates unless the woman is proven to have developed diabetes in pregnancy.

**Finding evidence**

The problem with deriving appropriate evidence arises because of the relatively rare nature of the adverse event – 1:200. For example, in the Dublin random controlled trial (RCT) of electronic fetal monitoring, the sample size of 10,000 women was not enough to deduce differences in perinatal mortality – even a study of this size was just not big enough. RCTs of screening procedures and interventions in low risk women would need hundreds of thousands of women to show a 10% improvement in rare outcomes. There is therefore a further complexity – we are asked to practice

'evidence-based' medicine in a context where the evidence is unlikely to be available in a 'gold-standard' form – the randomised controlled trial.

**Data in Wales**

National data are provided from the All Wales Perinatal Survey and the Congenital Anomaly Register Information Service (CARIS) both of which have core funding support from Welsh Government, but both rely on local notification from nominated staff in each maternity unit in Wales.

National statistics on deliveries are compiled using the Patient Episode Database for Wales (PEDW) which is a database of individual hospital patient records. Although the preferred Patient Administration System (PAS) for Wales – Myrddin – has developed a maternity module, there has been insufficient investment in completing the module enough for national implementation. There are local clinically useful maternity information systems in a minority of maternity units in Wales; clinicians' ability to perform surveillance or clinical audit routinely is limited by this on-going problem.

It would seem essential to establish a formal stillbirth register for Wales, funded appropriately and linked closely with the All Wales Perinatal Survey and CARIS.

**The 1000 Lives Plus Transforming Maternity Services mini-collaborative**

The overall aim of the Transforming Maternity Services Mini-Collaborative is to improve the experience and outcomes for women, babies and their families within Maternity Services. Two of the drivers in achieving this aim are to reduce the risk of venous thromboembolism in pregnancy and to improve the recognition and management of critically ill pregnant women in Wales, with a particular emphasis on sepsis.

The Transforming Maternity Services Mini-Collaborative brings together experts, clinicians and managers to effect change at the bedside (from the 'bottom up'). It is endorsed by Welsh Government, all Health Boards in Wales, the Royal College of Midwives (RCM), and the Royal College of Obstetricians and Gynaecologists (RCOG) in Wales. Crucially, it has found a pragmatic solution to reaching consensus for the implementation of pathways of care where the evidence base is unknown or uncertain. This was the situation when the mini-collaborative steering group considered the initial evidence-base for interventions – appendix 1. However, the methodology developed may be applicable to interventions aiming to reduce stillbirths in Wales.

This reducing stillbirth work stream was launched at a learning session of the mini-collaborative in May 2012.

- Ends -

**Reference:**

Warrander LK, Batra G, Bernatavicius G, Greenwood SL, Dutton P, et al. (2012) Maternal Perception of Reduced Fetal Movements Is Associated with Altered Placental Structure and Function. PLoS ONE 7(4): e34851. doi:10.1371/journal.pone.0034851

**APPENDIX 1:**

**1000 Lives Plus Transforming Maternity Services mini-collaborative:**
**Public Health Wales Review of the literature 2010.**

The following is taken from Dr Mary Webb, Public Health Practitioner, commissioned by Dr Alan Wilson, Director 1000 Lives Plus in November 2010 when looking at evidence-based care bundles for the Transforming Maternity Services mini-collaborative.

Standardising the detection and management of intrauterine growth restriction (IUGR) and the response to reduced fetal movements.

**Reduced fetal movements**
There is no evidence that any absolute definition of reduced fetal movements is of greater value than maternal subjective perception of reduced fetal movements in the detection of intrauterine fetal death or fetal compromise (2007 Cochrane review - 4 trials, 71,370 women).

There are many guidelines for the management of decreased fetal movements but as yet none have complete international acceptance. The NICE antenatal care guideline states that routine formal fetal-movement counting should not be offered[1]. For production of the NICE guidance one RCT was found that assessed the ability of the 'count to ten' method to reduce the prevalence of antenatal fetal death. The cluster RCT randomised 68,000 women to either routine formal fetal-movement counting or to standard care. It found that there was no decrease in perinatal mortality in the test group and this policy would have to be used by about 1,250 women to prevent one unexplained death. One paper has examined the apparent divided opinion on the NICE recommendation for abandoning routine monitoring of fetal movements. The question faced by professionals in antenatal care is when to accept that fetal movements have been reduced for long enough to warrant intervention. The author reviewed a wider category of evidence than would have been included for the NICE recommendation. He concluded that the evidence supported the recommendation for abandonment of routine monitoring of fetal movements, but that if pregnant women have noticed a decrease in fetal movements for more than 12 hours then further assessment in hospital is indicated[2].

St Thomas's Hospital research group is also looking at whether fetal movement is a useful measure of baby health. The group is currently recruiting 300 women who report reduced fetal movements to join a study that will test this theory. The women are assessed clinically, then a blood sample is taken and an ultrasound scan performed to measure fetal growth, the volume of liquor around the baby and blood flow through the umbilical cord. This will allow the evaluation of whether fetal movement monitoring combined with any of these investigations could decrease stillbirths. The group has also developed guidelines on fetal movements. The group's research has shown that reduced fetal movement is a very reliable predictor of pregnancy complications and that previous practice in this area was chaotic and non-evidence-based[3].

**Intrauterine growth restriction**
A major focus of prenatal care is to determine whether a fetus is at risk for growth restriction and to identify the growth restricted fetus. Fetal growth is important because there is an inverse relationship between the fetal/neonatal weight percentile and adverse perinatal outcome, with the greatest risk at

[1] National Institute for Health and Clinical Excellence. Antenatal Care: routine care for the healthy pregnant woman. CG 62; NICE 2008.
[2] Hill-Smith, I. Professional and patient perspectives of NICE guidelines to abandon maternal monitoring of fetal movements. Br J Gen Pract. 2004; 54: 858-86. (Evidence Level 3/4)
[3] St Thomas's Hospital. Pregnancy research. Available at: http://www.tommys.org. [Accessed 20th November 2010].

weights below the third percentile for gestational age. Intrauterine growth restriction (IUGR) / fetal growth restriction (FGR) is a condition where a baby's growth slows or ceases when it is in the uterus. It is part of a wider group under the term small for gestational age (SGA) fetuses which includes fetuses that have failed to achieve their growth potential and fetuses that are constitutionally small[4].

**INVESTIGATIONS**

Numerous approaches to differentiate the fetus or infant with growth restriction from the small, but otherwise healthy, baby have been proposed. Clinical assessment is a reasonable screening tool for FGR in low risk pregnancies, as there is no high quality evidence that alternative approaches, such as routine ultrasound examination, improve outcome over clinical assessment alone.

*Abdominal circumference*

Most studies report that reduced abdominal circumference (AC) is the most sensitive single morphometric indicator of FGR. The AC measurement is the best single measurement to assess fetal growth because where growth is restricted, the liver is usually affected[5].

*Abdominal palpation*

Clinical assessment of fetal size by abdominal palpation does not perform well as a test for detecting FGR with sensitivities ranging from 30% to 50%. Physical examination of the abdomen by inspection and palpation detects as little as 30% SGA foetuses. Therefore, if SGA is suspected, it is necessary to supplement abdominal palpation with ultrasound. Correct assessment of gestational age is essential and an ultrasound examination in the first trimester should be routine[4].

*Ultrasound diagnosis*

Clinical assessment alone is not adequate in pregnancies at high risk for FGR, given the low sensitivity. A variety of sonographic parameters has been used to screen for and diagnose FGR. A major limitation in interpreting the predictive value of ultrasound for diagnosing FGR and comparing predictive values derived from different studies is that these values depend upon the prevalence of FGR in the population studied. Thus, ultrasound results need to be interpreted in terms of pretest risk of FGR and take into account whether the subject population is at low, moderate, or high risk of fetal growth abnormality.

The use of Doppler ultrasonography to measure umbilical artery waveforms should be considered a part of fetal evaluation once IUGR is suspected or diagnosed. Modern techniques give very accurate information. One expert review indicates that the ultrasound criteria for IUGR include:

- An elevated ratio of femoral length to abdominal circumference
- An elevated ratio of head circumference (HC) to AC.
- Unexplained oligohydramnios

*Measurement of symphysis-fundal distance*

Measurement of the distance between the upper edge of the pubic symphysis and the top of the uterine fundus using a tape measure is a simple, inexpensive, and widespread procedure performed during antenatal care to detect fetuses that are growing poorly. The accuracy of fundal height measurements for screening for and diagnosis of FGR is controversial; a systematic review concluded there was not enough evidence to evaluate the use of this technique during antenatal care. Observational studies using symphysis-fundal height measurements have reported a wide range of sensitivities: 28% to 86% of small fetuses were detected. The NICE antenatal care guideline suggests that further research is needed to establish the diagnostic value and effectiveness of customised fetal growth charts to plot small for dates (SFD), particularly in relation to those pregnancies that appear small for gestational age[6].

[4] Patient UK. Intrauterine growth restriction. Patient UK 2010. Available at: http://www.patient.co.uk/doctor/Intrauterine-Growth-Retardation.htm. [Accessed 20th November 2010].
[5] Divon MY, Ferber A. Diagnosis of fetal growth restriction. UpToDate 2010: 1-25. (Evidence Level 2-)
[6] National Institute for Health and Clinical Excellence. Antenatal Care: routine care for the healthy pregnant woman. CG 62; NICE 2008.

**MANAGEMENT**

One review concluded that the optimal method of monitoring the fetus with suspected FGR has not been established. Periodic assessment, once or twice weekly from the age of viability, using the biophysical profile (BPP) and Doppler velocimetry is acceptable. The purpose of antenatal monitoring is to try to identify those fetuses that are at highest risk of in utero demise and neonatal morbidity, and thus may benefit from intervention by preterm delivery[5]. Ultrasound evaluation of fetal growth, fetal behaviour, amniotic fluid volume, and impedance to blood flow in fetal arterial and venous vessels, form the cornerstone of evaluation of the fetal condition and decision making. Serial examinations should be performed with the frequency based upon the severity of findings and whether the examinations are being done to monitor fetal well-being (one to seven times per week) or fetal growth (every three to four weeks).

*Medical interventions*

There was a paucity of evidence from randomised trials that any specific antenatal treatment for the growth restricted fetus is beneficial. Numerous approaches have been used, including nutritional supplementation, plasma volume expansion, low-dose aspirin, heparin, bed rest, maternal oxygen therapy, and beta-mimetics/calcium channel blockers to improve blood flow to the placenta. None have consistently been shown to be of value[5].

*Timing of delivery*

The growth restricted fetus should be delivered if the risk of fetal death, as determined by antepartum monitoring tests, exceeds the risk of neonatal death. The difficulty in making this assessment was illustrated by the Growth Restriction Intervention Trial (GRIT), which randomly assigned pregnant women between 24 and 36 weeks to immediate (n = 296) or delayed (n = 291) delivery if their obstetrician was uncertain about when to intervene.[7] Ninety percent of the pregnancies were complicated by clinical evidence of growth restriction and 40% had absent or reversed end diastolic umbilical artery flow. In the delayed delivery group, delivery occurred when the obstetrician was no longer uncertain about intervening (median delay 4.9 days). Deaths prior to hospital discharge were similar in both groups (29 deaths with immediate delivery and 27 deaths with delayed delivery). The immediate delivery group had fewer stillbirths (2 versus 9), but more neonatal and infant deaths (27 versus 18). Follow-up data at two years of age showed that the proportion of children with death or severe disability was similar for both groups (19% of immediate and 16% of delayed births)[8]. The small excess risk of mortality/severe disability in the immediate delivery group was primarily related to children randomised before 31 weeks of gestation. For this reason, the authors recommended delayed delivery in very preterm gestations if there was uncertainty about the need for intervention.

The NICE guideline for labour gives the following evidence statements[9] :-

- For FGR identified between 24 and 36 weeks of gestation, there is insufficient evidence to determine whether immediate or delayed birth is beneficial. [Evidence Level 1+]

- For FGR at term, one small RCT reported that induction of labour (with PGE2 and amniotomy/intravenous oxytocin) and expectant management achieved similar maternal and fetal outcomes. [Evidence Level 1+]

[7] The GRIT Study Group. When do obstetricians recommend delivery for a high-risk preterm growth-retarded fetus? Growth Restriction Intervention Trial. Eur J Obstet Gynecol 1996; 67:121. (Evidence Level 4)

[8] Thornton JG, Hornbuckle J, Vail et al. Infant wellbeing at 2 years of age in the Growth Restriction Intervention Trial (GRIT): multicentred randomised controlled trial. Lancet 2004; 364: 513. (Evidence Level 1-)

[9] National Institute for Health and Clinical Excellence. Intrapartum care: management and delivery of care to women in labour. CG55; NICE 2007.

- There is therefore little evidence of benefit for induction of labour in the presence of severe FGR. The guideline development group considered that labour in the presence of FGR may result in perinatal loss and that, in such cases, induction of labour should thus be avoided.

**PREVENTION**
In subsequent pregnancies, prevention methods should be aimed at encouraging smoking cessation, reduction of alcohol intake and a balanced energy/protein supplementation in women with significant nutritional deficiencies. Avoiding a short inter-pregnancy interval may also be beneficial. Although some randomised trials reported low-dose aspirin prophylaxis during pregnancy reduced the risk of recurrent FGR in women at high-risk (e.g. FGR in a previous pregnancy) larger randomised trials did not confirm significant risk reduction[5].

Aspirin may however be effective when FGR is related to pre-eclampsia. In a systematic review of 36 randomised trials including 23,638 women at high risk of developing pre-eclampsia, use of anti-platelet agents compared to placebo was associated with a 17% reduction in the risk of pre-eclampsia and a 10% reduction in the risk of SGA births (RR 0.90, 95% CI 0.83-0.98). Further study is urgently required[10].

**CONCLUSIONS** – Option 3
National evidence based guidelines do not recommend the use of routine monitoring of fetal movements. Expert reviews were used to inform the detection and management of intrauterine growth restriction (IUGR). Whilst some interventions were supported by good quality evidence there was inconsistency in the evidence for some interventions. These issues need to be addressed by large multicentre studies employing consistent definitions, randomly assigned interventions, and with long-term follow-up.

The evidence presented in this review, some of which is international, for IUGR, requires expert analysis by healthcare staff involved in maternity care in Wales to verify its appropriateness and applicability.

Summary of references from the main review text:


- Divon MY, Ferber A. Diagnosis of fetal growth restriction. UpToDate 2010: 1-25. (Evidence Level 2-)
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- Mangesi L, Hofmeyr GJ. Fetal movement counting for assessment of fetal wellbeing. Cochrane Database of Systematic Reviews 2007, Issue 1. Art. No.: CD004909. DOI: 10.1002/14651858.CD004909.pub2
(Evidence Level 1++)
- National Institute for Health and Clinical Excellence. Antenatal Care: routine care for the healthy pregnant woman. CG 62; NICE 2008.
- Hill-Smith, I. Professional and patient perspectives of NICE guidelines to abandon maternal monitoring of fetal movements. Br J Gen Pract. 2004; 54: 858-86. (Evidence Level 3/4)
- St Thomas's Hospital. Pregnancy research. Available at: http://www.tommys.org. [Accessed 20th November 2010].
- Patient UK. Intrauterine growth restriction. Patient UK 2010. Available at: http://www.patient.co.uk/doctor/Intrauterine-Growth-Retardation.htm. [Accessed 20th November 2010].


[10] Duley L, Henderson-Smart DJ, Meher S et al. Antiplatelet agents for preventing pre-eclampsia and its complications. Cochrane Database of Systematic Reviews 2007, Issue 2. Art. No.: CD004659. DOI: 10.1002/14651858.CD004659.pub2. (Evidence Level 1++)

# Y Pwyllgor Iechyd a Gofal Cymdeithasol

## HSC(4)-19-12 papur 10

## Ymchwiliad un-dydd i farw-enedigaethau yng Nghymru – Llywodraeth Cymru

**Diben**

1. Mae'r papur hwn yn darparu tystiolaeth ar gyfer ymchwiliad undydd y Pwyllgor Iechyd a Gofal Cymdeithasol i farw-enedigaethau yng Nghymru. Mae'n edrych ar weithrediad ac effeithiolrwydd y canllawiau a'r argymhellion presennol ar draws y gwahanol sectorau ac ar yr ymwybyddiaeth ohonynt, a hynny mewn perthynas ag atal marw-enedigaethau, yn enwedig mewn perthynas â rheoli diffyg twf y ffetws, lleihad yn symudiadau'r ffetws, a genedigaeth wedi'r cyfnod llawn, ac ymhle y gellid gwella.

2. Mae'r papur tystiolaeth:

- yn edrych ar y sefyllfa bresennol mewn perthynas â monitro marw-enedigaethau yng Nghymru
- yn ystyried beth rydym yn ei wneud i leihau'r nifer o farw-enedigaethau yng Nghymru
- yn edrych ar y 'Gweithgor Cenedlaethol ar Farw-enedigaethau' a sefydlwyd â chymorth Rhaglen Gydweithredol fach Trawsnewid Gwasanaethau Mamolaeth 1000 o Fywydau a Mwy, a'i nod o drawsnewid y canlyniadau i fenywod a'u teuluoedd.

**Crynodeb**

3. Mae gan effeithiolrwydd ac ansawdd gwasanaethau mamolaeth y GIG ran hanfodol i'w chwarae yn y gwaith o leihau risg marw-enedigaethau. Er nad yw achos y mwyafrif o farw-enedigaethau yn hysbys, mae cryn wybodaeth ar gael am yr hyn y gellid ei wneud i rwystro marw-enedigaethau yng Nghymru.

4. Gyda chymorth Rhaglen Gydweithredol fach Trawsnewid Gwasanaethau Mamolaeth 1000 o Fywydau a Mwy, mae Gweithgor Cenedlaethol ar Farw-enedigaethau bellach wedi cael ei sefydlu ac mae'n gwneud y canlynol:

a. datblygu strategaeth i leihau'r nifer o farw-enedigaethau

b. dynodi a hyrwyddo ymchwil pellach yng Nghymru i wella'r ddealltwriaeth o achosion marw-enedigaethau

c. cydweithio â menywod i gael y cydbwysedd gorau rhwng 'normaledd' ac 'ymyrraeth'

ch. hwyluso rhannu a hyrwyddo'r arferion gorau ar draws Cymru.

**Marw-enedigaethau yng Nghymru - y sefyllfa bresennol**

5. Yn 2010 roedd 190 o farw-enedigaethau yng Nghymru, ac er y flwyddyn 2000 mae'r gyfradd wedi amrywio rhwng 4.6 a 5.7 i bob mil o enedigaethau. Mae'r cyfraddau a gafwyd yn fwyaf diweddar yn dangos bod y duedd tuag at i lawr a welwyd yng Nghymru ac yng ngweddill y Deyrnas Unedig wedi ei atal yn y deng mlynedd diwethaf.

6. Prif achosion marw amenedigol yw cynamseroldeb ac anomaleddau cynhenid, er bod achos y gyfran helaethaf o farw-enedigaethau (41.7%) yn anhysbys.

7. Mae achosion hysbys marw-enedigaethau'n cynnwys anomaleddau cynhenid, rhai heintiau, pwysau gwaed uchel yn y fam (cyneclampsia) a gwaedu y tu ôl i'r brych (gwahanu'r brych).

8. Gwelwyd hefyd bod ffactorau'n ymwneud â ffordd o fyw yn cyfrannu at risg o farw-enedigaeth - ffactorau y gallai ymyrryd ar ran iechyd cyhoeddus gael dylanwad arnynt, fel mamau sy'n ysmygu, yn ordew ac yn cymryd cyffuriau ac alcohol.

**Ysmygu**

9. Mae menywod sy'n ysmygu yn ystod beichiogrwydd tua dwywaith mor debygol o gael rhwyg mewn pilenni a gwahaniad brych cynamserol, ac o gael babanod bychan (sy'n pwyso ar gyfartaledd 200 gram yn llai na babanod mamau nad ydynt yn ysmygu). Mae babanod sy'n cael eu geni i fenywod sy'n ysmygu mewn mwy o berygl o farw-enedigaeth, ac amcangyfrifir bod ysmygu'n cyfrif am 7% o'r risg yn y boblogaeth yn gyffredinol ond am hyd at 20% o'r risg mewn poblogaethau difreintiedig.

10. Dangosodd yr Arolwg Bwydo Babanod diweddaraf (2010) y canlynol:

- Roedd traean o'r mamau (33%) yng Nghymru yn ysmygu ar ryw adeg yn y 12 mis yn union cyn beichiogi neu yn ystod beichiogrwydd, sy'n gyfran uwch nag yng ngwledydd eraill y Deyrnas Unedig. O'r mamau a oedd yn ysmygu, rhoddodd tua 50% ohonynt y gorau iddi ar ryw adeg cyn yr enedigaeth, o gymharu â 54% yn y Deyrnas Unedig yn gyfan.
- Roedd un fam o bob chwech (16%) yng Nghymru yn dal i ysmygu trwy gydol ei beichiogrwydd.
- Cafwyd y cyfrannau uchaf o famau a oedd yn ysmygu cyn neu yn ystod beichiogrwydd ymhlith mamau mewn galwedigaethau corfforol a chyffredinol ac ymhlith mamau 20-24 oed.

**Gordewdra**

11. Mae data a gyhoeddwyd yn adroddiad y Ganolfan Ymchwiliadau i Ofal Iechyd Mamolaeth a Gofal Iechyd Plant (Centre for Maternal and Child Care Health Enquiries - CMACE) ar ordewdra yn ystod mamolaeth yn dangos mai yng Nghymru y mae'r ganran uchaf o ordewdra yn ystod beichiogrwydd yn y Deyrnas Unedig, canran o 6.5%.

12. Mae gordewdra yn ystod beichiogrwydd yn gysylltiedig â risg uwch o nifer o gymhlethdodau a chanlyniadau niweidiol cysylltiedig â beichiogrwydd, ac mae risg

uwch o farwolaeth amenedigol i fabanod menywod gordew o gymharu â'r boblogaeth gyffredinol o famau beichiog yn y Deyrnas Unedig. At hynny, mae cysylltiad uniongyrchol rhwng derbyniadau i unedau newyddenedigol (o fewn 24 awr i'r enedigaeth) a gordewdra mamau.

**Alcohol a chyffuriau**

13. Ar ddechrau ei beichiogrwydd, caiff pob menyw feichiog yng Nghymru ei holi am yr alcohol a'r cyffuriau a gymer, a chynigir cymorth i leihau dibyniaeth. Nid oes gan Lywodraeth Cymru ddata cywir ar gamddefnyddio cyffuriau yn ystod beichiogrwydd, ond mae hynny'n cael ei ddatblygu fel rhan o roi'r strategaeth famolaeth ar waith.

14. Bydd yfed alcohol yn ystod beichiogrwydd yn cael cryn effaith ar iechyd corfforol a meddyliol y fenyw, a gall arwain at Syndrom Alcohol y Ffetws. Mae'r anhwylder hwn yn arwain at broblemau deallusol ac ymddygiadol i'r plentyn sy'n para am ei oes. Mae'n anodd rhoi diagnosis o Syndrom Alcohol y Ffetws ac mae angen genetegydd i'w gadarnhau; mae'n debygol bod mwy o achosion nag yr adroddir amdanynt. Yng Nghymru, bu'r Gwasanaeth Cofrestr a Gwybodaeth Anomaleddau Cynhenid (CARIS) yn casglu data er 1998 ac mae'n nodi bod cyfradd o 0.07 i bob mil o enedigaethau byw.

15. Dyma'r prif ganfyddiadau ar gyfer y Deyrnas Unedig yn gyfan:

a. Roedd dros hanner (54%) y mamau yn yfed alcohol yn ystod beichiogrwydd. Er hynny, yn ystod beichiogrwydd roedd lefelau yfed alcohol yn isel. Dim ond wyth y cant o'r holl famau oedd yn yfed mwy na dwy uned o alcohol yr wythnos ar gyfartaledd.

b. Roedd bron i dri-chwarter y mamau (73%) a yfai yn ystod beichiogrwydd yn cael cyngor ynglŷn ag yfed, a bydwragedd oedd y ffynhonnell fwyaf cyffredin.

**Symudiadau'r Ffetws**

16. Yn dilyn cynllun prawf mawr tua ugain mlynedd yn ôl ar 'Gyfrif Ciciau', a ddangosodd na wnaeth fawr o wahaniaeth i farwolaethau babanod, rhoddwyd y gorau i ofyn i fenywod wneud hyn. Bellach mae'r arfer ar draws y Deyrnas Unedig ac Ewrop yn amrywio'n fawr.

17. Nid yw Canllawiau NICE yn cefnogi 'Cyfrif Ciciau' er mwyn asesu symudiadau'r ffetws yn ffurfiol, ond os yw'r ffetws yn symud llai maent yn argymell y dylai pob menyw grybwyll hynny, ac y dylid asesu cyflwr y ffetws.

18. Mae'r dystiolaeth yn awgrymu bod lleihad sylweddol neu newid sydyn mewn symudiadau yn arwydd clinigol pwysig. Fel arfer, nid yw llai o symudiadau yn arwydd bod rhywbeth o'i le gyda'r beichiogrwydd, ond weithiau gall fod yn rhybudd pwysig nad yw'r ffetws yn cael digon o ocsigen oddi wrth y fam, trwy'r brych.

19. Yn ddiweddar, dangosodd llai o farw-enedigaethau yn Norwy fod rhoi canllawiau ymarfer clinigol ar waith ynghyd â gwybodaeth i fenywod ar symudiadau'r ffetws yn rhoi canlyniadau calonogol, a bellach mae astudiaeth ehangach ar waith a chyfranogaeth y Deyrnas Unedig yn cael ei annog.

20. Yr her yw sut i ddiffinio lleihad mewn symudiadau a sut i fonitro menywod heb beri mwy o bryder. Y llynedd, cynhyrchodd Coleg Brenhinol yr Obstetregwyr a'r Gynaecolegwyr ganllawiau, sy'n edrych ar sut y dylai menywod fod yn ymwybodol o batrymau symud eu babi yn y groth, yn rhoi cyngor i glinigwyr, yn adolygu'r ffactorau risg a'r ffactorau sy'n dylanwadu ar dybiaethau mamau. Cefnogir y canllawiau hyn gan y Gymdeithas Marw-enedigaethau a Marwolaethau Newyddenedigol (SANDS).

21. Ar sail y dystiolaeth sydd ar gael bydd y Gweithgor Cenedlaethol ar Farw-enedigaethau yn datblygu protocol ar gyfer Cymru gyfan ar leihad yn symudiadau'r ffetws (gweler eitemau 36-38).

**Twf**

22. Gwyddom fod cysylltiad rhwng cyfyngiad ar dwf a marw-enedigaeth, ond ar hyn o bryd nid yw'n cael ei nodi'n dda iawn.

23. Mae ymchwilwyr wedi dangos nad yw mesur uchder y ffwndws [mesur o dwf y groth yn abdomenol â thâp mesur] mewn poblogaeth isel-risg yn fuddiol o ran canfod diffyg twf, gan nad yw'n ddigon cywir.

24. Er hynny, mae angen o hyd inni dynnu ar yr arferion gorau o bob rhan o Ewrop, yn rhyngwladol ac yng ngweddill y DU gyda golwg ar eu rhannu a/neu eu rhoi ar waith yng Nghymru.

25. Mae symudiadau'r ffetws yn ogystal â chyfyngiad ar dwf yn cael eu trafod gan y Gweithgor Cenedlaethol ar Farw-enedigaethau, sy'n cael ei gydlynu gan 1000 o Fywydau a Mwy.

**Post-mortem**

26. Y prif rwystr i ddeall achosion marw-enedigaethau yw'r gyfradd isel iawn o archwiliadau post-mortem pediatrig.

27. Mae'r gyfradd post-mortem amenedigol yn y Deyrnas Unedig yn dal yn isel, (42.4%), oherwydd trallod emosiynol ac yn rhannol oherwydd dylanwad y sgandalau cadw organau yn niwedd y 1990au. Yng Nghymru yn 2010, 44.4% o fenywod a roddodd ganiatâd ar gyfer post-mortem yn dilyn marw-enedigaeth.

28. Mae sawl rheswm pam y mae cyfraddau post-mortem ar fabanod mor isel:

- Mewn llawer achos, mae rhieni mewn profedigaeth yn peidio â rhoi caniatâd i bost-mortem oherwydd bod y broses o geisio caniatâd mor ddryslyd. Gall cymhlethdod y cwestiynau a ofynnir iddynt fod yn ormod i rieni a pheri dryswch iddynt.
- Yn 2008, ni chynigiwyd post-mortem i 9% o'r rhieni y cafodd eu babi ei eni'n farw neu y bu eu babi farw yn ystod wythnos gyntaf ei fywyd (cyf: adroddiad CEMACE 2008).

- Nid yw llawer o fydwragedd a doctoriaid yn cael eu hyfforddi am werth post-mortem nac am sut i geisio caniatâd, ac mae'n hawdd i rieni wangalonni os nad oes gan y staff hyder yn y broses.

**Beth rydym yn ei wneud i leihau'r nifer o farw-enedigaethau yng Nghymru**

**A. Gweledigaeth Strategol ar gyfer y Gwasanaethau Mamolaeth yng Nghymru**

29. Cafodd y Weledigaeth Strategol ar gyfer y Gwasanaethau Mamolaeth yng Nghymru ei lansio ym mis Medi 2011, ac mae'n canolbwyntio ar wella iechyd menywod a'u teuluoedd gyda phwyslais ar roi'r gorau i ysmygu, bwyta'n iach, deiet ac ymarfer, er mwyn helpu i wella'r canlyniadau i fabanod.

30. Y canlyniad y cytunwyd arno ar gyfer y boblogaeth yn gyffredinol yw 'menyw iach, babi iach a beichiogrwydd iach', ac erbyn diwedd mis Mehefin bydd Prif Weithredwr GIG Cymru yn cyhoeddi cyfres o ddangosyddion canlyniadau ar lefel y boblogaeth i weld i ba raddau yr ydym yn sicrhau hynny. At hynny, bydd yn cyhoeddi cyfres o fesurau perfformiad cenedlaethol y bydd yn eu defnyddio i gael y GIG i roi cyfrif o sut y mae menywod a'u babanod ar eu hennill o ganlyniad i ofal mamolaeth y GIG.

31. Er nad marw-enedigaethau yn unig y bydd y rhain yn eu holrhain, mae marw-enedigaethau yn cael eu cofnodi trwy gyfrwng y system gofrestru genedigaethau ac yn cael eu cofnodi'n fanwl gan Arolwg Amenedigol Cymru gyfan; a disgwylir i Fyrddau Iechyd Lleol gofnodi pob marw-enedigaeth fel Digwyddiad Niweidiol Difrifol, archwilio'r achosion a gweithredu ar y canfyddiadau.

**B. Lleihau'r risg o farw-enedigaethau - newidiadau ffordd o fyw cadarnhaol**

**Naw Mis a Mwy**

32. Caiff y llyfr Naw Mis a Mwy ei ddarparu ar hyn o bryd gan fydwragedd i bob darpar riant. Mae'n rhoi gwybodaeth am sut i wella iechyd a lles, a sicrhau beichiogrwydd iach.

**Y Rhaglen Newid am Oes**

33. Mae Newid am Oes yn 'chwaer-frand' i raglen Dechrau am Oes yr Adran Iechyd. Mae'n annog unigolion, teuluoedd a chymunedau i wneud newidiadau bychain i'w ffordd o fyw i wella iechyd hirdymor, yn arbennig mewn perthynas â deiet, alcohol ac ymarfer.

34. Mae Dechrau am Oes yn ymhelaethu i ymgorffori amrediad ehangach o faterion iechyd ac ehangu'r gynulleidfa i gynnwys menywod beichiog, tadau a theuluoedd gyda phlant o dan 5 oed (yn hytrach na phlant dwy oed). Mae swyddogion Llywodraeth Cymru'n trafod â'r Adran Iechyd i ystyried y cyfleoedd i ehangu cwmpas y rhaglen yng Nghymru.

**Ysmygu mewn mamau beichiog**

35. Mae Cynllun Gweithredu Cymru ar Reoli Tybaco yn ymrwymo i gael Iechyd Cyhoeddus Cymru i gydweithio â Byrddau Iechyd Lleol i gryfhau llwybrau atgyfeirio rhwng unedau mamolaeth a Dim Smygu Cymru ymhellach, fel bod gwell cyfle i ysmygwyr beichiog roi'r gorau i ysmygu. Nod hyn yw lleihau'r achosion o ysmygu ymhlith menywod beichiog.

**Y Rhaglen 1000 o Fywydau a Mwy**

36. Nod Rhaglen Gydweithredol fach Trawsnewid Gwasanaethau Mamolaeth 1000 o Fywydau a Mwy, a lansiwyd gan y Prif Swyddog Nyrsio ym mis Mawrth 2011, yw gwella profiadau a chanlyniadau menywod, babanod a'u teuluoedd yng ngwasanaethau mamolaeth Cymru. Ar hyn o bryd, mae'r gwaith yn canolbwyntio ar ymyriadau i adnabod yn well y fenyw sy'n gwaethygu'n ddifrifol, ac ymateb, ac atal thrombosis gwythiennau dwfn. Mae pob uned famolaeth yng Nghymru yn ymwneud â'r rhaglen sy'n cael ei goruchwylio gan Grŵp Llywio Cenedlaethol.

37. Yn ddiweddar mae'r Rhaglen Gydweithredol fach wedi dynodi maes marw-enedigaethau fel eu blaenoriaeth nesaf, a chynhaliwyd cyfarfod o'r Gweithgor Cenedlaethol ar Farw-enedigaethau. Y cylch gorchwyl yw:

- adolygu'r gronfa o dystiolaeth sydd ar gael mewn perthynas ag atal marw-enedigaethau a marwolaethau newyddenedigol
- datblygu strategaeth i leihau lefelau marw-enedigaethau a marwolaethau newyddenedigol
- dynodi a hyrwyddo ymchwil pellach yng Nghymru i wella'r ddealltwriaeth o achosion marw-enedigaethau a marwolaethau newyddenedigol
- hwyluso rhannu a hyrwyddo'r arferion gorau ar draws Cymru
- adnabod cyfyngiadau ac atebion i faterion clinigol a gweithredol penodol
- rhoi gwybodaeth i Lywodraeth Cymru ar faterion lleol a chynnydd o ran gweithredu
- cydweithio â SANDS a grwpiau priodol eraill i wella ymwybyddiaeth gyhoeddus o'r materion hyn.

38. Mae'r Grŵp wedi cytuno mai ar y canlynol y bydd y gwaith yn canolbwyntio i ddechrau:

- Cofrestr ac Ymchwiliad Cyfrinachol i Farw-enedigaethau i Gymru
- mwy o sganio ar ferched beichiog i ddynodi materion twf yn eu babanod yn gywir
- rheoli cymell geni yn achos beichiogrwydd 'wedi'r dyddiad'
- adolygiad Cymru gyfan o ganfod arafwch twf yn y groth
- protocol y cytunir arno ar gyfer Cymru gyfan ar leihad yn symudiadau'r ffetws
- cynnydd yn y caniatâd ar gyfer post-mortem yn dilyn marw-enedigaeth.

39. Byddaf yn parhau i fonitro'r gwaith a wneir i ymdrin â diogelwch ac ansawdd gwasanaethau mamolaeth ac i'w gwella.

**Health and Social Care Committee**

**HSC(4)-19-12 paper 11**

**Inquiry into Stillbirths in Wales – Written Evidence from Public Health Wales**


# Health and Social Care Committee. Evidence for Inquiry into still births in Wales

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| **Date:** 24 May 2012 | **Version:** 0a |

**Publication/ Distribution:**

- National Assembly for Wales Health and Social Care Committee

**Review Date:**

**Purpose and Summary of Document:** The purpose of this paper is to provide evidence on the preventable causes of stillbirth for consideration by the Health and Social Care Committee during their one day inquiry into the prevention of still births in Wales.

**Work Plan reference:**

## Key Messages

- Maternal overweight and obesity, advanced maternal age and maternal smoking are the highest ranking modifiable risk factors for still birth
- Rates of stillbirth are persistently higher in areas with high levels of deprivation

- Wales has highest rates of smoking and obesity in pregnancy than any other UK country

- The cause of still birth is unknown in the majority of cases. It is important to understand the impact of smoking and obesity on still birth rates, particularly in light of the known epidemiology of these risk factors such as rising levels of obesity in the population, and the higher rates of smoking in areas of deprivation.

- Supporting women to give up smoking during pregnancy through improved access to advice and NHS Stop Smoking services, and implementation of the NICE guidance systematically across Wales should be given the highest priority by the NHS and partners

- Women with a high BMI at the start of pregnancy should receive clinical care in line with NICE guidance[6] and CMACE[5] recommendations to minimise risks to mother and baby. This should include dietary interventions and advice on physical activity to minimise weight gain, improving outcomes for the pregnancy and subsequent pregnancies

- The public health role of the midwife and maternity services is vital to ensure the delivery of evidence based public health interventions

and partnership working to reduce the inequality that exists in still birth rates and other maternal and neonatal outcomes

- Partnership programmes targeted at areas of high deprivation such as Flying Start and Families First should ensure maternal obesity and maternal smoking are given a high priority within their work with communities and families. The NHS should work with partners to ensure accessible services exist in communities to support women before, during and after pregnancy

- Many health factors such as smoking and obesity in pregnancy are difficult to address once a pregnancy has started. The profile of the importance of preconception advice and support should be raised and opportunistic contacts with primary care, family planning and sexual health services should be maximised

- 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. A confidential enquiry focused on stillbirths is recommended, to gain insights into the main causes of stillbirth, to identify avoidable causes and to recommend improvements in clinical care and service provision.

## Background

The still birth rate in Wales is about 5 per 1,000 births and the rate has remained steady over the last 5 years, (about 200 babies a year in Wales)[1]. This is in contrast to the neonatal mortality rate in Wales which has declined from 4.1 per 1,000 live births in 1999 to 2.9 per 1000 live births in 2005 and has remained around this rate for the last 5 years. In the majority of cases the cause of stillbirth is not known. Stillbirth rates in Wales remain higher than in other European countries[1]

Rates of stillbirth are persistently higher in areas with high levels of deprivation[1,2]. Lifestyle factors are linked to deprivation and are an important contribution to health inequalities. Rates of smoking and obesity (both risk factors for stillbirth) have been shown to be higher in areas with high levels of deprivation[2].

A systematic review of major risk factors for stillbirth in high income countries has identified maternal overweight and obesity (body-mass index >25 kg/m2), advanced maternal age and maternal smoking as the highest ranking modifiable risk factors[3]. In the UK smoking accounts for up to 7% of all stillbirths but it is estimated that in disadvantaged populations maternal smoking contributes to up to 20% of stillbirths[1].

Smoking and obesity in particular have a high prevalence in the population and not only impact on rates of still birth, but are also linked to higher rates of miscarriage, maternal death, neonatal deaths, admission to neonatal care and low birth weight. The impacts on the use of maternity and neonatal services are significant[2]. These findings highlight the importance of public health initiatives to tackle smoking and obesity in women of reproductive age

In this paper we present the evidence for preventable risk factors associated with stillbirth and make recommendations for addressing these.

## Smoking in pregnancy

Wales has higher rates of smoking in pregnancy than any other UK country. Around a quarter (26%) of mothers in the UK smoked directly before or during their pregnancy. Smoking levels before or during pregnancy were highest in Wales (33%) and lowest in England (26%). Across the UK, one in eight mothers (12%) continued to smoke throughout pregnancy, and were still smoking after the baby was born. Mothers in Wales were most likely to smoke throughout their pregnancy (16%)[4].

Smoking in pregnancy is linked to a range of poor outcomes for mother and baby, including increased risk of stillbirth. A recent report by Public Health Wales, prepared as part of the Early Years Pathfinder Programme (see Appendix 2), has identified the population attributable risks associated with smoking in pregnancy from the available evidence[4] (see Table 1). This evidence suggests that 4-7% of all stillbirths can be attributed to maternal smoking.

## Table 1 – Outcomes associated with smoking during pregnancy[4]

| **Outcomes associated with cigarette smoking during pregnancy** | **Population attributable risk** **(Proportion of outcomes that could be attributed to maternal smoking in pregnancy based on data from studies carried out in the UK.** |
|---|---|
| Ectopic pregnancy | 8% |
| Low birth weight | 10% |
| Preterm birth | 13% |
| Premature rupture of the membranes | 11% |
| Placenta praevia | 14% |
| Placental abruption | 13% |
| Low birth weight | 10% - 27% |
| Small for gestational age | 25% |
| **Stillbirth** | **4-7%*** |
| Sudden Infant death syndrome | 26% |
| Respiratory distress | 10% |

*Based on results from a range of studies in high income countries

The evidence review conducted as part of the Public Health Wales report found that high quality evidence exists to support the effectiveness of interventions for promoting smoking cessation in pregnancy[4]. This evidence base, set out in NICE guidance, is not currently being fully implemented in a robust, coordinated and systematic way by the NHS in Wales. The report makes a series of recommendations including the need to ensure:

- Smoking in pregnancy is the highest priority area for public health action for the NHS in Wales.

- Health Boards, Public Health Wales/Stop Smoking Wales and Welsh Government work together in an integrated way to ensure the robust, systematic and coordinated implementation of the evidence base on smoking in pregnancy

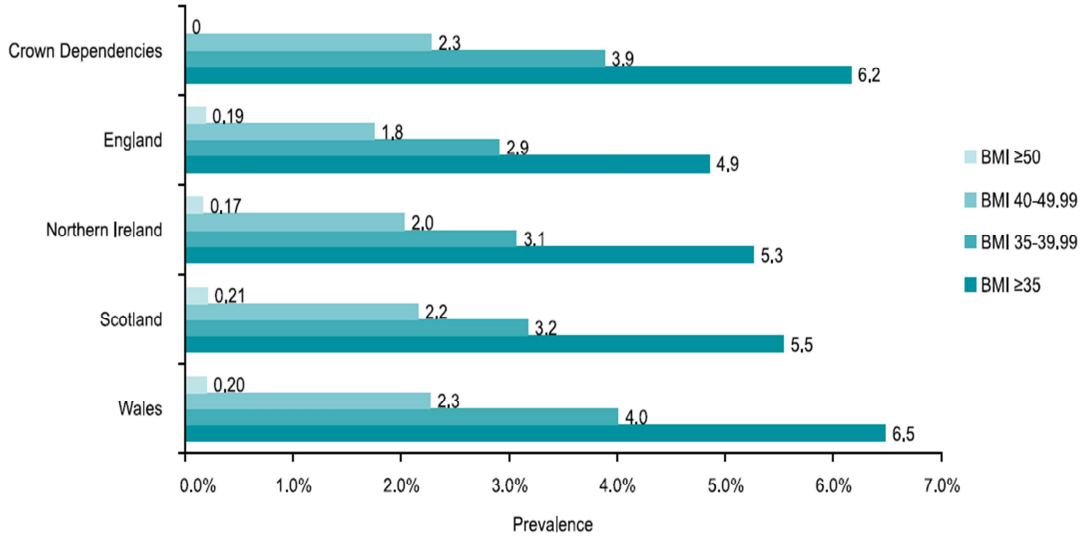
The recommendations arising from this report are being taken forward by Public Health Wales, in partnership with Health Boards. It is vital that these actions be prioritised by all partners and strongly supported by Welsh Government to ensure systematic implementation of NICE guidance and the development and implementation of better service models to increase uptake of Smoking Cessation services by pregnant women

## Maternal Obesity

Over half the population of Wales are currently overweight or obese (BMI >25). The 2010 Centre for Maternal and Child Enquiries report Maternal Obesity in the UK found that 6.5% of pregnant women in Wales had a BMI of 35 or more, compared to the UK average of 5% (see figure 1)[5]. Wales has the highest prevalence of maternal obesity of all the UK countries[5]. Obesity in pregnancy is currently one of the biggest threats to maternal and child health in developed countries. Women who are obese are more than twice as likely to have a stillborn baby, and the risk increases with increasing maternal BMI (see Table 2). Babies born to obese mothers are less likely to be breast fed, more likely to have congenital anomalies, especially neural tube defects, and to require admission to neonatal units. It is also more difficult to monitor the health of these babies during pregnancy and birth[5].

The mother's health is also at risk, as they are more likely to have pregnancy-related complications such as gestational diabetes, pre-eclampsia, haemorrhage following birth, thromboembolism and deliver their babies by caesarean section[5].

**Figure 1: Rates of Maternal Obesity in the UK**




Source: CMACE 2010

**Table 2: Fetal Risks associated with Maternal BMI >30**

| Risk | Odds Ratio |
|---|---|
| **Birth Defects** | **1.6** |
| **Prematurity** | **1.2** |
| **Macrosomia** | **2.4 – 3.1** |
| **Admission to NNU** | **1.3 – 1.5** |
| **Still Birth** | **2.1** |
| **Neonatal Death** | **2.6** |

Source: CMACE

The recent CMACE 3 year study into maternal obesity in the UK, highlights the scale of the issue and makes a series of recommendations in relation to the safe clinical management of pregnant women with raised BMI in

pregnancy[5]. It is important that Health Boards are taking forward these recommendations as part of clinical pathways in order to ensure risks of still birth (and other adverse outcomes associated with raised BMI) are minimised.

The Public Health Wales Early Years pathfinder programme is currently preparing a briefing paper, similar to that completed for Smoking in pregnancy which will set out the epidemiology, evidence base, population health impact and current situation in Wales in relation to maternal obesity. It will be important for the NHS to work in partnership to take forward these recommendations.

## The Way Forward

Still birth rates in Wales have not fallen in recent years. In the majority of cases, the cause of still birth is unknown. It is important to understand the impact that some of these preventable risk factors are having on still birth rates, particularly in light of the known epidemiology of these risk factors such as rising levels of obesity in the population, and the higher rates of smoking in areas of deprivation. A confidential enquiry into still birth rates in Wales would facilitate this understanding and identify areas for improvement.

Supporting women to give up smoking during pregnancy through improved access to advice and services, and implementation of the NICE guidance systematically across Wales should be given the highest priority by the NHS and partners.

Women with a high BMI at the start of pregnancy should receive clinical care in line with NICE guidance[6] and CMACE[5] recommendations to minimise risks to mother and baby. This should include dietary interventions and advice on physical activity to minimise weight gain, improving outcomes for the pregnancy and subsequent pregnancies[5,6].

The public health role of the midwife and maternity services is vital to ensure the delivery of evidence based public health interventions and partnership working to reduce the inequality that exists in still birth rates and other maternal and neonatal outcomes such as miscarriage, low birth weight and pre term births. There is a strong policy context for this[7,8] and a high priority should be given to ensuring staff working in maternity services have the skills and time to deliver the public health agenda.

Partnership programmes targeted at areas of high deprivation such as Flying Start and Families First should ensure addressing maternal obesity and maternal smoking is given a high priority within their work with communities and families. The NHS should work with partners to ensure accessible services exist in communities to support women before, during and after pregnancy

It is vital for women to be healthy at the start of pregnancy. This will significantly impact on the outcome of the pregnancy for both mother and baby. Many health factors such as smoking and obesity in pregnancy are difficult to address once a pregnancy has started. It is more effective if advice and behaviour change occur before conception. The latest Centre for Maternal and Child Enquiries report on maternal deaths highlights the benefits of providing targeted support and pre-pregnancy counselling to women with epilepsy, obesity, known significant mental ill health and congenital heart disease[9]. Whilst this advice is available from all GPs, midwives and health visitors there is a need for more proactive targeting of this advice to those who need it most. The profile of the importance of preconception advice and support should be raised and opportunistic contacts with primary care, family planning and sexual health services should be maximised.

Recommendations arising from the work of the Early Years Pathfinder Programme will support Health Boards in the implementation of the evidence base in relation to maternal smoking, obesity and preconception.

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# Appendix 1 – Background: Public Health Wales

Public Health Wales is an NHS organisation providing professionally independent public health advice and services to protect and improve the health and wellbeing of the population of Wales. Public Health Wales has four statutory functions:

- To provide and manage a range of public health, health protection, healthcare improvement, health advisory, child protection and microbiological laboratory services and services relating to the surveillance, prevention and control of communicable diseases;

- To develop and maintain arrangements for making information about matters related to the protection and improvement of health in Wales available to the public; to undertake and commission research into such matters and to contribute to the provision and development of training in such matters;

- To undertake the systematic collection, analysis and dissemination of information about the health of the people of Wales in particular including cancer incidence, mortality and survival; and prevalence of congenital anomalies; and

- To provide, manage, monitor, evaluate and conduct research into screening of health conditions and screening of health related matters.

Public Health Wales is currently taking forward an **Early Years Pathfinder Programme** to drive forward improvements in early years outcomes in Wales.

**Appendix 2: Smoking in Pregnancy: Briefing Paper**

# Smoking in Pregnancy: Briefing Paper Reproductive and Early Years Pathfinder Project

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**Date:** 21 March 2012

**Version:** Oe

**Publication/ Distribution:**

- **CONFIDENTIAL, INTERNAL PHW DISTRIBUTION ONLY**

**Review Date:**

**Purpose and Summary of Document:**

- Summarise evidence base on smoking in pregnancy
- Summarise likely impact of implementing evidence base on population health outcomes
- Provide overview on current service delivery in Wales

**Work Plan reference: Reproductive and Early Years Pathfinder Programme**

# Summary of key findings

- Smoking in pregnancy is associated with increased risk of miscarriage, perinatal death, prematurity, low birth weight and congenital anomalies in the baby in particular of the heart, face and limbs

- Wales has higher rates of smoking in pregnancy than any other UK country

- Estimation of trends in cigarette smoking prevalence in Wales and in sub-sections of the population are hampered by the lack of good quality routinely collected information

## Evidence Base

- High quality evidence exists on the effectiveness of interventions for promoting smoking cessation in pregnancy. This evidence base is not currently being fully implemented in a robust, coordinated and systematic way by the NHS in Wales

- Smoking cessation interventions can reduce smoking in late pregnancy by 3-6%

- Smoking cessation interventions can reduce low birthweight (RR 0.83, 95% CI 0.73 to 0.95) and preterm birth (RR 0.86, 95% CI 0.74 to 0.98), and increase mean birth weight by 53.91g (95% CI 10.44 g to 95.38 g). Four week quit rates for pregnant women using NHS Stop Smoking Services are 32-48%

- Smoking cessation interventions should be implemented in all maternity care settings and population based measures to reduce smoking and social inequalities should be supported

- Women in the UK under report smoking and CO monitoring can aid in the identification of smokers and support referral into NHS Stop Smoking Services

- There is insufficient evidence to conclude whether or not NRT is effective when used in pregnancy

- Financial incentives have been shown to be significantly more effective than other intervention strategies in US based research. Rigorous UK-based research is needed

- Professional barriers to supporting pregnant women include; health professionals not asking about smoking status for fear of damaging the relationship with the pregnant woman, limited knowledge on guidelines/protocols, staff perception that they have limited skills and knowledge, staff perception of lack of time and staff perception of the limited effectiveness of interventions

- Barriers for pregnant women are length of sessions, difficulty making phone contact, lack of transport or child care. Fear of failure, beliefs about control and concerns about being stigmatised have also been described as important barriers

- There is limited high quality evidence that the site or setting of the intervention (e.g. clinic based or home) influences the effectiveness of smoking cessation interventions for pregnant women in the UK

- There is limited high quality evidence in relation to effectiveness of midwives in delivering the intensive support as part of the Stop Smoking team

- Service evaluations from England and Scotland suggest flexibility around the site and setting and clinical staff delivering the intervention can improve engagement with the client, facilitate access to NRT and subsequently improve outcomes. Further high quality evidence is needed on this

- Using the NICE costing model[6]we estimate that 23 of 3368 cases of complications for the mother and the baby could be avoided each year (cost avoided to the NHS of £443,064), if uptake of stop smoking services for pregnant women increased from 11% to 25%.

# Summary of Key Recommendations

Due to the health, social and economic impacts smoking in pregnancy should be the highest priority area for public health action for the NHS in Wales.

- Health Boards, Public Health Wales/Stop Smoking Wales and Welsh Government should work together in an integrated way to improve services and ensure uptake of smoking cessation in pregnancy are increased to 25%. In particular ensuring:
    - Strong leadership from maternity services with a senior midwife identified in each Health Board area to work with Public Health Wales and Stop Smoking Wales to implement the evidence base.
    - Establish consistent data recording and collection to establish the baseline, monitor outcomes and the impact of service changes.
    - Improved referral systems and processes in place for all pregnant smokers to
    - Access to brief intervention/motivational interviewing training for midwives and support staff in all Health Boards, to address a suite of behavioural risks including smoking during pregnancy, as part of making every contact count
    - A review of the service model delivered by SSW to pregnant smokers, ensuring implementation of evidence base in order to maximise outcomes.

  **ACTION: A task and finish (5x5) group on tobacco has been set up to take this work forward.**

- Consideration should be given to undertaking a social profiling exercise in Wales in order to establish who the different groups of women who smoke are and what are the individual motivations/barriers, in order to target evidence based interventions accordingly.

  **ACTION: Once the data issues above are resolved we aim to complete this work by June 2013**

- Consideration should be given to how the NHS works in a more and integrated way on this key priority area, with a seamless approach to joint working across all NHS services and partner agencies. In particular the value of working with other agencies such as ASH Wales needs to be explored.

  **ACTION: Implementation plan to be developed autumn 2012.**

# 1 Background

The prevalence of smoking in the female population and the variation of smoking levels between the most and least deprived areas are important factors influencing maternal and child health outcomes within a population[1]. Maternal smoking is a key cause of poor outcomes for mothers, babies and children. Smoking in pregnancy is associated with increased risk of miscarriage, perinatal death, prematurity, low birth weight and congenital anomalies in the baby in particular of the heart, face and limbs[2]. In developed nations, the single most important factor that affects low birth weight is cigarette smoking during pregnancy[1,2].

Wales has higher rates of smoking in pregnancy than any other UK country. Around a quarter (26%) of mothers in the UK smoked directly before or during their pregnancy. Smoking levels before or during pregnancy were highest in Wales (33%) and lowest in England (26%). Across the UK, one in eight mothers (12%) continued to smoke throughout pregnancy, and were still smoking after the baby was born. Mothers in Wales were most likely to smoke throughout their pregnancy (16%)[3].

The smoking habits of teenage girls are a particular cause for concern as smoking rates in this group continue to increase despite a downward trend in all other areas. This will have a direct impact on future smoking in pregnancy rates[2].

Supporting pregnant women to stop smoking is a challenging area of public health and the numbers of women supported by NHS stop smoking services is low[4,5]. A study from Scotland found that in 2006 only 3.2% of identified pregnant smokers quit[5].

This briefing paper, developed as part of the Public Health Wales, Reproductive and Early Years Pathfinder Project, aims to give an overview of the evidence base on what works to support pregnant smokers to quit, what the implications would be for population health in Wales if this evidence was implemented in a robust and systematic way and an overview of how services are currently configured in Wales and progress towards implementing evidence based practice. It is hoped this paper will

guide the future development of services and support for pregnant women in order to maximise health outcomes for mothers and babies.

## Epidemiology of cigarette smoking during pregnancy in Wales

Cigarette smoking during pregnancy is associated with adverse perinatal outcomes for the mother and baby as illustrated in Table 1 below.

### Table 1 – Outcomes associated with smoking during pregnancy

| Outcomes associated with cigarette smoking during pregnancy | Population attributable risk (Proportion of outcomes that could be attributed to maternal smoking in pregnancy based on data from studies carried out in the UK. |
|---|---|
| Ectopic pregnancy | 8% [6] |
| Low birth weight | 10% [6] |
| Preterm birth | 13% [7] |
| Premature rupture of the membranes | 11% [6] |
| Placenta praevia | 14% [6] |
| Placental abruption | 13% [6] |
| Low birth weight | 10% [6], 27% [7] |
| Small for gestational age | 25% [7] |
| Stillbirth | 4-7%* [9] |
| Sudden Infant death syndrome | 26% [6] |

| | |
|---|---|
| Respiratory distress | 10% [6] |

*Based on results from a range of studies in high income countries[9]

The longer term impacts on the child from smoking during pregnancy include asthma[10], upper respiratory infections[10], behavioural problems[10], the effects of preterm birth such as neuro-developmental problems[11], the effects of low birth weight such as coronary heart disease and diabetes in adulthood[11].

Women who did not smoke during pregnancy were less likely to have a preterm birth (5.9% vs. 8.2%) or to give birth to a low birth weight baby (5.5% vs. 8.9%) than women who smoked at some time during the year before birth[(10)]. There was a reduction in the proportion of preterm births (6.7% vs. 9.1%) and low birth weight infants (7.9% vs. 9.6%) for women who quit smoking within the first trimester, compared with women who smoked beyond the first trimester[(10)]. Women who smoked during the first two trimesters of pregnancy had a 90% increase in risk for placenta praevia (OR = 1.9 [95% CI, 1.2–3.0]) than women who did not smoke during pregnancy[(10)]. The risks of small for gestational age births increased with the number of cigarettes smoked during the third trimester. The impact of smoking on low birth weight can be lessened if women quit before their third trimester. Similarly, for studying fetal growth restrictions, knowledge of smoking habits during the third trimester, the time when most of the growth in the fetus occurs, is of critical importance[(10)].

Emerging evidence suggests that reducing exposure to smoke during pregnancy improves outcomes at a population level, with a recent Scottish study highlighting findings suggesting that the introduction of national, comprehensive smoke free legislation was associated with significant reductions in pre term births and babies being born small for gestational age[20]

The UK Infant feeding survey estimates 33% of women in Wales smoke before or during pregnancy, and 16% smoke throughout pregnancy. This varies according to social class with higher prevalence in lower social classes. Across the UK, mothers in managerial and professional occupations were the least likely to have smoked before or during pregnancy (14%) whilst those in routine and manual occupations were the most likely to have done so (40%). Mothers in routine and manual occupations were five times more likely than those in managerial and

professional occupations to have smoked throughout pregnancy (20% and 4% respectively)[3].

Estimation of trends in cigarette smoking prevalence in Wales and in sub-sections of the population are hampered by the lack of good quality routinely collected information. Although all women are usually asked at their antenatal booking appointment about cigarette smoking and this information is recorded in their hand-held antenatal notes, this is not consistently reported to the local Child Health Systems across Health Boards, resulting in patchy completeness of data collected at a national level within The National Community Child Health Database (NCCHD) (Table 2). This data completeness issue is being addressed by an ongoing data quality improvement agenda by the NCCHD Steering Group. Further information of referral to smoking cessation services, or smoking status during late pregnancy is not recorded. It is important that we resolve these issues around data quality and completeness at a national level to enable more detailed analysis and social profiling of smoking during pregnancy to inform the targeting of services.

**Table 2 – Data completeness and maternal smoking prevalence by Health Board, Wales**

| Health Board | Total births | Data completeness (%) | Smoking prevalence (%) |
|---|---|---|---|
| Cwm Taf | 4253 | 94% | 26% |
| BCU | 6939 | 91% | 21% |
| Hywel Dda | 3438 | 52% | 14% |
| ABMU | 6365 | 23% | 8% |
| CVU | 6233 | 9% | 99% |
| AB | 6088 | 1% | 14% |

| | | | |
|---|---|---|---|
| Powys | 157 | 99% | 21% |

Source: NCCHD 2010

# 2 Methodology

### Overview of the evidence

The overview of the evidence presented in this paper was undertaken using a pragmatic high level search of key sources.

The Public Health Wales ATTRACT team undertook a series of literature searches to answer the following questions:

- What are the most effective interventions to support women to stop smoking during pregnancy?
- How effective are midwives at delivering smoking cessation interventions to pregnant women?
- What are the best models of service delivery for smoking in pregnancy services?
- Are home visits to support women to stop smoking in pregnancy more effective than clinic based interventions?
- How effective are pharmacists in supporting pregnant women to give up smoking?

In addition, the recently published National Institute for Health and Clinical Excellence (NICE) public health guidance 26 – How to stop smoking in pregnancy and following childbirth[4] was reviewed at length by the ATTRACT team and authors of this paper, and the key findings from the NICE evidence review are highlighted.

### Impact of implementing the evidence base on population health outcomes

The NICE Costing Template, a tool published as part of the NICE guidance 26 was used to estimate the economic and population health impact of smoking in pregnancy.[6]. The template estimates the potential number of cases and cost savings that would result in Wales, assuming there is no difference in the prevalence of these outcomes between England and Wales or uptake of smoking cessation services. We acknowledge that this model is limited as it does not take account of the wider health and social impacts of cigarette smoking and at best will provide a conservative estimate.

### Overview on current service delivery and outcomes in Wales

A mapping exercise was completed in August 2011 as part of the pathfinder project. This involved asking all Health Board's in Wales about the early years' interventions currently in place. This included smoking in pregnancy interventions and the mapping document is used to describe current practice in Wales and progress with implementation of the evidence base (Appendix 1). There were several limitations to this exercise. It was extremely difficult to compile a list of early interventions across Wales as there is no system or resource that captures this information. Collecting the information took a huge amount of chasing and the accuracy very much depended on interviewing the right individual in each Health Board about each intervention. Consequently there were some gaps, and it isn't possible to know if this is because interventions are not in place or that the right individual was not interviewed. Also the information provided by Health Board's was a snap shot, and developments in the individual areas are happening all the time. Regular surveys would be needed to capture progress on key programmes.

# 3 Overview of Evidence Base

## 3.1 Effectiveness of smoking cessation interventions in pregnancy

The evidence on the effectiveness of smoking cessation interventions has recently been reviewed and described in detail by NICE in public health guidance 26 – How to stop smoking in pregnancy and following childbirth[4]. The NICE evidence review found that there is high quality evidence on the effectiveness of interventions for promoting smoking cessation in pregnancy. A recently updated Cochrane review, showed a significant reduction in smoking in late pregnancy following interventions (risk ratio (RR) 0.94, 95% confidence interval (CI) 0.93 to 0.96), an absolute difference of six in 100 women who stopped smoking during pregnancy. When the review looked at the studies with the lowest risk of bias only, the interventions had less effect (RR 0.97,95% CI 0.94 to 0.99). Using the results of this systematic review it can be estimated that smoking cessation interventions can reduce smoking in late pregnancy by 3-6%[11].

The Cochrane review found that smoking cessation interventions reduced low birthweight (RR 0.83, 95% CI 0.73 to 0.95) and preterm birth (RR 0.86, 95% CI 0.74 to 0.98), and there was a 53.91g (95% CI 10.44 g to 95.38 g) increase in mean birthweight. There were no statistically significant differences in neonatal intensive care unit admissions, very low birthweight, stillbirths, perinatal or neonatal mortality but these analyses had very limited power. Appendix 2 gives a summary of the evidence on effect sizes resulting from individual smoking cessation interventions in pregnancy.

The Cochrane review concludes that smoking cessation interventions should be implemented in all maternity care settings and that population based measures to reduce smoking and social inequalities should be supported[11].

NICE reports good evidence to support that women in the UK under report smoking and that CO monitoring can aid in the identification of smokers and support referral into NHS Stop Smoking Services[4]. The evidence supports the role of NHS Stop Smoking Services and indicates that they are effective in supporting women to stop smoking. Four UK studies on outcomes, reported 4 week quit rates of 32-48% for pregnant women using NHS Stop Smoking Services[4]. A Scottish review of smoking cessation services for pregnancy did find that there was large variation in the reach and effectiveness of services, with some areas offering no tailored support[4].

The evidence supports the use of self help interventions to aid cessation in pregnant women, although the extent of UK evidence was found to be limited[4].

**Effectiveness of Nicotine Replacement Therapy in Pregnancy (NRT)**

The NICE review found that there was mixed evidence on the effectiveness of Nicotine Replacement Therapy (NRT) in pregnancy[4]. The Cochrane review conducted a meta-analysis on five trials and found NRT to be effective (RR 0.95, 95% CI 0.92 to 0.98). However a subsequent meta-analysis carried out to support development of the NICE guidance[12] concluded that the Cochrane review does not provide the most accurate possible estimate for the safety and effectiveness of NRT as:

- A large double blind placebo randomised trial has been published since and its findings need to be considered.

- The Cochrane reviews synthesises data from trials with multi-modal intervention strategies which often involve a number of different interventions being delivered. Whilst this permits maximum use of available research data, it is not necessarily an appropriate strategy for determining the effectiveness of the individual interventions.

- Cochrane analyses include one trial in which NRT was offered to women as part of a multi-modal treatment strategy and in which the level of behavioural support for smoking cessation offered in addition to NRT in the intervention group was substantially higher than the amount offered in the "routine care control group". As behavioural support is an effective treatment for smoking cessation in pregnancy, the inclusion of this trial has probably resulted in an over-estimate of the effectiveness of NRT in both the current and previous Cochrane reviews.

In the updated meta-analysis[12] findings of all trials suggest that NRT is effective for reducing smoking in later pregnancy [RR, 95% CI = 0.92 (0.87, 0.98)], but that all of the evidence for NRT being effective comes exclusively from the trials which are at highest risk of bias (non-placebo randomised studies [RR, 95% CI = 0.87 (0.81, 0.94)]). The most robustly designed trials (placebo randomised,) provide no evidence that

NRT is effective for smoking cessation in pregnancy [RR, 95% CI = 0.94 (0.87, 1.02)]. See Appendix 3 for results of this meta analysis.

The NICE evidence briefing also concluded that there is no evidence that NRT either increases or decreases low birth-weight and that there are insufficient data to form judgements about any impact of NRT on stillbirth or special care admissions[12]. Consequently there is currently insufficient evidence to conclude whether or not NRT is effective when used in pregnancy. A recent large, double blind placebo controlled trial of NRT in pregnancy conducted in England (SNAP) found that adding a nicotine patch (15 mg per 16 hours) to behavioural cessation support for women who smoked during pregnancy did not significantly increase the rate of abstinence from smoking until delivery or the risk of adverse pregnancy or birth outcomes. However, low compliance rates substantially limited the assessment of safety[21]

A statement from the UK teratology service on the use of NRT in pregnancy states[13]:

"Tobacco use and exposure through passive smoking during pregnancy is associated with an increased risk of intrauterine growth retardation, cleft lip and/or palate, ectopic pregnancy, spontaneous abortion, premature delivery, perinatal mortality and poor postnatal development.

The first choice treatment for tobacco use cessation during pregnancy would be through cognitive behavioural therapy (CBT). In non-pregnant populations, CBT combined with nicotine replacement therapy (NRT) has been shown to increase rates of tobacco use cessation.

Concerns exist over the efficacy and safety of NRT in pregnancy. An advantageous risk vs. benefit ratio has not, as yet, been adequately proven, however use of NRT may be preferable to continued fetal exposure to the many harmful constituents of tobacco smoke. The available data which investigate pregnancy outcomes, although limited, do not yet provide substantial evidence of an increased risk of adversity when NRT has been used during pregnancy.

Should CBT measures fail to control a patient's urge to use tobacco, NRT could be considered provided concomitant tobacco use is kept to an absolute minimum. When NRT is indicated it should be used at the lowest effective dose which controls symptoms of withdrawal and cravings".

**Effectiveness of financial incentives.**

The NICE guideline highlights that there is good evidence from the recent Cochrane review to support use of financial incentives in promoting smoking cessation in pregnancy. The meta analysis of the US based trials found that financial incentives were significantly more effective than other intervention strategies (RR 0.76, 95% CI 0.71 – 0.81)[4,11]. NICE state that rigorous UK-based research is needed to take account of cultural differences and stress the need to avoid a proliferation of local evaluations which may be insufficiently powered or inappropriately designed to determine whether incentives are effective[4].

## 3.2 Barriers to smoking cessation in pregnancy

There have been a number of qualitative studies looking at the barriers to pregnant women stopping smoking[4,11,14,15,16]. The professional barriers to supporting pregnant women to stop smoking have been described as; health professionals not asking about smoking status for fear of damaging the relationship with the pregnant woman, limited knowledge on guidelines/protocols in place, staff perception that they have limited skills and knowledge to implement successful interventions, staff perception of lack of time and staff perception of the limited effectiveness of interventions[4,11]. It has been suggested that the use of Numbers Needed to Treat (NNT) rather than absolute risk reduction data to express the efficacy of smoking cessation in pregnant women could help to overcome the pessimism of staff over the high failure rate. Data from systematic reviews suggest NNT's of between 17 and 33[11] which could be used in conjunction with data on success rates of NHS specialist services to encourage referral by staff[4,11].The barriers for pregnant women to stopping smoking have been described as length of sessions, difficulty making phone contact, lack of transport or child care[4,14,15]. Home visits or very local services and the provision of crèche facilities have been suggested as possible service options in order to address some of these barriers[14]. This is supported by NICE who recommend that home visits or alternative venues should be considered for those women who are reluctant to or find it difficult to attend the clinic[4]. Fear of failure, beliefs about control and concerns about being stigmatised have also been described as important barriers[15,16].

Consideration should be given to undertaking a social profiling exercise in Wales in order to establish who the different groups of women who smoke are and what are the individual motivations/barriers, in order to target the evidence based interventions accordingly

## 3.3 Models of service delivery

Following an extensive review of the evidence, NICE make the following recommendations in relation to the model of service delivery that should be in place to support women to stop smoking during pregnancy[4]:

**Role of Midwives at booking and subsequent appointments:**

- Assess woman's exposure to tobacco smoke through discussion and use of CO monitoring.

- Discuss health risks, benefits of stopping smoking and provide information.

- Refer all pregnant smokers, those with CO reading >7 ppm and those stopped in previous two weeks to NHS Stop Smoking Services on opt out basis using NICE referral pathway.

- All midwives should be trained in assessing and recording smoking status and readiness to quit, discussing health risks and making a referral into the local Stop Smoking Service. Midwives are not advised to carry out brief interventions, but should use their skills to initiate a referral into NHS Stop Smoking Services.

Other staff in wider health care team (GP's, Practice Nurses, HV's, Obstetricians, Paediatrician, Sonographers) should ask about smoking status at every opportunity and refer those who want to stop to the NHS Stop Smoking Service using local arrangements[4].

**Role of NHS Stop Smoking Services:**

- Attempt to contact woman by telephone twice and follow up with a letter.

- Attempt to see those who can't be contacted by phone. For example in a routine antenatal contact.

- Address any barriers to taking up smoking cessation services. Consider offering home visits or alternative locations for those who are reluctant or find it difficult to attend clinic.

- Feedback on individual clients should be given to the midwife.

- Provide intensive interventions and ongoing support throughout pregnancy and beyond (as detailed in NICE guidance).

- Discuss risks and benefits of NRT.

- For those women who are disadvantaged, the service should be offered in a flexible, client centred way. Interventions should be delivered in locations and times that mean they are accessible and tailored to individual needs. Services should work in an integrated way with other services such as substance misuse and teenage pregnancy support.

Evidence searches were undertaken by the ATTRACT team in order to answer the following questions:

- What are the most effective interventions to support women to stop smoking during pregnancy?

- How effective are midwives at delivering smoking cessation interventions to pregnant women?

- What are the best models of service delivery for smoking in pregnancy services?

- Are home visits to support women to stop smoking in pregnancy more effective than clinic based interventions?

- How effective are pharmacists in supporting pregnant women to give up smoking?

These searches found that there is limited high quality evidence that the site or setting of the intervention influences the effectiveness of smoking cessation interventions for pregnant women in the UK. There also appears to be little high quality evidence in relation to effectiveness of midwives in delivering the intensive support as part of the Stop Smoking team. The ATTRACT team found three papers[5,17,18] describing midwives delivering interventions, as part of the service. Two of these were evaluations of service delivery and one was an RCT of motivational interviewing approaches by midwives, which did not show significant increases in smoking cessation. NICE highlight that where midwives do deliver the intensive interventions they should be trained to the same standard as NHS stop smoking advisors[4].

There are a number of published evaluations of outcomes for smoking in pregnancy services in the UK. One mixed methods evaluation undertaken in Scotland found that most stop smoking services in Scotland offered home visits by trained advisers to pregnant women. An analysis of routine service data, suggested that for home based services for which data on engagement (whether a woman attended the first appointment with a specialist advisor) were available, about 50% of those referred engaged compared with 20% for clinic-based services[19].

An evaluation undertaken on the three beacon services in England found that those services that were delivering the best outcomes had several common features[17];

- Interventions delivered by small number of dedicated clinical staff (nurses or midwives)

- Full support from Heads of Midwifery

- Receive bulk of referrals from midwives

- Offer NRT to almost all pregnant smokers and have an efficient system for providing the prescriptions (eg PGD's)

- Offer flexible home visits

- Provide intensive multi session treatment delivered by small number of full time staff

Another evaluation of a service for young pregnant smokers highlighted the importance of good integration between maternity services and Stop Smoking Services. Although numbers participating were small, the project pointed to the value of midwife led home visits in engaging this group of women[18].

An observational study undertaken in Scotland, using routinely collected data found that a very low proportion of pregnant smokers are supported to quit in Scotland (3.2%)[5]. Poor outcomes were attributed to issues along the whole pathway in relation to identification, engagement and treatment[5]. The study suggests CO monitoring can be useful in encouraging midwives to ask about smoking and in addressing under reporting. A greater proportion of women set a quit date and quit when interventions were delivered at home. Costs were higher with home visits[5].

The ATTRACT team found very little evidence on the effectiveness of pharmacists in supporting pregnant women to stop smoking. This is one of a number of areas identified as needing further research.

## 3.4 Population health and economic impacts of implementing evidence base on smoking cessation in pregnancy

Using the NICE costing template it is possible to model the population health and economic impacts of increasing the uptake of women receiving NHS stop smoking support[6]. Table 3 models how many more women could be supported to quit in Wales if the uptake of smoking services increased to 25%. There are several assumptions that have been used in this model. Smoking prevalence is assumed to be 33%, taken from the infant feeding survey[3] and the current uptake of pregnant women

receiving support has been estimated at 11% using data from NHS Stop Smoking services in England. Data from one Health Board in Wales suggests that uptake of Stop Smoking Services by pregnant women is currently a lot lower than England (<5%). More work is being done to develop more robust data on uptake at an all Wales level. A sensitivity analysis has been carried out to model the assumptions at different levels of smoking prevalence and uptake of smoking cessation services (see Appendix 4)

**Table 3 Service delivery Statistics – Local assumptions**

| | Percentage | Number of people |
|---|---|---|
| Number of pregnant women | 100% | 34937 |
| Smoking prevalence in pregnancy[1] | 33% | 11529 |
| Current uptake of pregnant women receiving NHS stop smoking support[2] | 11% | 1268 |
| Future uptake of women receiving NHS Stop Smoking support[3] | 25% | 2882 |
| Additional pregnant women receiving NHS support | 14% | 1614 |
| Number of women successfully quitting smoking as a result of contact with NHS services[4] | 45% | 726 |
| Pregnant women who stopped as a % of all women who smoke[5] | 6.3% | 726 / 11,529 |
| Estimated number of births to women who smoke | 33% | 11,529 |

1. This is the percentage of women who smoked before or during pregnancy in Wales in 2010 from the Infant Feeding Survey 2010 http://www.ic.nhs.uk/webfiles/publications/003_Health_Lifestyles/IFS_2010_early_results/IFS_2010_headline_report_tables2.pdf

2. This is an estimate based on 188,023 pregnant women smoking in England (26% of 723,165 live births) in England in 2010 and 21,839 pregnant women in England setting a quit date in 2010/11 from Statistics on NHS Stop Smoking Services: England, April 2010-March 2011 http://www.ic.nhs.uk/webfiles/publications/003_Health_Lifestyles/NHS%20Stop%20Smoking%20Services%20201011/SSS_2010_11.pdf
3. This is an estimate for future uptake of NHS Stop Smoking services
4. This is an estimate for Wales based on the percentage of pregnant women who are successful quitters at 4 weeks in England from the NHS Stop Smoking Services report above. The number is 45% of 2306, the additional women who contact Stop Smoking Services if uptake is increased to 25%.
5. This is calculated by taking 1,038 as a percentage of 11,529, the number of additional quitters as a percentage of those women who smoke during pregnancy.we have used the number of live births
6. The number of pregnant women was taken as the number of live births, so the number of births to women who smoke is the same as the number of pregnant women who smoke.

Assuming that the prevalence of the complications is the same in Wales as in England, the following table estimates the number of cases with infant and maternal complications. It also estimates the number of cases due to smoking using Population Attributable risks. If the uptake of stop smoking services for pregnant women increased to 25% then it is estimated that 6.3% of all pregnant women who smoke will quit. Population Attributable risks have been calculated from these figures and used to estimate the number of complications due to smoking. The calculations below estimate that an uptake of 25% would result in 234 out of 3368 maternal or infant complications being avoided.

**Table 4 Maternal and infant complications: general cases in pregnancy and associated cases due to smoking.**

| | | Estimate of number of cases based on births[1] | Cases due to smoking |
|---|---|---|---|
| Maternal Complications | Ectopic pregnancy | 182.80 | 9.71 |
| | Premature rupture of membranes | 1045 | 79.23 |

| | | | |
|---|---|---|---|
| | Placenta Praevia | 70 | 7.32 |
| | Abruption placenta | 43 | 3.97 |
| | Pre-term delivery | 614 | 46.46 |
| | Pre-eclampsia | 214 | -5.56 |
| | Total Maternal complications | **2171** | **141.01** |
| Infant Complications | Low birth weight | 791 | 55.56 |
| | Respiratory distress | 336 | 23.62 |
| | Sudden Infant Death Syndrome (SIDS) | 70 | 13.71 |
| | Total Infant complications | **1197** | **92.89** |
| | Total | 3368 | 233.89 |
| | Total cases that could be avoided | | **234** |

These calculations estimate that £443,064 could be saved in a year in Wales if uptake of stop smoking services for pregnant women increased to 25%. This is illustrated in Table 5. The NICE costing templates are set up to calculate direct costs to NHS, they do not take into account the medium and long term implications of some of these complications. The overall cost to society from smoking and pregnancy will be higher. An economic evaluation of smoking in pregnancy undertaken to support the NICE review found that all effective interventions were shown to reduce costs and increase Quality Adjusted Life Years (QALY), for both the mother and the child[22]. Furthermore, at a societal level, the net benefit (i.e. accounting for money and health gains), could be in excess of £500 million[22].

**Table 5 Savings from cases of maternal and infant complications avoided**

| | | Cases due to smoking | Unit cost £ [1] | Total cost £ |
|---|---|---|---|---|
| Maternal Complications | Ectopic pregnancy | 9.71 | 1081 | 10497 |
| | Premature rupture of membranes | 79.23 | 2679 | 212257 |
| | Placenta Praevia | 7.32 | 2679 | 19610 |
| | Abruption placenta | 3.97 | 2679 | 10636 |
| | Pre-term delivery | 46.46 | 2679 | 124466 |
| | Pre-eclampsia | -5.68 | 2679 | -15217 |
| | Total Maternal complications | **141.01** | | **362,249** |
| Infant Complications | Low birth weight | 55.56 | 870 | 48337 |
| | Respiratory distress | 23.62 | 870 | 20549 |
| | Sudden Infant Death Syndrome (SIDS) | 13.71 | 870 | 11928 |
| | Total Infant complications | **92.89** | | **80,814** |
| | Total savings | 233.9 | | **443,064** |

1 The unit costs are based on the NHS national tariff for 2010/11

The limitations of the NICE costing models for public health interventions are a subject of debate particularly due to the difficulty of obtaining robust utility scores for use in cost-effectiveness models. Further work is required to develop a more robust model that addresses the current limitations.

# 4.0 What is currently happening in Wales?

The mapping exercise carried during 2011 and completed in Aug 2011 asked all Health Boards in Wales to report progress on Smoking in Pregnancy. Three out of seven Health Boards reported to have the NICE opt out referral pathway in place, with one additional Health Board reporting that it is in place in 1 out of 3 of the locality areas. Three out of seven Health Boards reported having a lead midwife identified to champion implementation of the NICE guidance and act as a link between Stop Smoking Wales and the maternity service. One additional Health Board reported that this is in place in 1 out of 3 of the locality areas. Two out of seven Health Boards reported having bespoke smoking in pregnancy training for midwives in place (See Appendix 1). There were some limitations to this exercise (see methodology section) and caution should be applied to the interpretation of these findings.

In relation to the delivery of interventions to pregnant women by Stop Smoking Wales, the service currently offers the following:

- Referrals received by SSW from midwives. Advisors contact the pregnant women to discuss benefits of quitting, offer support and arrange assessment session

- SSW attempt to contact client twice by telephone, and send follow up letter if no response. Clients are fast tracked into an appointment to allow for the longest cessation period during their pregnancy

- Clients are offered sessions for intensive support at existing community based groups, on a one to one basis at a clinic/venue where SSW usually hold sessions, or support over the phone.

- Women are given 7 sessions of intensive support. If the client feels they are not ready to quit at the assessment session there is a four week flexibility within which time treatment can start.

- Risks/benefits of NRT are discussed in the sessions.

- If the client requires additional support following the seven sessions, the advisor will arrange to telephone in two weeks time to check progress.

There are several areas in relation to the service delivery model that are recommended by NICE that are not currently being implemented in Wales. These are:

- Carbon monoxide monitoring is not done routinely in Wales as part of the booking visit and NICE referral pathway.
- No attempts are made to see women i.e in antenatal clinics, if they are unable to be contacted by SSW.
- Women are not currently supported throughout their pregnancy and after delivery.
- There is variable practice in relation to feedback on the progress of individual clients from SSW to midwives.
- There is currently very little flexibility in the model of support for pregnant women in relation to offering sessions at home or at alternative venues for women who are disadvantaged, are reluctant or find it difficult to access the services on offer.

# 5.0 Conclusions

Smoking in pregnancy is a major preventable cause of poor outcomes and inequalities in maternal and child health in the short, medium and long term. Wales is doing worse than any other UK country in relation to the number of women that continue to smoke throughout pregnancy.

High quality evidence exists to support smoking cessation interventions in pregnancy, and there are key recommendations from NICE highlighting what NHS and partners should be providing as part of an effective, cost effective integrated system to support women to stop smoking during pregnancy. This evidence base is not currently being fully implemented in a robust, coordinated and systematic way across by the NHS in Wales.

Smoking in pregnancy is an extremely challenging area of public health. Evidence on the barriers to smoking cessation in pregnancy suggests that pregnant smokers are different to other adult smokers who are motivated to quit and self refer to SSW. There are practical issues with access to services, such as childcare. Rurality is a big issue for the population in Wales and services such as smoking cessation services need to be

provided as locally as possible. In addition, stigma, beliefs about control and the fear of failure are often reported by pregnant women as barriers to engaging with smoking cessation services. The NICE guidance and evaluations of services from other UK countries suggest that a flexible approach is needed for pregnant women, particularly those who are disadvantaged, with the services being offered in a client centred way throughout pregnancy and following childbirth.

Flexibility may also be required in relation to thinking about innovative and alternative ways to decrease levels of smoking in pregnancy at a population level, including the role of joint working with Welsh Government and agencies such as ASH Wales. There may be a number of different ways to support pregnant women to stop smoking. Strong evidence is emerging on financial incentive schemes which highlight an urgent need to evaluate these schemes in a UK setting. Other health professionals, such as pharmacists or other primary care staff, may have a role, particularly in rural or remote areas. Again, this needs further research. There are a number of areas where we don't have high quality evidence to support practice such as the site or setting of the interventions or the professional delivering the interventions (i.e. midwife vs. smoking cessation advisor). There are evaluations from England and Scotland that suggest that flexibility around the site and setting and clinical staff delivering the intervention can improve engagement with the client, facilitate access to NRT and subsequently improve outcomes; further high quality evidence is needed on this.

# 6.0 Recommendations

The following are the key recommendations arising from this paper:

- Due to level of harm to maternal and child health, and the evidence on effectiveness of cessation, smoking in pregnancy should be the highest priority area for public health action for the NHS in Wales.

- Health Boards, Public Health Wales/Stop Smoking Wales and Welsh Government should work together in an integrated way to ensure the robust, systematic and coordinated implementation of the evidence base on smoking in pregnancy. In particular ensuring:

- Strong leadership from maternity services with a senior midwife identified in each Health Board area to work with Public Health Wales and Stop Smoking Wales to implement the evidence base[4].

- Opt out referral pathways based on NICE guidance in place in each Health Board area to facilitate referral of all pregnant smokers into SSW[4].

- CO monitors are routinely used as part of the NICE referral pathway[4].

- Access to bespoke smoking in pregnancy training for midwives and support staff in all Health Boards[4].

- A review of the service model delivered by SSW to pregnant smokers, ensuring implementation of evidence base in order to maximise outcomes.

- A review of the availability of accurate data in order to establish the baseline, monitor outcomes and the impact of service changes.

- NHS and partners in Wales need to urgently consider areas for innovation and evaluation. Section 7 of this report includes areas for potential research and evaluation within smoking cessation in pregnancy.

- Consideration should be given to undertaking a social profiling exercise in Wales in order to establish who the different groups of women who smoke are and the differentials in uptake and prevalence among different socio-economic groups. Including what are the individual motivations/barriers, in order to target evidence based interventions accordingly.

- Consideration should be given to how the NHS works in a more and integrated way on this key priority area, with a seamless approach to joint working across all NHS services and partner agencies. In

particular the value of working with other agencies such as ASH Wales needs to be explored.

# 7.0 Areas for further research

This evidence review and that undertaken by NICE highlighted a number of important areas that require further high quality research to be undertaken in order to determine effectiveness:

- Site or setting used to deliver interventions for pregnant women.
- Financial incentive schemes in a UK setting.
- Increasing contact of smoking cessation services with pregnant women who smoke.
- Role of pharmacists in supporting pregnant women to stop.
- Self help interventions in a UK setting.
- How and why some women spontaneously quit smoking when they become pregnant
- Interventions across different socio-economic groups

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## Appendix 1 – Mapping of Smoking in Pregnancy Interventions in Health Boards across Wales

| Health Boards (HB) | **Progress with maternal smoking interventions** |
|---|---|
| HB A | - Smoking Cessation in pregnancy implementation group in place<br>- BI Training programme for midwives/HVs set up<br>- Lead midwife identified<br>- NICE Pathway agreed<br>- Fax referral mechanism has commenced<br>- Systems for data sharing between Stop Smoking Wales & midwives are starting to be set up |
| HB B | - Smoking and Maternity Smoking Cessation agreed as an outcome to 'Smoke Free UHB' Action Plan 2010-2011<br>- Midwifery Service has agreed to implement the SSW Maternity Smoking Cessation Programme and use the 'opt out' referral form at booking appointment which is carried out in a hospital setting<br>- Agreed to use SSW standardised 'opt out' referral form but want additional 'carbon copies' added to this<br>- Lead Midwife agreed<br>- 2 Brief Intervention for Smoking Cessation Training Courses held for Midwifery Care Assistants (MCAs) (who carry out 'booking' clinics) and Community Midwives.<br>- Programme officially launched February 2011<br>*Smokebugs*, *Assist* and *Smokefree Class Competition* initiatives in place for generic smoking prevention |
| HB C | - **<u>Locality 1</u>**<br>o Brief Intervention Training delivered to:<br>▪ 1st, 2nd and 18 month undergraduate student midwives at Swansea University August 2010, and a lecture was given to the new 1st year intake in December 2010 |

| | |
|---|---|
| | ▪ Teenstart Team (Midwives, Health visitors, Students, Community Nurses, Link Workers, etc.<br><br>o Awareness Raising Session delivered to Antenatal Day Assessment Unit<br><br>- **<u>Locality 2</u>**<br>o Task and Finish group established<br><br>o Awareness Raising Session delivered to Community Midwives and staff<br><br>o Launch of maternity referral pathway – August 2010 and ongoing<br><br>- **<u>Locality 3</u>**<br>o Deputy Head Midwife – Lead, member of Task and Finish Group<br><br>o Raising Awareness Sessions currently being delivered by SSW Practitioner<br><br>o Awaiting launch of referral pathway |
| HB D | - Working with Stop Smoking Wales<br><br>- Training in how to deliver 'brief interventions for smoking cessation' delivered to Sure Start Health Visitors<br><br>Midwives provide systematic brief interventions for smoking cessation |
| HB E | - Direct referral pathway in place to SSW<br><br>- Bespoke training delivered to midwifery staff. BI training programme for midwife/HV available<br><br>- Consultant midwife lead identified<br><br>- Systems for data sharing between SSW & midwives currently being established<br><br>Pharmacy-based generic community smoking cessation scheme also open to pregnant women |
| HB F | - Working with SSW for individual referrals.<br><br>- Roll out of National Smoking Cessation Pathway |

| | |
|---|---|
| | All Midwives & Health Visitors give information and support/ signposting to cessation services and inform about the risks of passive smoking with infants. |
| HB G | Routine referral to Stop Smoking Wales but no follow-up undertaken |

## Appendix 2 – Overview of evidence base on effect sizes of smoking cessation interventions in pregnancy

| Life course stage | Intervention | Effect size | Type of study | Comments | Source |
|---|---|---|---|---|---|
| Antenatal | All smoking cessation interventions | Absolute difference of 6% of women in intervention groups who quit smoking during pregnancy (RR 0.94, 95% CI 0.93, 0.96) | Meta-analysis of 65 RCTs, quasi-RCTs and cluster RCTs | High heterogeneity between interventions, even after subgroup analysis | Lumley et al, 2009 |
| Antenatal | Incentives to stop smoking | 24% reduction in smoking in intervention group (RR 0.76, 95% CI 0.71, 0.81) | Meta-analysis of 4 RCTs and quasi-RCTs | USA setting. Financial incentives might have a different impact in UK and further research required to explore applicability in UK (Bauld and Coleman, 2010). | Lumley et al, 2009 |
| Antenatal | Cognitive behaviour strategies | 5% reduction in smoking in intervention group (RR 0.95, 95%CI 0.93-0.97) | Meta-analysis of 31 RCTs, quasi-RCTs and cluster RCTs | | Lumley et al, 2009 |
| Antenatal | Nicotine replacement therapy | 5% reduction in smoking in intervention group (RR 0.95, 95%CI 0.92-0.98) | Meta-analysis of 5 RCTs and quasi-RCTs | No clear evidence of safety of nicotine replacement therapy in terms of perinatal outcomes | Lumley et al, 2009 |

| | | | | | |
|---|---|---|---|---|---|
| | | No reduction in smoking (RR 0.96, 95% CI 0.85-1.09) | RCT | Not included in Cochrane meta-analysis (Lumley et al, 2009). | Oncken et al, 2008 in Bauld and Coleman, 2010 |
| Antenatal | Stages of change theory (precontemplation, contemplation, preparation and action) | No evidence of effectiveness (RR 0.99 95%CI 0.97, 1.00) | Meta-analysis of 11 RCTs, quasi-RCTs and cluster RCTs | | Lumley et al, 2009 |
| Antenatal | Feedback | No evidence of effectiveness (RR 0.92, 95% CI 0.84-1.02) | Meta-analysis of 4 RCTs and quasi-RCTs | | Lumley et al, 2009 |
| Antenatal | Self-help interventions | Intervention group more likely to quit smoking compared with usual care 13.2% vs 4.9% (OR 1.83, 95% CI 1.23-2.73) | Meta-analysis of 12 RCTs and quasi-RCTs | All studies involved dissemination of written materials to participants | Naughton et al, 2008 in Bauld and Coleman, 2010 |
| Antenatal | NHS smoking cessation services | Quit rate of 20% at 3 months and 12.7% at one year (CO validated) | Mixed methods | Intervention consisted of behavioural support and motivational interviewing and NRT (Scotland) | Bryce et al, 2007 in Bauld and Coleman, 2010 |

| | | | | | |
|---|---|---|---|---|---|
| | | Quit rate 32% at 4 weeks (self reported) | Mixed methods | Intervention consisted of behavioural support and motivational interviewing and NRT (Scotland) | McGowan et al, 2008 in Bauld and Coleman, 2010 |
| | | Quit rate 0.4-5.4% at 4 weeks | Mixed methods | Reach and type of interventions varied (Scotland) | Macaskill et al, 2008 in Bauld and Coleman, 2010 |
| | | Quit rate 37-48% at 4 weeks at three Stop Smoking services | Qualitative | England | Lee et al, 2006 in Bauld and Coleman, 2010 |
| Antenatal | Exercise with behavioural support | Quit rate 25% at eight months gestation | Cross sectional study | Pilot study – 32 participants | Ussher et al, 2008 in Bauld and Coleman, 2010 |



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SNAP – Smoking, Nicotine and Pregnancy – trial underway

LEAP – London Exercise and Pregnant Smokers – trial underway

Trial of financial incentives for smoking cessation during pregnancy under proposal

## Appendix 3 – Results of meta-analysis of trials assessing effectiveness of NRT in pregnancy[12]

### Table 2 Nicotine replacement therapy for smoking cessation in pregnancy: all trials

| **Intervention** | | **Control** | | Risk Ratio | |
|---|---|---|---|---|---|
| Events | Total | Events | Total | Weight | MH, Fixed 95% CI |
| Kapur 2001 | 13 17 | 13 13 | | 5.0% | 0.78 [0.58, 1.03] |
| Hotham 2005 | 17 20 | 20 20 | | 6.7% | 0.85 [0.70, 1.05] |
| Pollak 2007 | 105 122 | 58 59 | | 25.7% | 0.88 [0.81, 0.95] |
| Wisborg 2000 | 102 124 | 109 126 | | 35.5% | 0.95 [0.85, 1.06] |
| Oncken 2008 | 82 100 | 80 94 | | 27.1% | 0.96 [0.85, 1.09] |
| **Total (95% CI)** | **383** | **312** | | **100.0%** | **0.92 [0.87, 0.98]** |
| Total events | 319 | 280 | | | |

Heterogeneity: Chi² = 4.26, df = 4 (P = 0.37); I² = 6%
Test for overall effect: Z = 2.80 (P = 0.005)

### Table 3 Nicotine replacement therapy for smoking cessation in pregnancy: placebo controlled trials

| **Intervention** | | **Control** | | Risk Ratio | |
|---|---|---|---|---|---|
| Events | Total | Events | Total | Weight | MH, Fixed 95% CI |
| Kapur 2001 | 13 17 | 13 13 | | 2.5% | 0.78 [0.58, 1.03] |
| Oncken 2008 | 82 100 | 80 94 | | 13.3% | 0.96 [0.85, 1.09] |
| Wisborg 2000 | 102 124 | 109 126 | | 17.4% | 0.95 [0.85, 1.06] |
| **Total (95% CI)** | **241** | **233** | | **33.1%** | **0.94 [0.87, 1.02]** |
| Total events | 198 | 201 | | | |

Heterogeneity: Chi² = 1.89, df = 2 (P = 0.39); I² = 0%
Test for overall effect: Z = 1.47 (P = 0.14)

### Table 4 Nicotine replacement therapy in pregnancy for smoking cessation: non-placebo controlled trials

| **Intervention** | | **Control** | | Risk Ratio | |
|---|---|---|---|---|---|
| Events | Total | Events | Total | Weight | MH, Fixed 95% CI |
| Hotham 2005 | 17 20 | 20 20 | | 6.7% | 0.85 [0.70, 1.05] |
| Pollak 2007 | 105 122 | 58 59 | | 25.7% | 0.88 [0.81, 0.95] |
| **Subtotal (95% CI)** | **142** | **79** | | **32.4%** | **0.87 [0.81, 0.94]** |
| Total events | 122 | 78 | | | |

Heterogeneity: Chi² = 0.05, df = 1 (P = 0.82); I² = 0%
Test for overall effect: Z = 3.60 (P = 0.0003)

## Appendix 4 – Sensitivity Analysis – economic modelling

The following table shows the number of maternal and infant complications that could be avoided and the cost savings that could be made, with different variables used in the calculations.

- Smoking prevalence is taken as being 16% (number of women who smoked throughout pregnancy) or as 33% (number of women who smoked before or during pregnancy)[3].
- A current uptake of 11% is used which mirrors the estimates for England, and 5% is also used which perhaps better reflects the current situation in Wales
- A number of figures are used for future uptake, demonstrating varying levels of increase in service uptake.

| Smoking prevalence | Current uptake | Future uptake | No. smoking related adverse events avoided | Total cost saving |
|---|---|---|---|---|
| Smoking prevalence at **16%** with **low** estimate of current uptake | | | | |
| 16% | 5% | 10% | 43 | 81,261 |
| 16% | 5% | 15% | 83 | 157,514 |
| 16% | 5% | 20% | 121 | 228,708 |
| 16% | 5% | 25% | 156 | 296,439 |
| Smoking prevalence at **16%** with **high** estimate of current uptake | | | | |
| 16% | 11% | 15% | 35 | 65,547 |
| 16% | 11% | 20% | 75 | 142,156 |
| 16% | 11% | 25% | 113 | 241,840 |
| Smoking prevalence at **33%** with **low** estimate of current uptake | | | | |
| 33% | 5% | 10% | 88 | 166,973 |
| 33% | 5% | 15% | 171 | 324,382 |
| 33% | 5% | 20% | 249 | 471,936 |
| 33% | 5% | 25% | 323 | 611,622 |
| Smoking prevalence at **33%** with **high** estimate of current uptake | | | | |
| 33% | 11% | 15% | 71 | 134,928 |
| 33% | 11% | 20% | 155 | 293,682 |
| 33% | 11% | 25% | 234 | 443,064 |

# All Wales Perinatal Survey

## http://www.cf.ac.uk/medic/awps/

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The All Wales Perinatal Survey (AWPS) was established in 1992 as a continuous, accurate, complete and timely surveillance of perinatal and infant mortality in Wales. It is based on deaths of babies from 20 weeks gestation to one year of age, whose mother is usually resident in Wales, or who die in a Welsh hospital. The survey continuously collects and reports on stillbirths in Wales annually.

The survey is funded by Welsh Government and is located within the Department of Child Health, Cardiff University, School of Medicine. The survey has in the past conducted several confidential enquiries working alongside the Centre for Maternal and Child Enquiries (CMACE) formerly Confidential Enquiry into Maternal and Child Health (CEMACH).

In this paper we present an overview of stillbirth data for Wales, focusing on trends, risk factors and causes of stillbirths.

## Summary/Key messages

1. The stillbirth rate in Wales has remained between 4.5 and 5.0 per 1000 registrable births over the last 17 years.
2. This is in contrast to the neonatal mortality rate in Wales which has declined from 4.1 per 1,000 live births in 1999 to 2.9 per 1000 live births in 2005 and has remained around this rate for the last 5 years.
3. In the majority of cases the cause of stillbirth is not known.
4. Stillbirth rates in Wales remain higher than in other European countries.
5. Some differences may be due to different methods of case ascertainment and measuring, however there remains a need to understand why the rate in Wales has not decreased.
6. It is essential to investigate the rate of stillbirth in Wales including the reasons why the rates have not fallen. As an initial step we would like to propose a confidential enquiry focused on stillbirths, to gain insights into the main causes of stillbirth, to identify avoidable causes and to recommend improvements in clinical care and service provision. This will also enable improved dialogue between interested parties with a view to identifying areas that would require further investigation. The All Wales Perinatal Survey has run confidential enquiries in the past and is well placed to conduct such confidential enquiries in Wales.

# Stillbirth data for Wales

We have used the UK definition of stillbirth which is late fetal death from 24 weeks gestation. The stillbirth rate in Wales in 2010 was 5.2 per 1000 births, which is similar to the 2009 rate and to the annual rate for the combined 3 years 2007-2009. The stillbirth rate in England in 2010 was 5.1 per 1,000 registrable births (ONS)[1], 4.9 per 1,000 registrable births in Scotland[2], and 4.1 per 1,000 registrable births in Northern Ireland[3]. These rates include late terminations. The stillbirth rate in Wales excluding late terminations in 2010 was 4.6 per 1,000 registrable births.

Figure 1 shows the trend in stillbirth rates since 1993 for Wales. The declining trend of recent years seems to have reached a plateau. Similar trends are observed for stillbirth rates in Welsh NHS regions and Health Boards (Table 1), which are also presented as funnel plots to facilitate comparison between Local Authority areas. (Fig 5)

Figure 2 shows the trend for neontal mortality rate. The neonatal death rate for wales has shown improvement and has been stable at around 3.0 per 1000 livebirths for the past 5 years. This is in contrast to the stillbirth rate which has not shown a similar trend.

Figures 3 and 4 show stillbirth rates for England and English regions for comparison with Welsh rates. These data are from the Office for National Statistics (ONS).

Within Europe data on stillbirths are available for 2004, collated in the European Perinatal Health Report[4]. Stillbirth rates (from 28 weeks gestation) ranged from 1.7 per 1,000 births in the Slovak Republic to 4.9 per 1,000 births in Latvia and France. However, differences in ascertainment and registration may contribute to some of this observed variation such that direct comparisons between countries may be inaccurate[5]. Within the UK the rate for stillbirths (from 28 weeks gestation) was 4.6 per 1,000 births in Scotland, 3.8 per 1,000 births in Northern Ireland and 4.1 per 1,000 births in Wales in 2004. Data on stillbirths using this definition were not available for England.

A recent report on stillbirth rates[6] estimated there were 2.6 million stillbirths (at least 1000g birthweight or at least 28 completed weeks gestation) globally in 2009. Globally the stillbirth rate has declined by 14.5% from 22.1 per 1,000 births in 1995 to 18.9 per 1,000 births in 2009. The estimated rate for the UK using this definition was 3.4 per 1,000 total births. The rate for Wales using this definition was 3.9 per 1,000 births in 2009 and 4.0 per 1,000 births in 2010.

**Figure 1**

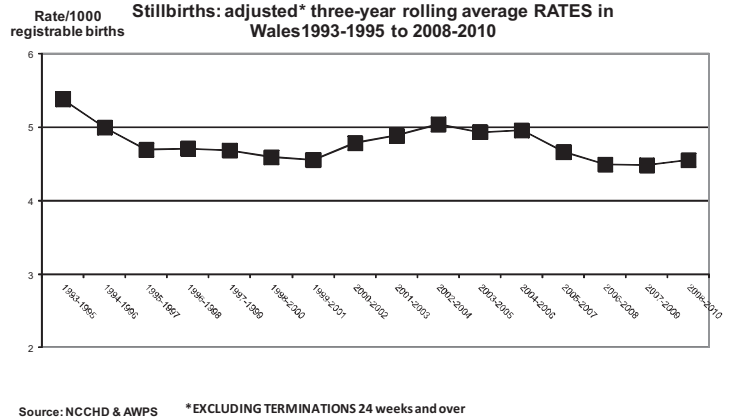



**Figure 2**

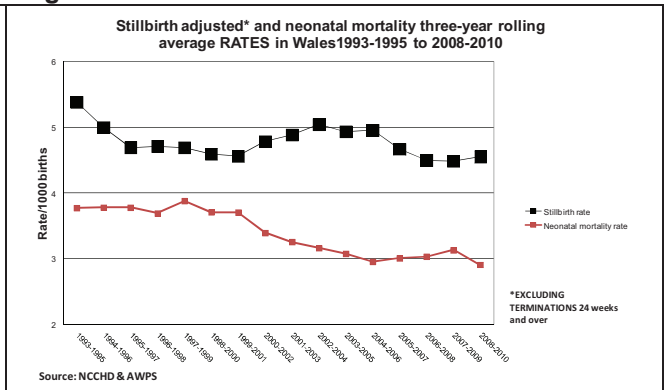


**Figure 3**

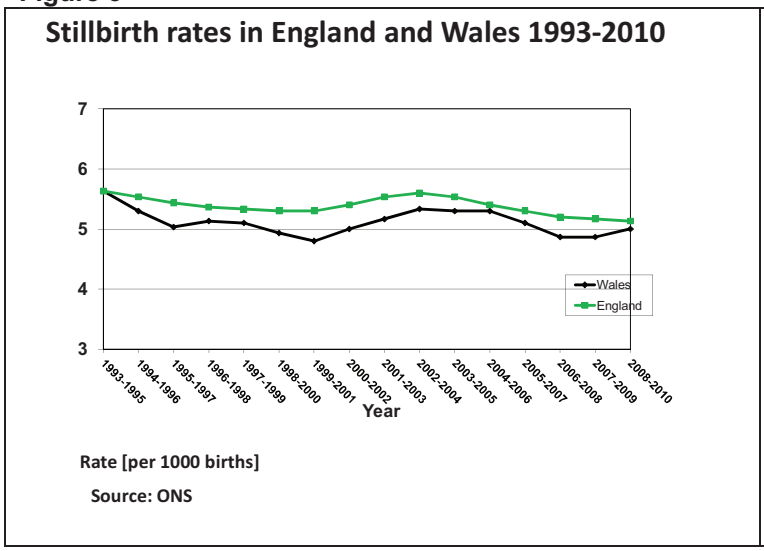



**Figure 4**

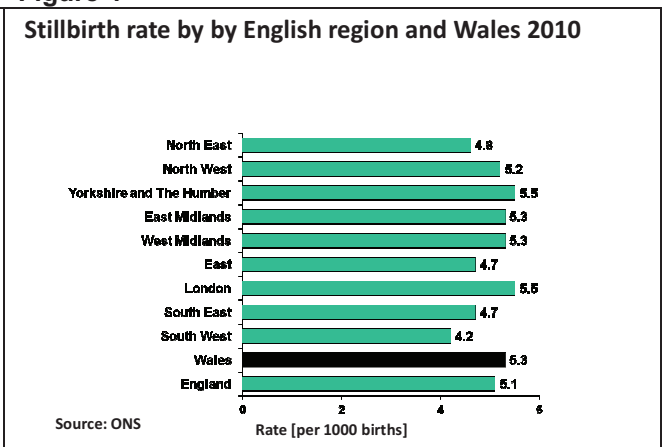
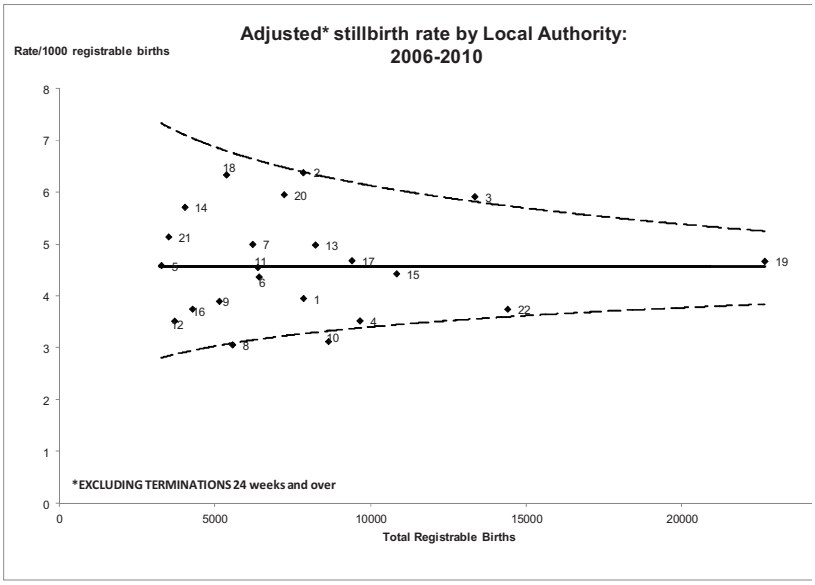



**Table 1 Stillbirths: adjusted* three-year rolling average RATES by Local Authority and NHS Region 1999-2001 to 2008-2010 and 2010 with 95% CI**

| Health Board | Local Authority and NHS Region | 1999-2001 | 2000-2002 | 2001-2003 | 2002-2004 | 2003-2005 | 2004-2006 | 2005-2007 | 2006-2008 | 2007-2009 | 2008-2010 | 2010 | 95% CI | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Abertawe Bro Morganwg University Health Board | Bridgend | 4.71 | 4.41 | 4.67 | 4.81 | 5.56 | 5.30 | 4.14 | 3.02 | 1.93 | 4.62 | 9.0 | (5.5 | 14.9) |
| | Neath Port Talbot | 3.38 | 3.85 | 5.02 | 4.12 | 3.69 | 4.66 | 6.36 | 6.49 | 5.78 | 5.87 | 6.8 | (3.8 | 12.1) |
| | Swansea | 5.29 | 5.49 | 4.49 | 4.14 | 3.92 | 5.43 | 6.14 | 5.93 | 5.78 | 5.15 | 5.7 | (3.5 | 9.2) |
| Hywel Dda Health Board | Carmarthenshire | 3.29 | 3.53 | 2.77 | 3.43 | 4.15 | 4.59 | 5.01 | 4.14 | 4.14 | 3.10 | 1.5 | (0.5 | 4.5) |
| | Ceredigion | 5.60 | 5.19 | 3.50 | 4.48 | 3.86 | 3.33 | 3.21 | 3.73 | 6.15 | 5.51 | 4.1 | (1.4 | 12.0) |
| | Pembrokeshire | 3.78 | 2.97 | 4.08 | 4.93 | 4.79 | 4.08 | 3.99 | 4.98 | 4.98 | 3.90 | 2.3 | (0.8 | 6.8) |
| Powys Teaching Health Board | Powys | 4.67 | 4.73 | 5.81 | 6.65 | 6.47 | 6.06 | 4.30 | 3.72 | 5.25 | 5.66 | 3.4 | (1.3 | 8.6) |
| **Mid and West Wales** | | **4.38** | **4.36** | **4.34** | **4.51** | **4.56** | **4.95** | **5.04** | **4.78** | **4.81** | **4.75** | **4.9** | **(3.7** | **6.3)** |
| Betsi Cadwaladr University Health Board | Conwy | 3.71 | 5.42 | 4.58 | 3.89 | 2.90 | 3.11 | 3.74 | 3.62 | 3.64 | 2.38 | 1.8 | (0.5 | 6.4) |
| | Denbighshire | 5.03 | 5.12 | 6.12 | 6.69 | 6.20 | 5.14 | 3.05 | 2.61 | 2.91 | 4.79 | 8.6 | (4.5 | 16.2) |
| | Flintshire | 4.91 | 5.89 | 4.47 | 3.91 | 3.03 | 3.56 | 4.13 | 3.49 | 3.46 | 2.31 | 1.1 | (0.3 | 4.2) |
| | Gwynedd | 3.02 | 2.86 | 4.12 | 4.35 | 4.73 | 3.72 | 3.42 | 3.94 | 4.75 | 5.77 | 6.4 | (3.2 | 12.6) |
| | Isle of Anglesey | 4.99 | 5.41 | 5.46 | 5.28 | 4.59 | 5.04 | 3.84 | 3.26 | 3.60 | 3.52 | 2.5 | (0.7 | 9.1) |
| | Wrexham | 6.52 | 6.73 | 5.28 | 4.09 | 4.93 | 6.11 | 6.90 | 5.37 | 5.20 | 4.09 | 3.0 | (1.3 | 6.9) |
| **North Wales** | | **4.74** | **5.31** | **4.91** | **4.53** | **4.29** | **4.41** | **4.37** | **3.85** | **4.03** | **3.75** | **3.7** | **(2.5** | **5.3)** |
| Aneurin Bevan Health Board | Blaenau Gwent | 4.92 | 5.22 | 4.28 | 6.61 | 7.78 | 8.37 | 7.41 | 4.97 | 4.94 | 5.25 | 8.6 | (4.2 | 17.6) |
| | Caerphilly | 4.44 | 4.70 | 5.21 | 5.74 | 5.62 | 5.40 | 5.13 | 4.36 | 4.05 | 4.08 | 4.4 | (2.4 | 8.1) |
| | Monmouthshire | 2.16 | 2.56 | 3.28 | 4.29 | 3.87 | 3.95 | 3.23 | 3.86 | 4.30 | 4.22 | 3.4 | (1.2 | 10.1) |
| | Newport | 3.92 | 4.59 | 6.13 | 6.50 | 6.37 | 6.22 | 4.80 | 5.10 | 3.66 | 4.58 | 5.1 | (2.8 | 9.3) |
| | Torfaen | 3.75 | 4.08 | 5.52 | 6.07 | 5.29 | 5.96 | 4.97 | 5.99 | 5.95 | 6.47 | 6.4 | (3.1 | 13.1) |
| Cardiff and Vale University Health Board | Cardiff | 5.64 | 5.10 | 4.00 | 4.66 | 5.27 | 5.38 | 4.83 | 4.84 | 4.39 | 4.77 | 5.2 | (3.5 | 7.7) |
| | The Vale of Glamorgan | 4.75 | 5.44 | 6.75 | 6.05 | 5.16 | 3.57 | 3.91 | 5.12 | 7.95 | 7.51 | 3.5 | (1.5 | 8.1) |
| Cwm Taf Health Board | Merthyr Tydfil | 4.21 | 7.12 | 7.07 | 6.92 | 4.15 | 5.08 | 4.44 | 5.10 | 5.22 | 5.23 | 5.7 | (2.2 | 14.5) |
| | Rhondda Cynon Taff | 4.83 | 4.76 | 6.11 | 5.91 | 5.77 | 4.75 | 3.98 | 4.08 | 3.60 | 4.00 | 4.3 | (2.5 | 7.4) |
| **South East Wales** | | **4.60** | **4.83** | **5.25** | **5.65** | **5.52** | **5.30** | **4.67** | **4.74** | **4.60** | **4.89** | **5.0** | **(4.0** | **6.1)** |
| **WALES** | | **4.56** | **4.79** | **4.89** | **5.05** | **4.94** | **4.96** | **4.67** | **4.50** | **4.49** | **4.55** | **4.6** | **(4.0** | **5.4)** |

*excludes terminations 24 weeks and over

## Figure 5

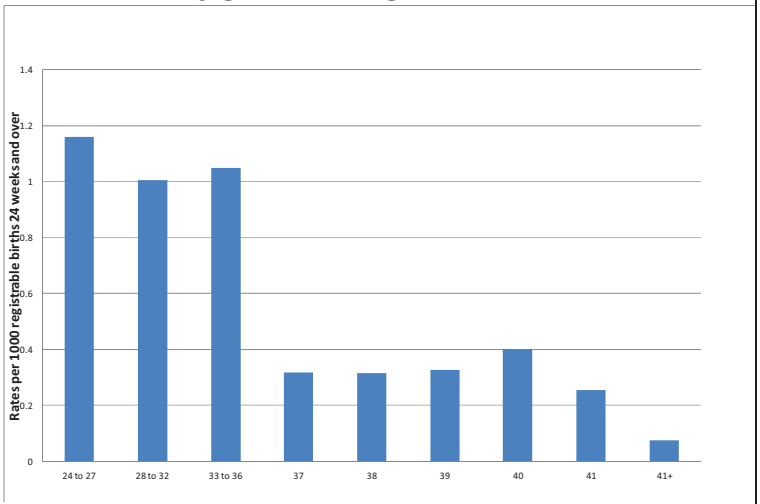



| | | |
|---|---|---|
| 1 | Bridgend | Abertawe Bro Morganwg University He |
| 2 | Neath Port Talbot | Abertawe Bro Morganwg University He |
| 3 | Swansea | Abertawe Bro Morganwg University He |
| 4 | Carmarthenshire | Hywel Dda Health Board |
| 5 | Ceredigion | Hywel Dda Health Board |
| 6 | Pembrokeshire | Hywel Dda Health Board |
| 7 | Powys | Powys Teaching Health Board |
| 8 | Conwy | Betsi Cadwaladr University Health Boa |
| 9 | Denbighshire | Betsi Cadwaladr University Health Boa |
| 10 | Flintshire | Betsi Cadwaladr University Health Boa |
| 11 | Gwynedd | Betsi Cadwaladr University Health Boa |
| 12 | Isle of Anglesey | Betsi Cadwaladr University Health Boa |
| 13 | Wrexham | Betsi Cadwaladr University Health Boa |
| 14 | Blaenau Gwent | Aneurin Bevan Health Board |
| 15 | Caerphilly | Aneurin Bevan Health Board |
| 16 | Monmouthshire | Aneurin Bevan Health Board |
| 17 | Newport | Aneurin Bevan Health Board |
| 18 | Torfaen | Aneurin Bevan Health Board |
| 19 | Cardiff | Cardiff and Vale University Health Boar |
| 20 | The Vale of Glamorgan | Cardiff and Vale University Health Boar |
| 21 | Merthyr Tydfil | Cwm Taf Health Board |
| 22 | Rhondda Cynon Taff | Cwm Taf Health Board |

We compare mortality rates between Local Authorities using funnel plots. These funnel plots show the mortality rate for each Local Authority plotted against the number of births in each. The average mortality rate in Wales is indicated by the solid horizontal line. The curved lines represent limits within which 95% of results should lie if the average rate in Wales applied to all. Rates above or below these dashed lines are considered to be statistically significantly different from the average rate. The plots are calculated using the Wilson score interval. This method is generally regarded as an improvement over the normal approximation interval[7, 8] and has the advantage that the lower line of the funnel plot cannot reach implausible values i.e. below zero. These funnel plots are calculated assuming that the populations of women giving birth are directly comparable between Local Authority. Therefore they do not allow for any heterogeneity (for example differences in case mix) between Local Authority. Hence there may be plausible reasons for the significantly higher or lower rates in the Local Authorities that are identified as outliers.

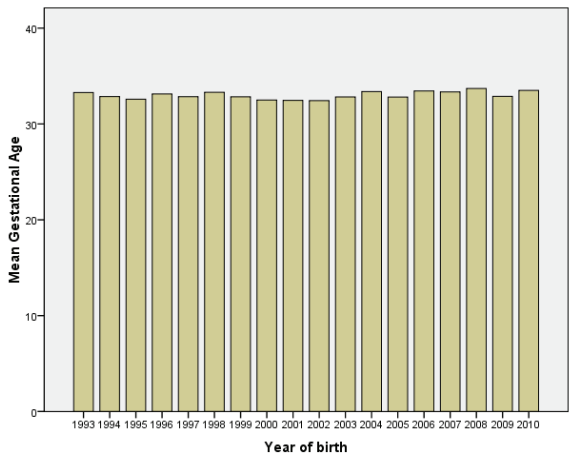
Figure 6 below shows the rate of stillbirth by gestational age at birth from 1993 to 2010. Rates are higher for babies born before 37 weeks gestation (1 to 1.2 per 1,000) compared to 0.3 per 1,000 for babies born at 37 weeks or later. The mean gestational age of stillbirths is 33 weeks, and this has not changed over time (Figure 7). Ten percent of babies born at 37 weeks or later are small for gestational age (have low birth weight). The stillbirth rate for these babies is 4.9 per 1,000 compared to 1.4 per 1,000 for babies who have birth weight appropriate for gestational age.

**Figure 6**
**Stillbirth* rate by gestational age – 1993 to 2010**




*excludes terminations*

**Figure 7**
**Stillbirths* 1993 to 2010 by mean gestational age**

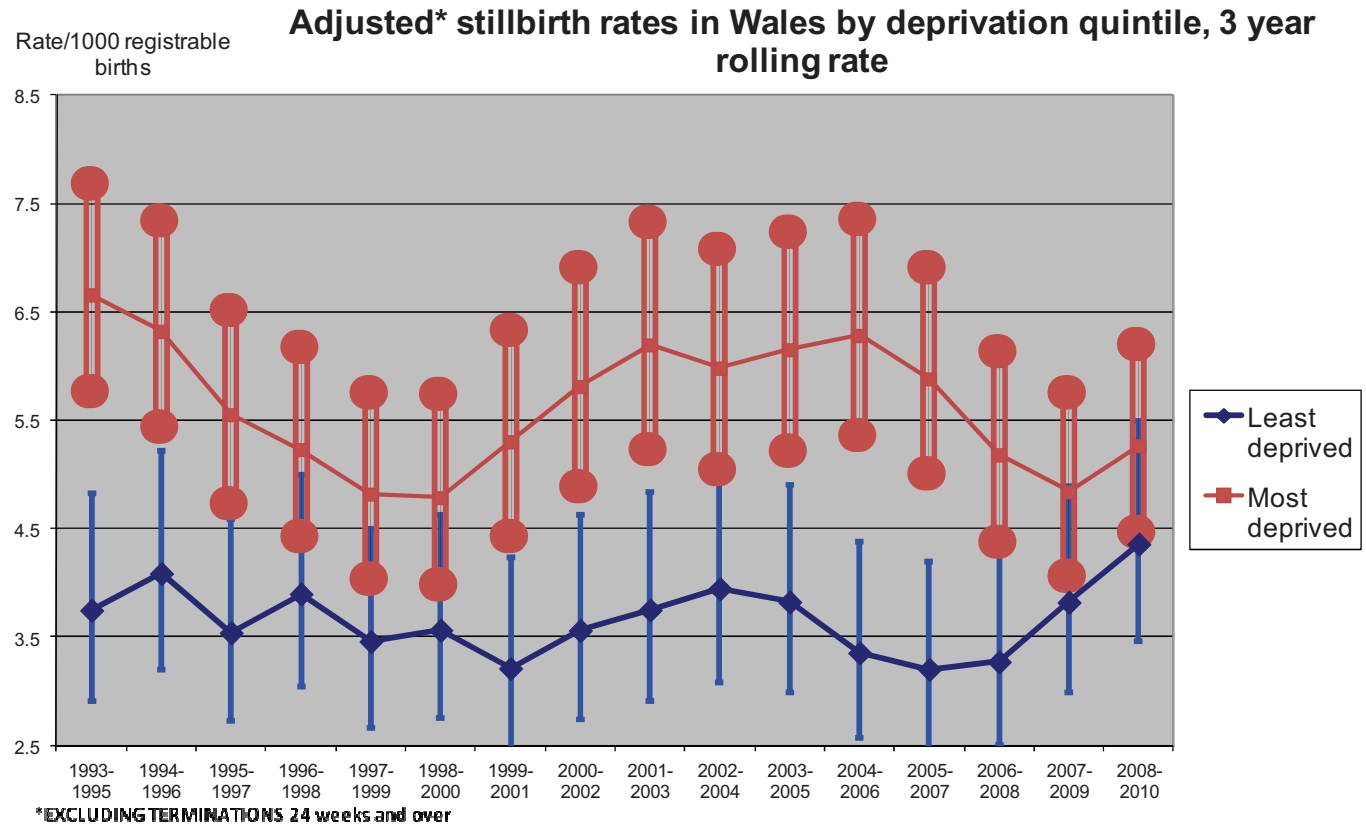



*excludes terminations*

## Social Deprivation Quintile

Within Wales, stillbirth rates are persistently higher in the most deprived quintile of social deprivation measured using the Welsh Index of Multiple Deprivation (WIMD_2008), although rates over the last decade suggest a slight narrowing of the gap between the most deprived and least deprived quintiles (Figure 4). Similar trends have been observed in England[9].

**Figure 8**




The chart shows the rates in the highest and lowest quintiles of the population as given by the Welsh Index of Multiple Deprivation (WIMD_2008). The vertical lines show the 95% CI at each point. Cases were allocated to the appropriate quintile of deprivation based on mother's residence and LSOA. These scores were based on the mothers, not babies, and for multiple pregnancies only the first born babies were assigned a deprivation score, to avoid double counting.

## Risk factors for stillbirth

A systematic review of major risk factors for stillbirth in high income countries has identified maternal overweight and obesity (body-mass index >25 kg/m$^2$), advanced maternal age and maternal smoking as the highest ranking modifiable risk factors[10]. In the UK smoking accounts for 7% of all stillbirths but it is estimated that in disadvantaged populations maternal smoking contributes to up to 20% of stillbirths. These findings highlight the importance of public health initiatives to tackle smoking and obesity in women of reproductive age. Data from the Infant Feeding Survey for Wales 2010[11] show that 16% of pregnant women smoke throughout pregnancy. Data published in the CMACE report on maternal obesity shows that Wales has the highest prevalence of obesity in pregnancy in the UK at 6.5%, compared with 5.5% in Scotland, 4.9% in England and 5.3% in Northern Ireland[12].

## Cause of death in stillbirths

Classification systems for stillbirths are used to give as much insight as possible into the underlying cause of death or events leading up to death, in order to explore any trends or variation in causes of death and identify areas that can be addressed.

We present stillbirths (excluding late terminations) by the Aberdeen classification (also known as the 'Obstetric' classification) (Tables 2 and 3). These systems allow for the classification of deaths according to the clinical factors that preceded death, for example preterm labour, congenital abnormalities and fetal growth restriction. However the limitation of this system is that a large proportion of stillbirths are classified as 'unexplained', 61.7% of stillbirths in 2010. A new classification that takes account of both obstetric and fetal factors was proposed and adapted for use by CMACE in 2008[13]. This year we also present data on cause of death in stillbirths using this CMACE classification (Table 4 and Figure 9). Using the CMACE classification only 41.7% of stillbirths were 'unexplained'.

Ante-partum haemorrhage and congenital anomalies remain leading causes of stillbirth. Screening and monitoring in pregnancy are used to identify high risk pregnancies to provide appropriate clinical management. However a recent systematic review of screening and monitoring interventions in pregnancy has reported there is limited evidence for the impact of these interventions on stillbirth[14]. Screening and interventions to reduce antepartum stillbirth as a result of placental dysfunction has been identified as a priority for future research[15-17].

**Table 2 Aberdeen Classification* by Welsh NHS Region 2006-2010 – Stillbirths****

| Aberdeen Classification 2006-2010 | MW n=268 | N n=147 | SE n=386 | WALES n=801 |
|---|---|---|---|---|
| Antepartum haemorrhage (APH) | 9.7% | 10.9% | 10.4% | 10.2% |
| Congenital anomaly | 7.1% | 3.4% | 6.7% | 6.2% |
| Maternal Disorder | 8.6% | 7.5% | 6.0% | 7.1% |
| Mechanical | 9.3% | 4.1% | 4.4% | 6.0% |
| Miscellaneous | 4.1% | 6.1% | 6.5% | 5.6% |
| Pre-eclampsia | 1.9% | 4.1% | 2.1% | 2.4% |
| Unclassifiable | 0.4% | 2.0% | 0.5% | 0.7% |
| Unexplained | 59.0% | 61.9% | 63.5% | 61.7% |

*For definitions see Appendix E in AWPS annual report^
**excludes 91 terminations of pregnancy from 24 weeks gestation (87 congenital anomalies, 2 maternal disorder, 2 miscellaneous)

**Table 3 Aberdeen Classification* 3 year rolling rates – Stillbirths****

| | 1993-1995 | 1994-1996 | 1995-1997 | 1996-1998 | 1997-1999 | 1998-2000 | 1999-2001 | 2000-2002 | 2001-2003 | 2002-2004 | 2003-2005 | 2004-2006 | 2005-2007 | 2006-2008 | 2007-2009 | 2008-2010 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % | % |
| Antepartum haemorrhage | 17.5 | 17.4 | 19.7 | 20.0 | 20.7 | 17.0 | 15.9 | 14.4 | 15.7 | 17.6 | 16.8 | 16.3 | 12.1 | 9.6 | 7.0 | 9.0 |
| Congenital anomaly | 3.1 | 3.0 | 3.7 | 4.7 | 6.3 | 7.4 | 10.0 | 9.1 | 8.9 | 6.8 | 7.1 | 6.5 | 7.0 | 6.2 | 6.3 | 6.1 |
| Iso-immunisation | 0.3 | 0.2 | 0.2 | 0.0 | 0.0 | 0.0 | 0.2 | 0.2 | 0.2 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Maternal Disorder | 7.3 | 7.6 | 9.6 | 9.6 | 8.7 | 8.1 | 6.3 | 6.4 | 6.3 | 8.9 | 8.2 | 7.1 | 5.9 | 6.8 | 7.4 | 7.4 |
| Mechanical | 3.1 | 4.0 | 4.3 | 4.1 | 2.3 | 2.0 | 2.1 | 3.2 | 3.6 | 3.2 | 2.5 | 4.1 | 5.5 | 6.4 | 5.1 | 5.3 |
| Miscellaneous | 4.7 | 4.0 | 4.9 | 4.9 | 5.3 | 5.1 | 4.0 | 2.5 | 2.9 | 2.5 | 2.9 | 1.6 | 2.1 | 3.0 | 6.3 | 8.0 |
| Pre-eclampsia | 5.5 | 6.4 | 7.7 | 8.0 | 6.6 | 4.5 | 3.5 | 4.8 | 5.6 | 6.4 | 5.5 | 4.9 | 4.7 | 3.4 | 2.5 | 1.2 |
| Unclassifiable | 0.2 | 0.0 | 0.0 | 0.0 | 0.4 | 0.7 | 0.9 | 0.7 | 0.4 | 0.4 | 0.4 | 0.4 | 0.4 | 0.6 | 1.3 | 1.0 |
| Unexplained | 58.2 | 57.4 | 50.0 | 48.7 | 49.7 | 55.3 | 57.0 | 58.7 | 56.4 | 54.2 | 56.5 | 59.1 | 62.4 | 64.0 | 64.1 | 61.9 |
| | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n | n |
| Total | 577 | 528 | 492 | 489 | 473 | 447 | 428 | 438 | 447 | 472 | 476 | 491 | 473 | 470 | 474 | 488 |

*For definitions see Appendix E in AWPS annual report^
**excludes terminations of pregnancy from 24 weeks gestation

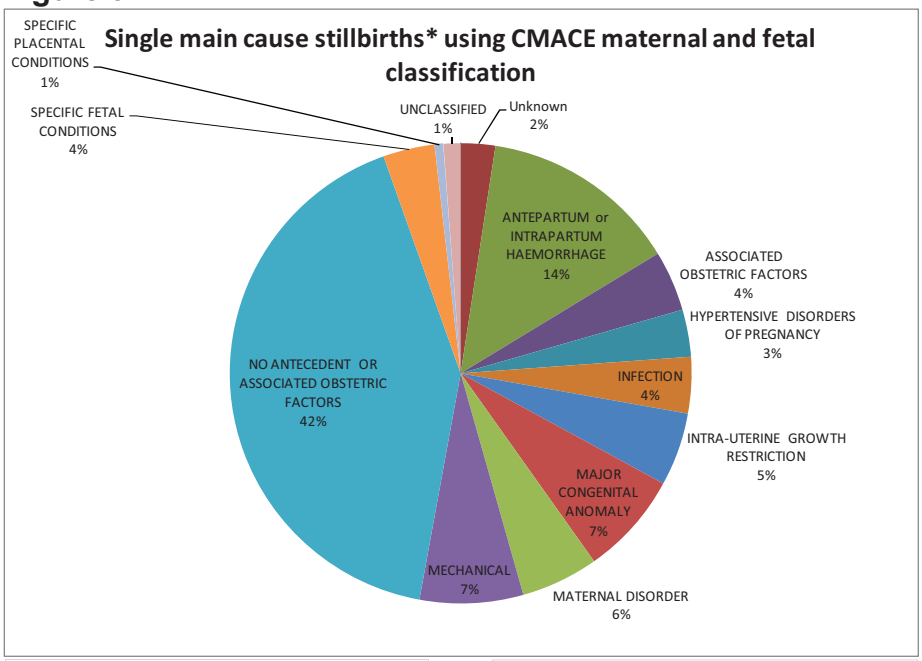
**Table 4 CMACE classifications* for stillbirths** by Welsh NHS Region 2009-2010**

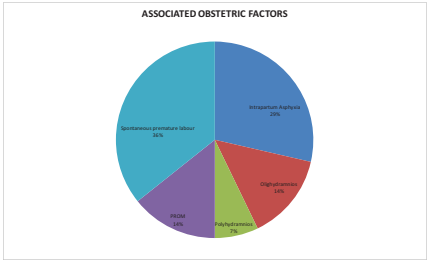
| *Single main cause stillbirths using CMACE maternal and fetal classification 2009-2010* | *MW n=113* | *N n=61* | *SE n=157* | *WALES n=331* |
|---|---|---|---|---|
| Unknown | 2.7% | 1.6% | 2.5% | 2.4% |
| ANTEPARTUM or INTRAPARTUM HAEMORRHAGE | 15.0% | 14.8% | 12.7% | 13.9% |
| ASSOCIATED OBSTETRIC FACTORS | 6.2% | 0.0% | 4.5% | 4.2% |
| HYPERTENSIVE DISORDERS OF PREGNANCY | 2.7% | 4.9% | 3.2% | 3.3% |
| INFECTION | 3.5% | 9.8% | 1.9% | 3.9% |
| INTRA-UTERINE GROWTH RESTRICTION | 4.4% | 3.3% | 6.4% | 5.1% |
| MAJOR CONGENITAL ANOMALY | 8.0% | 6.6% | 7.0% | 7.3% |
| MATERNAL DISORDER | 4.4% | 0.0% | 8.3% | 5.4% |
| MECHANICAL | 10.6% | 8.2% | 4.5% | 7.3% |
| NO ANTECEDENT OR ASSOCIATED OBSTETRIC FACTORS | 38.1% | 42.6% | 43.9% | 41.7% |
| SPECIFIC FETAL CONDITIONS | 2.7% | 4.9% | 3.8% | 3.6% |
| SPECIFIC PLACENTAL CONDITIONS | 0.9% | 0.0% | 0.6% | 0.6% |
| UNCLASSIFIED | 0.9% | 3.3% | 0.6% | 1.2% |

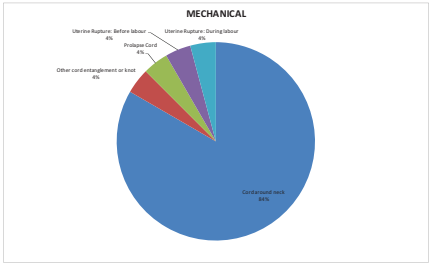
*For definitions see Appendix E in AWPS annual report^

**excludes 41 terminations of pregnancy from 24 weeks gestation, all congenital anomalies (6 Cardiovascular System, 13 Central Nervous System, 8 Chromosomal Disorders, 8 Multiple Anomalies, 3 Musculo-Skeletal System, 1 Other major congenital anomaly, 2 Urinary Tract)

## Figure 9




*excludes 41 terminations of pregnancy from 24 weeks gestation, all congenital anomalies (6 Cardiovascular System, 13 Central Nervous System, 8 Chromosomal Disorders, 8 Multiple Anomalies, 3 Musculo-Skeletal System, 1 Other major congenital anomaly, 2 Urinary Tract)

## The way forward

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. A confidential enquiry focused on stillbirths would enable us to investigate stillbirths, to establish whether anything could have been done to prevent them through better clinical care. This process will allow the details of each stillbirth to be reviewed by a team of multidisciplinary experts (obstetricians, midwives, public health professionals and pathologists) with the aim of gaining insights into the main causes of stillbirth, to identify avoidable causes and to recommend improvements in clinical care and service provision. A confidential enquiry process will provide a mechanism for understanding why the stillbirth rate in Wales has not decreased. The All Wales Perinatal Survey has run confidential enquiries in the past and is well placed to take this forward in Wales.

^The data collected by The All Wales Perinatal Survey are presented in an Annual report, printed as hard copy and also available online as a PDF via the website. This report is distributed to NHS Trusts, LHBs, Health Authorities, Academic Staff, Libraries, Universities. http://www.cf.ac.uk/medic/awps/

### References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# Y Pwyllgor Iechyd a Gofal Cymdeithasol

## HSC(4)-19-12 papur 13

## Ymchwiliad un-dydd i farw-enedigaethau yng Nghymru - Bwrdd Iechyd Cwm Taf

**TEITL YR ADRODDIAD TROSOLWG**

Atal Genedigaethau Marw

**SEFYLLFA / DIBEN YR ADRODDIAD**

Ymateb i'r "Pwyllgor Iechyd a Gofal Cymdeithasol" mewn perthynas â'r Ymchwiliad i Enedigaethau Marw yng Nghymru

**CEFNDIR / RHAGAIR**

Mae pob genedigaeth farw'n drychineb. Cysylltir genedigaethau marw â llu o achosion megis mamau iau (dan 25 oed), neu famau hŷn (dros 40 mlynedd), gordewdra (Mynegai Màs Corff sy'n uwch na 35), beichiogiadau lluosol, ysmygu yn ystod beichiogrwydd, cymhlethdodau yn ystod beichiogrwydd megis cyneclampsia, anhwylderau meddygol sy'n bodoli eisoes megis diabetes, anhwylderau'r brych, abnormaleddau cynhenid ac ethnigrwydd. Serch hynny, mewn llawer achos o enedigaeth farw mae'r rheswm yn aros yn anhysbys. Yr un mor ansicr yw'r rhesymau dros yr amrywiadau o ranbarth i ranbarth yn y gyfradd genedigaethau marw, ond mae menywod sy'n byw yn yr ardaloedd mwyaf difreintiedig 1.7 gwaith yn debycach o ddioddef genedigaeth farw na menywod sy'n byw yn yr ardaloedd lleiaf difreintiedig. Mae gan Fwrdd Iechyd Cwm Taf lefel uchel o fynegeion iechyd gwael ar draws ei boblogaeth. Yn ogystal â'r effeithiau corfforol, mae genedigaeth farw'n gallu gadael effaith emosiynol, seicolegol a chymdeithasol ddwfn ar y rhieni a'r teulu i gyd.

Mae pob gwasanaeth mamolaeth ledled y wlad yn adrodd am enedigaethau marw, ac mae'r sgôr ddosbarthu ddiwygiedig wedi arwain at welliant yn y modd o hel data a fydd yn helpu gweithwyr proffesiynol i ddarganfod patrymau a thrwy hynny ddeall pam mae genedigaethau marw yn digwydd. Mae unedau mamolaeth yn adolygu ac yn monitro eu cyfraddau eu hunain hefyd fel y gellir rhoi prosesau a gweithdrefnau ar waith i wella eu gwasanaethau.

Mae darparu gofal mamolaeth ar gyfer menywod sy'n byw yn nalgylch Cwm Taf yn creu heriau sy'n deillio o iechyd gwael y boblogaeth a'r amddifadedd cymdeithasol sydd yn yr ardal. Mae gan Fwrdd Iechyd Cwm Taf y ganran uchaf yng Nghymru o enedigaethau ymhlith mamau dan 20 mlwydd oed (10.7%) (WIMD, 2008). Mae hyn, ochr yn ochr ag amddifadedd cymdeithasol, yn gysylltiedig â lefelau uchel o ysmygu, defnyddio alcohol, babanod isel eu pwysau adeg y geni ac afiechydon meddyliol, sydd i gyd ar lefelau uchel yn ardal Cwm Taf. Mae gordewdra yn gyffredin iawn ymhlith darpar famau yng Nghymru, a gwelir llu o fenywod yn nalgylch Bwrdd Iechyd Cwm Taf (BICT/CTHB) â mynegai màs corff (MMC/BMI) uchel.

Dangoswyd bod gordewdra'n cynyddu amlder cyneclampsia, gwaedlifau cyn geni a diabetes, sydd yn ffactorau a gysylltir â genedigaethau marw.

Nifer y genedigaethau byw yn nalgylch Bwrdd Iechyd Cwm Taf yn ystod 2011 oedd 4310, o'i chymharu â 4345 o enedigaethau byw yn 2010. Bu 16 o enedigaethau marw yn 2011, o'u cymharu â 17 o enedigaethau marw yn 2010. Mae hyn yn cyfateb i 4% o gyfanswm y genedigaethau yn ystod y ddwy flynedd, sy'n is na'r ganran ar gyfer Cymru Gyfan.

Mae'r Ystadegau Cenedlaethol diweddaraf a gyhoeddwyd gan Lywodraeth Cymru ar enedigaethau a marwolaethau babanod yn dangos bod 35,952 o fabanod wedi cael eu geni'n fyw, y nifer uchaf mewn blwyddyn ers 1993. Er bod nifer y babanod a anwyd gan fenywod dan 20 mlwydd oed wedi syrthio, bu cynnydd o 50 % yn nifer y babanod a anwyd gan fenywod dros 40 mlwydd oed yn Nghymru. Mae'r duedd genedlaethol yn y gyfradd genedigaethau marw wedi gostwng ers 2000 o 5.4 (2000) i 5.2 (2009) i bob 1,000 o enedigaethau. Mae'r gyfradd genedigaethau marw ar gyfer gefeilliaid wedi syrthio yn ogystal.

## Y Sefyllfa Bresennol ym Mwrdd Iechyd Cwm Taf

Mae Bwrdd Iechyd Cwm Taf yn darparu gofal dan arweiniad ymgynghoryddion a bydwragedd ar gyfer menywod beichiog mewn dau Ysbyty Cyffredinol Dosbarth. Mae menywod sydd â ffactorau risg penodol yn derbyn gofal gan obstetrydd ymgynghorol, ac mae menywod ag anhwylderau meddygol yn derbyn gofal cydranedig a ddarperir gan obstetrydd ar y cyd â ffisigydd neu lawfeddyg arbenigol. Cynigir gofal dan arweiniad bydwraig i fenywod heb ffactorau risg, ac mae cysylltiadau ardderchog rhwng y bydwragedd a'r obstetryddion fel y gellir darparu gwasanaeth cyfannol ac integredig gwydn.

Mae gweithwyr proffesiynol ym Mwrdd Iechyd Cwm Taf yn gweithredu'n rhagweithiol at leihau'r risgiau i fenywod beichiog, ac maent yn ymwybodol o'r cyfarwyddyd cyfredol a'r argymhellion ynghylch atal

genedigaethau marw. Mae'r gweithrediadau canlynol mewn grym gyda golwg ar leihau'r gyfradd genedigaethau marw:

- Mae pob menyw yn derbyn gofal mamolaeth a gofal obstetrig sy'n seiliedig ar ganllawiau NICE ynghylch Gofal Cyn, Yn Ystod ac Ar Ôl Genedigaeth

- Mae gan y Bwrdd Iechyd lu o gyfarwyddiadau penodol sy'n cynnwys cyfarwyddyd ynghylch gofalu am fenywod beichiog sydd â'r anhwylderau canlynol - diabetes, gordewdra, cyn eclampsia ac eclampsia.

- Mae gan y Bwrdd Iechyd gyfarwyddiadau hefyd yng nghyswllt beichiogiadau lluosol a newidiadau yn symudiadau'r ffetws.

- Mae gan y Bwrdd Iechyd gyfarwyddyd penodol ynghylch Gofal Cyn Geni sy'n nodi meini prawf penodol ar gyfer trefnu gofal dan arweiniad bydwragedd ac ymgynghoryddion.

- Ar adeg trefnu'r gofal ac yn ystod y cyfnod cyn geni, cynhelir asesiadau risg parhaus ar fenywod, a darperir cynllun rheolaeth clir ar sail anghenion yr unigolyn.

- Mae clinigau cyn geni cyfunol dan arweiniad ffisigydd/llawfeddyg arbenigol ac obstetrydd ar gael i fenywod uchel eu risg, ac mae ymgysylltiadau ardderchog rhwng y gwahanol arbenigeddau.

- Ar ben hyn, cynhelir cysylltiadau rheolaidd rhwng menywod diabetig a'r Nyrs Diabetes Arbenigol trwy gydol eu beichiogrwydd a'r cyfnod cynnar ar ôl y geni.

- Cynhelir mesuriadau o uchder y *fundus* yn ystod pob ymweliad â chlinig cyn geni.

- Darperir sganiadau uwchsain rheolaidd fel mater o drefn ar gyfer menywod â ffactorau risg penodol e.e. mesur babanod sy'n fach o ystyried y dyddiad, hanes o fabanod blaenorol a oedd yn fach o ystyried y dyddiad, anhwylderau meddygol penodol.

- Cynhelir profion goddef glwcos fel mater o drefn ar fenywod diabetig neu fenywod sydd â hanes pendant o ddiabetes yn y teulu.

- Cynhelir adolygiad cyn geni ar fenywod sydd â BMI dros 40 yn y cyfnod cyn geni, a datblygir cynllun rheolaeth clir ar gyfer cyfnod y beichiogrwydd a'r esgoriad.

- Mae menywod â ffactorau risg penodol yn cael eu gweld yn yr Uned Asesu Mamolaeth Dydd, sy'n darparu gofal wedi'i addasu ar gyfer yr unigolyn a mynediad uniongyrchol at gyngor gan ymgynghorydd.

- Cynigir cymorth a chyngor fel mater o drefn yng nghyswllt rhoi'r gorau i ysmygu. Cynigir atgyfeiriad at y Fydwraig Dros Roi'r Gorau i Ysmygu, ac mae rhaglenni rhoi'r gorau i ysmygu personol ar gael ar draws y Bwrdd Iechyd.

- Mae bydwragedd yn cynnig cyngor a chymorth i bob menyw ynghylch deiet, ysmygu, a chadw'n iach trwy gydol y beichiogrwydd ac yn ystod y cyfnod ôl-geni.

- Cynigir addysg a chymorth trwy gyfrwng dosbarthiadau rhianta rheolaidd.

- Darperir gwasanaeth monitro cardiotocograff parhaus yn ystod yr esgoriad ar gyfer menywod sydd mewn perygl uchel o gymhlethdodau obstetrig.

- Mae rhaglenni hyfforddiant ar gael i fydwragedd ac obstetryddion ar sail argymhellion yr Ymchwiliad Cyfrinachol i Iechyd y Fam a'r Plentyn.

Cedwir llygad ar effeithioldeb y modd o roi'r gweithrediadau uchod ar waith yn y ffyrdd canlynol:

Cydrannu gwybodaeth a'r gwersi a ddysgir trwy gyfrwng cyfarfodydd aml-ddisgyblaethol.

- Archwiliadau clinigol

- Adolygiadau clinigol a Dadansoddi Achosion Sylfaenol.

- Defnyddir y dangosfwrdd bydwreigiaeth i wneud cymariaethau a monitro'n barhaus.

- Trefniadau Llywodraethedd y Gyfarwyddiaeth Obstetreg, Gynecoleg ac Iechyd Rhywiol.

- Mae digwyddiadau rhybuddiol (sentinel) – sy'n gallu cynnwys genedigaethau marw – yn arwain at adolygiad gan y Cyfarwyddydd Meddygol a'r Cyfarwyddydd Nyrsio, ac maent yn cael eu hadrodd ymlaen at Lywodraeth Cymru a'r Bwrdd Iechyd.

**GWEITHREDIADAU PARHAUS**

Mae'r gweithrediadau canlynol yn cael eu cyflawni ar hyn o bryd o fewn Bwrdd Iechyd Cwm Taf gyda golwg ar yrru'r gyfradd genedigaethau marw ymhellach i lawr:

- Ail-werthuso cynnwys dosbarthiadau rhianta, gyda golwg ar eu gwneud yn fwy perthnasol ac yn fwy hygyrch a sicrhau eu bod yn apelio at ystod ehangach o fenywod beichiog. Rhoi pwyslais cynyddol ar addysg a chyngor ynghylch bwyta'n iach, rhoi'r gorau i ysmygu a sylweddoli pwysigrwydd sicrhau ei bod hi'n bosibl teimlo symudiadau'r ffetws o ddydd i ddydd.

- Adolygu a all dosbarthiadau colli pwysau lleol arwain mwy o bobl at ymuno â dosbarthiadau rhiant er mwyn ehangu eu hapêl.

- Mynd ati'n weithgar i ragnodi triniaeth ddisodli nicotîn ar gyfer pob menyw feichiog sy'n ysmygu.

- Ail-werthuso'r hyfforddiant a roddir i fydwragedd ac obstetryddion yng nghyswllt darganfod arafiad twf yn y groth.

- Datblygu'r rhaglenni hyfforddiant ar gyfer bydwragedd ac obstetryddion ymhellach er mwyn sicrhau mwy o bwyslais ar faterion ym maes iechyd cyhoeddus megis rhoi'r gorau i ysmygu a bwyta'n iach.

- Datblygu siartiau 'cic y ffetws' cyn-enedigol newydd.

- Datblygu argymhellion dros ehangu a gwella gwasanaethau gofal cyn-cenhedlu.

- Parhau i archwilio genedigaethau marw 2011 – 2012 er mwyn dod i adnabod y tueddau.

- Archwilio'r profion goddef glwcos a gynhelir.

Mae'r Bwrdd Iechyd wedi cynnal canran o enedigaethau marw sy'n is na'r cyfartaledd Cymreig, a hynny er gwaethaf mynegeion iechyd heriol sylweddol ymhlith y boblogaeth. Rydym yn ymdrechu'n barhaus i wella, ac mae safonau'r driniaeth a'r gofal a ddarperir yn y gwasanaethau obstetreg a bydwreigiaeth yn cael eu craffu a'u monitro'n astud trwy gyfrwng strwythurau llywodraethu'r Bwrdd Iechyd.

Allison Williams, Prif Weithredydd
Bwrdd Iechyd Cwm Taf.

25ain Mai 2012.

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

**Grŵp Rhaglen Glinigol Merched**
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Mr Mark Drakeford AM
Cadeirydd yr Pwyllgor Iechyd a Gofal Cymdeithasol
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Annwyl Mr Mark Drakeford,

**Parthed: Ymchwiliad Pwyllgor Iechyd a Gofal Cymdeithasol Cynulliad Cenedlaethol Cymru i mewn i farw-enedigaethau yng Nghymru.**

Ar ran Bwrdd Iechyd Prifysgol Betsi Cadwaladr, hoffwn ddiolch am y cyfle hwn i gyflawni tystiolaeth ysgrifenedig ar gyfer ymchwiliad Pwyllgor Iechyd a Gofal Cymdeithasol Cymru i mewn i farw-enedigaethau yng Nghymru.

Fel y Pennaeth Staff Cysylltiol ar gyfer Gwasanaethau Merched a Phennaeth Bydwreigiaeth, rwyf yn amgau cynllun gweithredu lleol a ddatblygwyd i leihau nifer yr achosion o farw-enedigaethau yng Ngogledd Cymru. Cafodd y ddogfen hon ei chydgasglu o ddeunydd a ddarparwyd gan gydweithwyr ar draws Bwrdd Iechyd Prifysgol Betsi Cadwaladr a Thîm Iechyd Cyhoeddus Gogledd Cymru.

Os bydd angen unrhyw fanylion neu eglurhad pellach arnoch, mae croeso i chi gysylltu â mi.

Yr eiddoch yn gywir,

**Fiona Giraud**
**Pennaeth Staff Cysylltiol – Nyrsio a Bydwreigiaeth**
**Associate Chief of Staff – Nursing and Midwifery**

**Bwrdd Iechyd Prifysgol Betsi Cadwaladr**
**Tystiolaeth ar gyfer ymchwiliad Pwyllgor Iechyd a Gofal Cymdeithasol Cynulliad Cenedlaethol Cymru i mewn i farw-enedigaethau yng Nghymru**

## Mesurau Atal 'Achub y Blaen'

| Elfennau/Ffactorau Risg sy'n Hysbys | Bwriad | Cynllun | Cynnydd |
|---|---|---|---|
| Gofal cyn beichiogi ar gyfer Cyflyrau Meddygol penodol yn cael eu blaenoriaethu | Mae babanod yn cael eu geni'n iach | ▪ Adolygiad cyflawn o ddarpariaeth gyfredol cefnogaeth a chyngor cyn beichiogi ar draws Gogledd Cymru mewn partneriaeth â chydweithwyr Iechyd Cyhoeddus Lleol.<br>▪ Datblygu Cynllun Gweithredu i roi argymhellion ar waith. | ▪ Mae adolygiad a chrynodeb o argymhellion wedi cael eu cwblhau. |
| Gordewdra yn ystod Beichiogrwydd | Mae babanod yn cael eu geni'n iach | ▪ Datblygu Llwybr Gordewdra Gogledd Cymru.<br>▪ Datblygu cynigiad ar gyfer mynediad ar sail ardal leol at wasanaethau ar gyfer rheoli pwysau.<br>▪ Adeiladu gallu cymunedau i gefnogi bwyta'n iach ac atal diffyg maeth trwy alluogi staff cymunedol i weithio mewn partneriaeth ag asiantaethau eraill. | ▪ Mae'r Bwrdd Iechyd wedi blaenoriaethu'r Llwybr Gordewdra Mamolaeth.<br>▪ Lansiwyd Llwybr fel dogfen yn y Gynhadledd Iechyd Cyhoeddus Tadolaeth Lleol yng Ngogledd Cymru ar 3.5.12 |
| Ysmygu | Mae babanod yn cael eu geni'n iach | ▪ Rhoi Cynllun Rheoli Tybaco BIPBC ar waith - sy'n nodi elfennau sy'n ymwneud â rhoi'r gorau i ysmygu yn ystod beichiogrwydd. | ▪ Bellach mae 40% o Fydwragedd Cymunedol wedi cael eu hyfforddi i ddarparu cefnogaeth rhoi'r gorau i ysmygu - negeseuon ymyrraeth gynnar<br>▪ a mynd ati i ddangos y ffordd i |

| Elfennau/Ffactorau Risg sy'n Hysbys | Bwriad | Cynllun | Cynnydd |
|---|---|---|---|
| | | | ferched i Wasanaethau Rhoi'r Gorau i Ysmygu Cymru.<br>▪ Bydd profi Carbon Monocsid yn ystod beichiogrwydd yn cael ei roi ar beilot yn ardal y Fflint. |
| Merched sy'n byw mewn ardaloedd o Amddifadedd Cymdeithasol | Mae babanod yn cael eu geni'n iach | Mae ymwneud parhaus yn bodoli â datblygiad prosiect Teuluoedd yn Gyntaf ac â phrosiectau penodol e.e. mentrau Dechrau'n Deg yn y Gymuned. | Adolygiad parhaus o ddarpariaeth yng ngoleuni anghenion y boblogaeth sy'n cael eu cyrchu bob blwyddyn. |
| Merched o grwpiau ethnig lleiafrifol | Mae babanod yn cael eu geni'n iach | ▪ Cyfarwyddyd NICE am Beichiogrwydd a Ffactorau Cymdeithasol Cymhleth yn cael eu rhoi ar waith mewn canllawiau ymarfer lleol. | ▪ Mae Cyfarwyddyd NICE wedi cael ei integreiddio mewn polisïau ac ymarfer lleol.<br>▪ Adolygiad o Wasanaethau Mamolaeth, Newydd-anedig, Paediatrig ac Iechyd Plant lleol - argymhellion yn adlewyrchu anghenion y boblogaeth leol. |
| Mamau yn eu harddegau | Mae babanod yn cael eu geni'n iach | ▪ Gweithio mewn partneriaethau ag Iechyd Cyhoeddus Cymru i gyflwyno'r prosiect LARC.<br>▪ Gweithio mewn partneriaeth â Grŵp Rhaglen Glinigol Plant a Phobl Ifanc i ddatblygu mynediad cyfartal at addysg rhyw a pherthnasau mewn ysgolion ar draws Gogledd Cymru.<br>▪ Bydwraig Beichiogrwydd yn ystod yr Arddegau mewn swydd. | ▪ Cyflwyno'r prosiect yn lleol yn y cyfnod cynllunio.<br>▪ Yn barhaus. |
| Alcohol | Mae babanod yn cael eu geni'n iach | ▪ Mewn partneriaeth ag Iechyd Cyhoeddus Cymru lleol, adolygu tystiolaeth i ddarparu gwybodaeth ar gyfer dull systematig a chydlynol o fynd i'r afael â Chamddefnyddio Alcohol a Sylweddau yn ystod | ▪ Datblygiadau cenedlaethol wedi'u nodi o fewn Iechyd Cyhoeddus. Darpariaeth leol negeseuon allweddol i ferched |

| Elfennau/Ffactorau Risg sy'n Hysbys | Bwriad | Cynllun | Cynnydd |
|---|---|---|---|
| | | beichiogrwydd, a'i ddatblygu – yn gysylltiedig â gwaith Sefydliad Iechyd y Cyhoedd. | yn barhaus fel gofal fel mater o drefn. |

## Ymarfer ar Sail Tystiolaeth - Atal Cyn Geni

| Cyfarwyddyd/Ymarfer | Bwriad | Cynnydd |
|---|---|---|
| "Antenatal Care Guidance: routine care for healthy pregnant women" NICE. | Mae babanod yn cael eu geni'n iach | ▪ Mae Cyfarwyddyd ac ymarfer lleol wedi'u seilio ar y canllawiau hyn.<br>▪ Mae archwiliadau rheolaidd yn cael eu cynnal i sicrhau bod gofal yn adlewyrchu cyfarwyddyd.<br>▪ Mae beichiogrwydd sydd â risg o gymhlethdodau a marw-enedigaethau yn cael eu nodi ar adeg bwcio ac mae'r risg yn cael ei hasesu yn barhaus yn ystod y beichiogrwydd ac yn ystod pob cyswllt clinigol - ac mae merched risg uchel yn cael eu cyfeirio yn briodol i'r Tîm Obstetrig neu asiantaethau/timau meddygol eraill perthnasol yn unol ag anghenion clinigol. Yna bydd gofal yn cael ei gydlynu gan y fydwraig a enwyd yn unol â "Midwifery 20:20".<br>▪ Yna bydd Cynlluniau Gofal arbennig yn cael eu datblygu i gynyddu lles gymaint â phosibl a lleihau risg yn unol â chyfarwyddyd a seiliwyd ar dystiolaeth leol.<br>▪ Mae hanes blaenorol cymhlethdodau beichiogrwydd a marw-enedigaethau yn cael eu cyfeirio i'r tîm obstetrig a chytunir ar gynllun penodol â threfniadau monitro. |
| Cyfarwyddyd a Phrotocolau Sgrinio Cyn Geni Cymru. | Mae babanod yn cael eu geni'n iach | Mae BIPBC yn cydymffurfio â Safonau a Chyfarwyddyd Cenedlaethol SCG Cymru. Mae safonau a chydymffurfiad yn cael eu monitro bob chwarter. |
| Sgrinio Twf Ffetws | Mae babanod yn cael eu geni'n iach | Mae polisïau/cyfarwyddyd ac ymarfer lleol yn adlewyrchu canllawiau Gofal Cyn Geni NICE o ran mesur uchder y ffwndis |

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| | | symffysis. Mae unrhyw wyriad yn cael ei gyfeirio yn briodol ar gyfer asesiad pellach o angen a monitro. |
| Lleihad mewn Symudiadau'r Ffetws (RFM) Cyflwyniad RCOG – "Green-top Guideline 57 – Reduced Fetal Movements". | Mae babanod yn cael eu geni'n iach | ▪ Mae gwybodaeth ar gyfer staff a chleifion wedi cael ei chyhoeddi yn y flwyddyn ddiwethaf parthed rheoli RFM.<br>▪ Mae llwybr/cyfarwyddyd lleol ar gyfer rheoli RFM ar sail cyfarwyddyd y RCOG wedi cael ei ddatblygu ac ar hyn o bryd mae allan ar gyfer ymgynghori cyn ei ddilysu.<br>▪ Hefyd mae taflenni gwybodaeth i gleifion sy'n adlewyrchu cyfarwyddyd y RCOG wedi cael eu datblygu ac maent yn aros am gymeradwyaeth derfynol. |

## Mecanweithiau Monitro/Adrodd ar gyfer marw-enedigaethau.

Adroddir i LIC am bob genedigaeth fyw a marw-enedigaeth fel crynodeb chwarterol gorfodol ar y QSI.
Adroddir i Arolwg Amenedigol Cymru Gyfan am bob marw-enedigaeth.
Adroddir i Fwrdd GRhG Merched bob mis am farw-enedigaethau ar Ddangosfwrdd Mamolaeth y RCOG.
Adolygir pob marw-enedigaeth yn fewnol gan y GRhG Merched a bydd gwersi a ddysgwyd yn cael eu rhannu ar draws y gwasanaeth.
Adroddir i LIC am bob marw-enedigaeth mewn-enedigol a bydd SIR priodol yn cael ei gynnull. Bydd y GRhG Merched yn monitro argymhellion a chynlluniau gweithredu unrhyw ddysgu, gan y Grŵp Diogelwch Cleifion lleol, yn y Bwrdd Iechyd a bydd newyddion diweddaraf yn cael ei ddarparu yn syth i LIC yn unol â'r amserlen.



## Datblygiadau Cenedlaethol – 1000 o Fywydau – Ymarfer Cwmpasu Grŵp Gwaith Cenedlaethol Marw-Enedigaeth

- Bydd Arweinydd BIPBC yn cael ei nodi i arwain y gwaith hwn ac adrodd yn ôl i'r ymarfer cwmpasu.

# Y Pwyllgor Iechyd a Gofal Cymdeithasol

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|---|---|
| Lleoliad: | **Canolfan Catrin Finch, Prifysgol Glyndŵr, Wrecsam** |
| Dyddiad: | **Dydd Iau, 14 Mehefin 2012** |
| Amser: | **10:45 – 13:00** |

Cynulliad Cenedlaethol Cymru
National Assembly for Wales

Gellir gwylio'r cyfarfod ar Senedd TV yn:
http://www.senedd.tv/archiveplayer.jsf?v=cy_800000_14_06_2012&t=0&l=cy

## Cofnodion Cryno:

| | |
|---|---|
| Aelodau'r Cynulliad: | **Mark Drakeford (Cadeirydd)**<br>**Mick Antoniw**<br>**Rebecca Evans**<br>**Vaughan Gething**<br>**William Graham**<br>**Elin Jones**<br>**Kirsty Williams** |
| Tystion: | **Matthew Flinton, BUPA**<br>**Mario Kreft, Fforwm Gofal Cymru**<br>**Jim McColl, Four Seasons**<br>**Peter Regan, cartref gofal Haulfryn**<br>**Sandra Regan, cartref gofal Haulfryn**<br>**Eithne Wallis, Terra Firma**<br>**Mary Wimbury, Fforwm Gofal Cymru** |
| Staff y Pwyllgor: | **Meriel Singleton (Clerc)**<br>**Catherine Hunt (Dirprwy Glerc)**<br>**Stephen Boyce (Ymchwilydd)** |

### 1. Cyflwyniad, ymddiheuriadau a dirprwyon

1.1 Cafwyd ymddiheuriadau gan Darren Millar, Lynne Neagle a Lindsay Whittle. Nid oedd unrhyw ddirprwyon.

### 2. Ymchwiliad i ofal preswyl i bobl hŷn – Tystiolaeth gan ddarparwyr preifat

2.1 Bu'r tystion yn ateb cwestiynau gan aelodau o'r Pwyllgor ynghylch gofal preswyl i bobl hŷn.

2.2 Cytunodd Mario Kreft i ddarparu gwybodaeth ysgrifenedig am y trefniadau trwyddedu sydd wedi'u cynnwys yn y Papur Gwyn ar Wasanaethau Cymdeithasol.

2.3 Cytunodd Matthew Flinton i ddarparu copi o'r dystiolaeth a gyflwynwyd gan BUPA i Gomisiwn Dilnot; gwybodaeth ysgrifenedig am drosiant y cwmni mewn perthynas â chartrefi gofal ym Mhowys; a rhagor o wybodaeth ynghylch a oes angen i bobl symud rhwng cartrefi gofal BUPA ym Mhowys wrth i'w cyflwr newid neu waethygu a pa effaith y gallai hyn ei chael o gofio am natur wledig y sir.

## 3. Papurau i'w nodi

3.1 Nododd y Pwyllgor gofnodion y cyfarfod a gynhaliwyd ar 24 a 30 Mai.

### 3a. Y Flaenraglen Waith - Haf 2012

3.2 Nododd y Pwyllgor y papur ar y flaenraglen waith ar gyfer haf 2012.

**TRAWSGRIFIAD**

Gweld trawsgrifiad o'r cyfarfod.