National Assembly for Wales Health and Social Care Committee

One-day inquiry into stillbirths in Wales

February 2013

The National Assembly for Wales is the democratically elected body that represents the interests of Wales and its people, makes laws for Wales and holds the Welsh Government to account.

An electronic copy of this report can be found on the National Assembly's website **www.assemblywales.org**

Copies of this report can also be obtained in accessible formats including Braille, large print; audio or hard copy from:
Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

Tel: 029 2089 8403 Fax: 029 2089 8021

Email: HSCCommittee@wales.gov.uk

© National Assembly for Wales Commission Copyright 2013
The text of this document may be reproduced free of charge in any format or medium providing that it is reproduced accurately and not used in a misleading or derogatory context. The material must be acknowledged as copyright of the National Assembly for Wales Commission and the title of the document specified.

National Assembly for Wales Health and Social Care Committee

One-day inquiry into stillbirths in Wales

February 2013

Health and Social Care Committee

The Committee was established on 22 June 2011 with a remit to examine legislation and hold the Welsh Government to account by scrutinising expenditure, administration and policy matters encompassing: the physical, mental and public health of the people of Wales, including the social care system.

Current Committee membership



Mark Drakeford (Chair) Welsh Labour Cardiff West



Mick Antoniw Welsh Labour Pontypridd



Rebecca Evans Welsh Labour Mid and West Wales



Vaughan Gething Welsh Labour Cardiff South and Penarth



William GrahamWelsh Conservatives
South Wales East



Elin Jones Plaid Cymru Ceredigion



Darren Millar Welsh Conservatives Clwyd West



Lynne NeagleWelsh Labour
Torfaen



Lindsay Whittle Plaid Cymru South Wales East



Kirsty WilliamsWelsh Liberal Democrats
Brecon and Radnorshire

Contents

Chair's foreword	5
Glossary of terms	7
The Committee's key conclusion and recommendations	8
1. Introduction	11
2. Stillbirth: the facts	13
What is stillbirth?	13
How common is it?	13
What causes it?	14
Are there warning signs?	16
Restricted foetal growth	16
Reduced foetal movements	17
'High risk' and 'low risk' pregnancies	18
3. Awareness of stillbirth and its risk factors	20
Public awareness	20
Professional awareness	22
Training	23
Guidance	24
Standard and continuity of care	27
4. Identifying and assessing the risk of stillbirth	29
Identifying high risk babies	29
Post-term delivery	30
Possible screening methods	32
Resources	35
5. Understanding the underlying causes of stillbirth	38
Health inequalities	38
Data and review	39
Perinatal review	39
Post-mortem	43
Research	45

Annex A - Witnesses	48
Annex B - Written evidence	50

Chair's foreword

The stillbirth of a child is a tragedy which devastates families. Yet our awareness, as a population, of stillbirth – particularly its causes and what can be done to prevent it – is worryingly low.

There are approximately four stillbirths in Wales every week. In 2011, 150 Welsh babies were stillborn. While neonatal and infant mortality rates have improved significantly over the last decade, stillbirth rates have barely changed since the early 1990s. The stillbirth rate in Wales – and across the UK – remains higher than in most other European countries. In a recent Lancet analysis, the UK ranks 33rd out of 35 countries of similar income in terms of the rate of stillborn babies.

The evidence we heard during our inquiry was startling. Stillbirth remains more common than Down's syndrome and ten times more common than cot death. It is Wales's most common form of child mortality. And yet we do not talk about it. We fail to discuss it as a matter of course with our expectant parents; the training of our health professionals about the subject is patchy; we struggle to review stillbirths when the tragedy occurs; and we fail to undertake the vital research needed to understand its underlying causes.

As a Committee we are in no doubt that the current rate of stillbirths in Wales is unacceptable. More needs to be done to raise public and professional awareness of stillbirths and the risk factors that contribute towards it. More also needs to be done to understand the underlying causes of stillbirth, particularly with over half of all occurrences currently classified as 'unexplained'. Careful consideration is also needed of the relatively small steps that can be taken to improve stillbirth rates. We cannot expect one action to transform the whole picture – the nature of stillbirths is too complex to assume that a simple solution exists. But to refrain from doing things we already know can help, just because we cannot solve everything at the moment, is not acceptable.

While across the UK the numbers of stillbirths have remained largely unchanged for over a quarter of a century, we also know that other countries have succeeded in reducing their rates of stillbirth over that same time frame. It is now incumbent on us to do the same in Wales

by raising our awareness of stillbirths, investing our efforts in understanding its underlying causes, and focusing our efforts on preventing these often avoidable, yet tragically frequent, losses.

We hope our findings and recommendations to the Welsh Government will draw attention to an area too long neglected and in much need of improvement.

Mark Treakeras.

Mark Drakeford AM

Chair of the Health and Social Care Committee February 2013

Glossary of terms

Stillbirth

Stillbirth refers to the death of a baby after 24 weeks of pregnancy but before birth. A miscarriage is the loss of a baby before 24 weeks of pregnancy.

Intra-partum stillbirth

An intra-partum stillbirth refers to the death of a baby during labour.

Intra-uterine / antepartum stillbirth

An intra-uterine or antepartum stillbirth refers to the death of a baby in the womb.

Small for gestational age (SGA) foetus

A term used to describe a situation where a baby fails to reach a certain expected weight threshold by particular stages of a pregnancy.

Intrauterine growth restriction (IUGR)

A term which refers to the poor growth of a baby in the mother's womb.

Antenatal

Of, relating to, characteristic of, or denoting the period before a baby is born.

Neonatal

Of, relating to, or characteristic of a new born child.

Postnatal

Of, relating to, characteristic of, or denoting the period after childbirth.

Perinatal

Of, or relating to the time, usually a number of weeks, immediately before and after birth.

The Committee's key conclusion and recommendations

The Committee's key conclusion and recommendations to the Welsh Government are listed below. Please refer to the relevant pages of the report to see the supporting evidence:

Key conclusion: There is no single step which, if taken, would remedy the risk of stillbirths in Wales. Yet, we believe that progress towards that end has been held back by a frame of mind in which the search for the perfect has driven out the possible. Consideration of the relatively small steps that have already been devised – or can be devised relatively straightforwardly – to make a difference to the rates of stillbirth in Wales is long overdue. These steps need to be taken now. (Page 35)

Recommendation 1. Public awareness of stillbirth and its risk factors is essential to reducing stillbirth rates in Wales. We recommend that the Welsh Government take an active lead – via the recently established National Stillbirth Working Group – in developing key public health messages as a matter of priority. This will raise the awareness of expectant parents and those planning to start a family of the risks of stillbirth and allow them to make more informed choices about their health and pregnancy. (Page 22)

Recommendation 2. We recommend that the Welsh Government work with professional bodies and health boards in Wales to ensure that all expectant parents receive adequate information from clinicians and midwives about stillbirth and its associated risks. Discussion of stillbirth should form a routine part of the conversation held between health professionals and expectant parents during the course of a pregnancy. (Page 22)

Recommendation 3. We recommend that the Welsh Government work with professional and regulatory bodies, and relevant academic institutions, to ensure that stillbirth, its associated risk factors and interventions, and bereavement training are more prominently featured in Welsh midwifery and obstetric training curricula. The Welsh Government should work with health boards to monitor and regularly review the training needs and competence of health professionals in relation to stillbirth. (Page 24)

Recommendation 4. We recommend that the Welsh Government scope the viability of establishing a maternity network to drive the standardisation of care across Wales. We believe that at least a virtual clinical network should be established within the next 12 months.

(Page 28)

Recommendation 5. We recommend that the Welsh Government undertake a review of the number of women in Wales who deliver more than thirteen days after their due date. The outcome of those pregnancies and the factors that led to the decision not to induce within the recommended guideline time should be considered in every case. Further consideration ought to be given to whether women with other high risk factors such as advanced maternal age, smoking or weight should be induced closer to their due date. (Page 31)

Recommendation 6. We recommend that the Welsh Government investigate and report on evidence presented to the Committee that having to seek specialist foetal medicine consultations outside Wales now exceeds the cost of providing the service within Wales. The Welsh Government should also explore the proposal that specialist foetal medicine services should be commissioned at the tertiary rather than secondary level. (Page 37)

Recommendation 7. We recommend that a national minimum standard for reviewing perinatal deaths should be developed and rolled out across Wales. We also recommend that a wider, more imaginative approach to Welsh Government funding for medical research and investigation is adopted, and that the Welsh Government seek detailed costings for a national perinatal audit for Wales from the All Wales Perinatal Survey. We believe that the initial investment in this audit could yield significant benefits in the future detection and prevention of stillbirth. (Page 42)

Recommendation 8. We recommend that the Welsh Government publish a detailed plan of how it proposes to tackle the problem caused by the low rate of post-mortem for stillborn babies. The plan should include:

 details of how training will be delivered to health professionals in order that they are better equipped to raise this very difficult issue with grieving parents;

- details of what improved information will be developed for parents so that they are able to make more informed decisions;
 and
- an assessment of the actions needed to improve the provision of perinatal pathology. (Page 45)

Recommendation 9. In the absence of the large charities and interested industry that fund the bulk of research for other health conditions, we recommend that the Welsh Government, through the National Institute for Social Care and Health Research's Clinical Research Centre, commission a comprehensive piece of work on the underlying causes of stillbirth. This work should be undertaken in cooperation with health professionals and academics with expertise in this field, and should draw on international knowledge of stillbirth. This work should be completed by the end of this Assembly. (Page 47)

1. Introduction

- 1. Stillbirth is the most common form of child mortality in Wales.¹ In 2011, 150 Welsh babies were stillborn.² As a cause of death for children, stillbirths are ten times more common than cot death, forty times more common than child road deaths, and eighty times more common than childhood meningitis.³
- 2. It is these stark figures that compelled the Health and Social Care Committee to undertake a one-day inquiry into stillbirths in Wales. The purpose of our inquiry was to examine the awareness, implementation and effectiveness of current guidance and recommendations across the different sectors with regard to stillbirth prevention, and where potential improvements could be made.
- 3. Shortly after the launch of our inquiry the Welsh Government announced its intention to establish a National Stillbirth Working Group to:
 - review the available evidence base in relation to prevention of stillbirth and neonatal deaths;
 - develop a strategy aimed at reducing levels of stillbirths and neonatal deaths;
 - identify and promote further research within Wales to improve understanding of why stillbirths and neonatal deaths occur;
 - facilitate the sharing and promulgation of best practice across Wales;
 - identify constraints and solutions to specific clinical and operational issues;
 - provide the Welsh Government with intelligence on local issues and progress with implementation;

¹ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 16]</u> 28 June 2012 [accessed 17 January 2013]

² All Wales Perinatal Survey <u>Annual Report 2011 (v2</u>) p4 - table 1, 10 December 2012 [accessed 17 January 2013]

³ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB6 - Sands</u> p5 [accessed 17 January 2013]

- work with Sands, the Stillbirth and Neonatal Death charity, and other appropriate groups to improve public awareness of these issues.⁴
- 4. The Committee welcomes the establishment of this group and hopes that our findings will assist its work. An early indication of the importance of the Group's work came in an update of its activities, published in January 2013 which suggested, inter alia, that at least 1 in 3 stillbirths are associated with substandard care.⁵
- 5. During the course of our inquiry we heard from bereaved parents, doctors, midwives, academics and charities about the impact stillbirth has on families. We learned that although neonatal and infant mortality rates have improved significantly over the last decade, stillbirth rates have barely changed since the early 1990s. Despite the medical advances of the last quarter of a century, approximately four stillbirths a week still occur in Wales. Both the Committee and our witnesses were of the unanimous view that this rate is unacceptable in twenty first century Wales.
- 6. We would like to thank all those who gave evidence to the Committee to inform our inquiry, particularly those who attended the day of oral evidence sessions on 28 June 2012. Some of those who spoke to us had themselves experienced the tragedy of stillbirth personally; our heartfelt thanks to them for their willingness to break the silence that so often accompanies this subject.
- 7. We would like to note our particular thanks to Isobel Martin founder of the Holly Martin Stillbirth Research Fund, established in memory of her daughter who was stillborn in 1985 who drew our initial attention to this important area of work.

913] bid <u>Additional information – Al 1 – National Stillbirth Working (</u>

⁴ National Assembly for Wales, Health and Social Care Committee <u>HSC(4)-19-12 paper</u> <u>10 - Evidence from the Welsh Government</u> p6, 28 June 2012 [accessed 17 January 2013]

⁵ Ibid <u>Additional information - Al 1 - National Stillbirth Working Group</u> p2 [accessed 23 January 2012]

2. Stillbirth: the facts

What is stillbirth?

8. In the UK, stillbirth refers to the death of a baby after 24 weeks of pregnancy but before birth. The loss of a baby before 24 weeks of pregnancy is referred to as a miscarriage.

How common is it?

- 9. Stillbirth is the most common cause of child mortality in Wales. The stillbirth rate in Wales has remained between 4.2 and 5.0 per 1,000 registrable births since the 1990s. 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 1,000 live births in 2005 and has remained around the same rate for the last 5 years.⁶ Approximately one in every two hundred babies born after 24 weeks is stillborn in Wales. This equates to around 180 stillbirths on average every year.⁷
- 10. Although similar to stillbirth rates across the rest of the UK, stillbirth rates in Wales remain higher than in other European countries. A recent analysis by the Lancet⁸ showed that similar high income countries have lower stillbirth rates, with the UK ranking 33rd out of 35 similar nations. Furthermore, while other countries are reducing their stillbirth rate most notably in Scandinavia rates in Wales and England have not changed for more than a decade.⁹
- 11. While some differences in stillbirth rates may be attributable to different measuring methods in different countries¹⁰, Wales's inability to reduce its rate remains to be understood.¹¹ Yet we know, as the British Medical Association (BMA) told the Committee, that if Wales

_

⁶ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u>
Response SB1 -All Wales Perinatal Survey p1 [accessed 17 January 2013]
7 Ibid Consultation Response SB4 - Dr. Alexander Heazell p1 [accessed 17 January 2013]

⁷ Ibid <u>Consultation Response SB4 - Dr Alexander Heazell</u> p1 [accessed 17 January 2013]

⁸ V Flenady et al. *Stillbirths: the way forward in high-income countries* The Lancet 2011, Vol. 377, Issue 9778, Pages 1703-1717

⁹ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB6 - Sands</u> p5 [accessed 17 January 2013]

¹⁰ Ibid <u>Consultation Response SB12 - British Medical Association</u> p2 [accessed 17 lanuary 2013]

¹¹ Ibid <u>Consultation Response SB1 -All Wales Perinatal Survey</u> p1 [accessed 17 January 2013]

were to reduce its stillbirth rate to levels comparable with Scandinavian countries, there would be at least 64 fewer stillbirths here each year.¹²

What causes it?

12. The Committee was told that, in almost half of all cases of stillbirths, the direct cause of the baby's death cannot be established.¹³ Where a direct cause of death can be established, one of the factors listed in the table below is usually identified as the cause or a contributory factor.

Table 1 - Causes of stillbirth¹⁴

Bleeding (haemorrhage)

The mother bleeding either before or during labour.

Problems with the placenta

The placenta can separate from the womb before the baby is born (placental abruption), or the placenta can fail to provide the baby with sufficient oxygen and nutrients which means that the baby does not grow properly (intra-uterine growth restriction (IUGR) - this is associated with one-third of all stillbirths).

Problems with the umbilical cord

The cord can slip down through the entrance of the womb before the baby is born (known as cord prolapse and it occurs in about 1 in 200 births), or it can wrap around the baby's neck.

Pre-eclampsia

A condition that can cause high blood pressure in the mother; mild pre-eclampsia can affect up to 10 per cent of first time pregnancies and more severe pre-eclampsia can affect 1-2 per cent of pregnancies.

Congenital abnormality

This is a genetic physical defect in the baby.

Maternal infection or condition

This can include a liver disorder called obstetric cholestasis (which causes a build-up of bile acids in the body) or an infection.

¹² National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB12 - British Medical Association</u> p2 [accessed 17 January 2013]

¹³ Ibid <u>Consultation Response SB1 -All Wales Perinatal Survey</u> p6 [accessed 17 January 2013

¹⁴ NHS Choices, Stillbirth - Causes [accessed 17 January 2012]

13. There are also factors which increase the risk of stillbirth, with stillbirths occurring more frequently when they are present. Some of these factors are outlined in Table 2.

Table 2 - Risk factors for stillbirth¹⁵

Twin or multiple pregnancies

The odds of having a stillbirth increase with multiple births. In Wales the stillbirth rate was 14.5 per 1,000 twin births and 11.3 per 1,000 triplet births for the 9 years from 2002 to 2010. This compares with a rate of 4.5 in 1,000 for pregnancies involving a single baby for the same period [the figures quoted should be interpreted with caution as the number of multiple pregnancies are relatively small]. 16

Maternal age

The odds of having a stillbirth increase steadily with age in mothers over the age of 35, doubling for mothers over 40.¹⁷ The risk of a stillbirth is also higher for mothers under 20 years of age.¹⁸

Maternal smoking

Up to 7 per cent of stillbirths are attributable to maternal smoking. Women who smoke more than 10 cigarettes a day double their risk of stillbirth. In Wales 16 per cent of mothers continue to smoke through pregnancy.¹⁹

Maternal obesity

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.²⁰

Social deprivation

Women living in the most deprived areas are 1.7 times as likely to suffer a stillbirth compared with women living in the least deprived areas.²¹

¹⁵ Sands, Causes and risk factors for stillbirth [accessed 17 January 2013]

¹⁶ Information provided by the All Wales Perinatal Survey

¹⁷ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB6 - Sands</u> p6 [accessed 17 January 2013]

¹⁸ Sands, *Causes and risk factors for stillbirth* [accessed 17 January 2013]

¹⁹ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB6 - Sands</u> p6 [accessed 17 January 2013]

²⁰ Ibid <u>Consultation Response SB5 - Public Health Wales</u> p6 [accessed 17 January 2013]

²¹ Ibid <u>Consultation SB14 - Cwm Taf Health Board</u> p1 [accessed 17 January 2013]

14. Evidence to the Committee also identified a strong link between post-term delivery and stillbirth. According to Mr Bryan Beattie, Consultant in Foetal Medicine at the University Hospital Wales and representative of the Royal College of Obstetricians and Gynaecologists, placental failure increases as a pregnant woman passes her due date. This, in turn, increases the risk of stillbirth.²² As such, the recommendation in the UK has been to induce labour at around 10 to 12 days past the due date as there is increasing placental failure beyond that point. Post-term delivery is discussed in more detail in chapter 4.

Are there warning signs?

- 15. The Committee was told that, to date, clinicians' understanding of what causes stillbirth and what its warning signs are has been limited. Although the risk factors and causes outlined above have been identified, almost half of all stillbirths remain unexplained. Evidence to the Committee suggested strongly that risk assessment for stillbirth is not very advanced and further research is needed to better understand its underlying causes.²³
- 16. Written and oral evidence submitted to this inquiry does suggest, however, that two factors in addition to those outlined earlier may act as warning signs for stillbirth: restricted foetal growth and reduced foetal movements.

Restricted foetal growth

17. Restricted foetal growth occurs when a baby fails to reach a certain expected weight threshold by a certain point during a pregnancy. A baby with restricted growth in the womb is often described as 'small for gestational age' (SGA). A variety of methods are used to detect babies who are small for their gestational age including abdominal palpation, measurement of symphyseal fundal height²⁴ and ultrasound scanning.

16

²² National Assembly for Wales, Health and Social Care Committee <u>RoP [para 154]</u> 28 June 2012 [accessed 17 January 2013]

²³ Ibid <u>Consultation Response SB11 - Royal College of Obstetricians and Gynaecologists</u> p1 [accessed 17 January 2013]

²⁴ A measurement is taken from the pubic bone (symphysis pubis) to the top of the uterus or fundus, giving a fundal height in centimetres. The measurement in centimetres should closely match the foetus gestational age in weeks, within 1 or 2cm e.g. a pregnant woman's uterus at 22 weeks should measure 20 to 24cm.

- 18. According to Sands, growth restriction of this kind is strongly associated with stillbirth, with 60 per cent of stillborn babies presenting signs of restricted growth.²⁵ Professor Jason Gardosi of the West Midlands Perinatal Institute provided evidence that pregnancies with intrauterine growth restriction (IUGR)²⁶ have a seven fold increased risk of stillbirth. According to his work, this risk is significantly reduced when IUGR is detected antenatally that is, before the baby is born. It was his view that a large proportion of the number of stillbirths classified as 'unexplained' are, in fact, attributable to growth restriction.²⁷
- 19. Despite this recognised link, the Welsh Government's evidence acknowledges that identification of growth restriction is very poor in Wales and that more work needs to be done in this area.²⁸ This is explored further in chapter 4.

Reduced foetal movements

- 20. Foetal movements are first perceived between 18 and 20 weeks of pregnancy and rapidly conform to an observable pattern. Foetal movements consist of any discrete kick, flutter, swish or roll. A significant reduction or sudden alteration in foetal movement could be seen as an important clinical sign and reduced or absent foetal movements could be a warning sign of foetal distress.
- 21. Evidence to the Committee notes, however, that:
 - there is currently no standard definition of reduced foetal movements;
 - the relationship between a mother's perception of a reduction in foetal movement and stillbirth is not fully understood; and

17

²⁵ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 76]</u> 28 June 2012 [accessed 17 January 2013]

²⁶ Intrauterine growth restriction (IUGR) refers to poor growth of a baby while in the mother's womb during pregnancy. It can be caused by a variety of factors including poor maternal nutrition or lack of adequate oxygen supply to the foetus.

²⁷ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB13 – West Midlands Perinatal Institute</u> p1[accessed 17 January 2013] ²⁸ Ibid <u>HSC(4)-19-12 paper 10 - Evidence from the Welsh Government</u> p4, 28 June 2012 [accessed 17 January 2013]

- there remains uncertainty about which investigations should be carried out after a mother presents with reduced foetal movements.²⁹
- 22. Practice in Norway, where a comprehensive strategy has been introduced for improving the management of decreased foetal movements, was cited during the inquiry. Although those giving evidence noted that there is no definitive evidence to show that this strategy has led to the reduction in stillbirth rates in Norway, circumstantial evidence suggests that the reduction accompanied this programme of tackling decreased foetal movement management.³⁰
- 23. The Welsh Government's evidence to the Committee acknowledged that although formal recording of foetal movements is not recommended by current National Institute for Health and Clinical Excellence (NICE) guidelines, evidence does suggest that a significant reduction or sudden change in movement is an important clinical sign.³¹ Challenges relating to monitoring and reacting to reduced foetal movements are explored in more detail in chapter 4.

'High risk' and 'low risk' pregnancies

- 24. All pregnancies are classified under the conventional categories of high risk or low risk, depending on some of the factors outlined earlier in this report. A mother who is clinically obese, for example, will be classified high risk from the beginning of her pregnancy.
- 25. In written and oral evidence, the majority of witnesses highlighted the fact that the care and management of pregnancies deemed high risk has led to improved stillbirth rates.³² This, it was argued, is partly attributable to improved therapies and surveillance that is, improved care but also to the fact that the obstetrician is able to deliver the baby when the risk of remaining in the womb outweighs the risk of premature birth.³³

²⁹ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB4 - Dr Alexander Heazell</u> p1 [accessed 17 January 2013]

³⁰ Ibid *RoP [para 42]* 28 June 2012 [accessed 17 January 2013]

³¹ Ibid <u>HSC(4)-19-12 paper 10 - Evidence from the Welsh Government</u> p3, 28 June 2012 [accessed 17 January 2013]

³² Ibid <u>Consultation Response SB12 - British Medical Association</u> p4 [accessed 17 January 2013]

³³ Ibid

26. It is clear, therefore, that most stillbirths occur in pregnancies classified as 'low risk' – that is, where no maternal risk has been identified.³⁴ According to the Royal College of Obstetricians and Gynaecologists:

"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."³⁵

27. The classification of pregnancies as high risk and low risk and the associated impact this has on care is explored in chapter 4.

Gynaecologists p1 [accessed 17 January 2013]

19

³⁴ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB12 - British Medical Association</u> p5 [accessed 17 January 2013]
35 Ibid <u>Consultation Response SB11 - Royal College of Obstetricians and</u>

3. Awareness of stillbirth and its risk factors

- 28. In written and oral evidence to this inquiry the majority of witnesses highlighted a lack of awareness and understanding not only among the general public but, more alarmingly, among some health professionals about stillbirth. The relative ignorance of its associated risk factors and appropriate interventions if risks are identified was startling.³⁶
- 29. Strong evidence emerged suggesting that stillbirth is a taboo subject, shied away from by many health professionals when undertaking early conversations with prospective parents. It was also argued that risk identification and assessment is variable across Wales. These issues are explored in this chapter.

Public awareness

30. Sands told the Committee that:

"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 more deaths are rarely mentioned."³⁷

- 31. Evidence presented to the Committee suggests a general reluctance among medical professionals to discuss stillbirth and its risk factors with expectant parents. According to the Royal College of Obstetricians:
 - "...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

³⁶ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 23]</u> 28 June 2012 [accessed 17 January 2013]

³⁷ Ibid <u>Consultation Response SB6 - Sands</u> p7 [accessed 17 January 2013]

can be normalised, as it is for cot death and Down's syndrome."38

32. The tendency to shy away from discussing stillbirths was acknowledged in evidence by midwife,³⁹ doctor⁴⁰ and local health board⁴¹ representatives. Furthermore, evidence suggested that expectant parents require more information about stillbirth in order to make informed choices about their pregnancies, for example to stop smoking or drinking to reduce their risk. Public Health Wales told the Committee:

"It is important when we talk to women not to induce fear but to have an open and honest and a partnership approach, because they need to make some decisions about their risk and they need to have all the information to make an informed choice about whether to carry on with a specific behaviour and whether to access some of the support that we can offer to address some of their risk factors."⁴²

33. The Welsh Government's Chief Nursing Officer acknowledged the historical reluctance amongst clinicians and health professionals to raise the issue of stillbirth and provide information on its risk factors. She told the Committee:

"We need to be much clearer in our message to mothers-to-be about some of the risk factors [of stillbirth] and make it much more obvious to them. In the past, professionals have been reluctant to raise it."43

34. The Committee welcomes the fact that improving public awareness of stillbirths and its associated risks falls within the remit of the newly established National Stillbirth Working Group. We also welcome the intention of the Group to work with Sands and other appropriate groups to deliver this work. We hope that the Group's work will very quickly move to incorporate activity to raise public awareness.

³⁸ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB11 - Royal College of Obstetricians and Gynaecologists</u> p1 [accessed 17 January 2013]

³⁹ Ibid *RoP [para 218]* 28 June 2012 [accessed 17 January 2013]

⁴⁰ Ibid *RoP [para 253]* 28 June 2012 [accessed 17 January 2013]

⁴¹ Ibid *RoP [para 421]* 28 June 2012 [accessed 17 January 2013]

⁴² Ibid *RoP [para 377]* 28 June 2012 [accessed 17 January 2013]

⁴³ Ibid *RoP [para 295]* 28 June 2012 [accessed 17 January 2013]

35. It is a matter of concern to us that health professionals are reluctant to raise stillbirth and its risk factors with expectant parents, despite the relative openness with which issues such as Down's syndrome and cot death are discussed. In our minds, ensuring that this dialogue takes place with all expectant mothers is crucial to tackling the stubbornly static rate of stillbirth in Wales. We agree with the BMA that:

"When you take your driving test, you discuss that you are going to put a seatbelt on because you might write yourself off in the car; that is a rare event, but we think about it every time we put a seatbelt on. Cot death is 10 times less common than stillbirth and we are shying away from discussing this. If we discuss stillbirth openly, people will know what to look for and will be able to park it in context so that they can get on with enjoying their normal pregnancy."

Recommendation 1: Public awareness of stillbirth and its risk factors is essential to reducing stillbirth rates in Wales. We recommend that the Welsh Government take an active lead - via the recently established National Stillbirth Working Group - in developing key public health messages as a matter of priority. This will raise the awareness of expectant parents and those planning to start a family of the risks of stillbirth and allow them to make more informed choices about their health and pregnancy.

Recommendation 2: We recommend that the Welsh Government work with professional bodies and health boards in Wales to ensure that all expectant parents receive adequate information from clinicians and midwives about stillbirth and its associated risks. Discussion of stillbirth should form a routine part of the conversation held between health professionals and expectant parents during the course of a pregnancy.

Professional awareness

_

36. Evidence provided to the Committee suggests that awareness among some health professionals of stillbirths and its risk factors is inadequate. The Royal College of Obstetricians and Gynaecologists

⁴⁴ National Assembly for Wales, Health and Social Care Committee *RoP [para 253]* 28 June 2012 [accessed 17 January 2013]

acknowledged that greater awareness among clinicians is required, and noted that there is a need to ensure that health professionals are made fully aware of the risk of stillbirth as part of their education. 45 This was reiterated by the Royal College of Midwives, who told the Committee that stillbirths and its associated risks must be more prominently featured in their training.46

Training

37. According to Dr Alexander Heazell, Clinical Lecturer in Obstetrics from the University of Manchester, clinical curricula fail to concentrate sufficiently on stillbirth. He told the Committee:

> "We surveyed a number of curricula and, surprisingly, in many midwifery colleges, stillbirth is covered for perhaps a day during a three-year course [...] If one in 200 people they look after is going to experience this, there needs to be a greater focus on it in the course. That is even more the case with medical curricula because there is such a pressure to fit a great deal in. Many medical schools are reducing their obstetric curricula rather than extending them."47

- 38. This suggested lack of awareness and limited training among health professionals is cited as the reason why many women who do exhibit risk factors are not identified during their pregnancies. 48 Both reduced foetal movements and restricted foetal growth are possible indicators of stillbirth (see paragraphs 17 - 23 for more information) however the Royal College of Midwives noted its concern that, despite training, inconsistencies exists in how professionals measure restricted foetal growth, for example.49
- 39. It was clear from evidence received by the Committee that health professionals' knowledge with regard to foetal growth restriction and reduced foetal movements varies. 50 Furthermore, the effectiveness of certain monitoring techniques, such as the tape measure for

⁴⁵ National Assembly for Wales, Health and Social Care Committee Consultation Response SB11 - Royal College of Obstetricians and Gynaecologists p1 [accessed 17 January 2013]

⁴⁶ Ibid RoP [paras 211 and 216] 28 June 2012 [accessed 17 January 2013]

⁴⁷ Ibid *RoP [para 130]* 28 June 2012 [accessed 17 January 2013]

 ⁴⁸ Ibid <u>Consultation Response SB6 - Sands</u> p7 [accessed 17 January 2013]
 49 Ibid <u>Consultation Response SB10 - Royal College of Midwives</u> p4 [accessed 17 January 20131

⁵⁰ See chapter 4

monitoring fundal height, are reliant on their being performed properly and any risk recognised and managed accordingly.

40. The Welsh Government confirmed that it is undertaking work to improve the training standards around cardiographic foetal monitoring to ensure that medical, nursing and midwifery practitioners are adequately skilled.⁵¹ Furthermore, it is also working with the Royal College of Midwives on auditing training on motivational interviewing with the aim of improving midwives' communication skills, particularly in relation to discussing difficult issues such as stillbirth.⁵² We hope that this will contribute to improving the unacceptable situation reported to the Committee in which some staff, on the one hand, feel ill-equipped to deal with parents who lose a child to stillbirth and some parents, on the other, report inadequate bereavement and counselling support following a stillbirth.

Recommendation 3: We recommend that the Welsh Government work with professional and regulatory bodies, and relevant academic institutions, to ensure that stillbirth, its associated risk factors and interventions, and bereavement training are more prominently featured in Welsh midwifery and obstetric training curricula. The Welsh Government should work with health boards to monitor and regularly review the training needs and competence of health professsionals in relation to stillbirth.

Guidance

41. In addition to insufficient training, evidence to our inquiry suggested that the implementation of relevant guidance (a list of which is provided in Table 3) is inconsistent across Wales.⁵³ This inconsistency is illustrated by the differing approaches to the implementation of guidance adopted by Betsi Cadwaladr Health Board,⁵⁴ Powys Health Board⁵⁵ and Cwm Taf Health Board⁵⁶.

⁵¹ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 290]</u> 28 June 2012 [accessed 17 January 2013]

⁵² Ibid *RoP [para 292]* 28 June 2012 [accessed 17 January 2013]

⁵³ Ibid <u>Consultation Response SB10 - Royal College of Midwives</u> p4 [accessed 17 January 2013]

⁵⁴ Ibid <u>Consultation Response SB3 - Betsi Cadwaladr University Health Board</u> p4 [accessed 17 January 2013]

⁵⁵ Ibid <u>Consultation Response SB9 - Powys Teaching Health Board</u> Annex - p2 [accessed 17 January 2013]

42. According to the Royal College of Midwives the inconsistent implementation of relevant guidance is attributable, at least in part, to a lack of training. In its view, more needs to be done to embed understanding of existing guidance in the on-going training and professional development of staff. 57

Table 3 - Current antenatal guidance

National Institute for Clinical Excellence (NICE) guidance

Antenatal care: routine care for the health pregnant woman⁵⁸
This guidance provides information for health professionals on best practice for baseline clinical and antenatal care of all pregnancies and provides evidence-based information on appropriate treatment in specific circumstances.

Royal College of Obstetricians and Gynaecologists guidance

Investigations and management of small for gestational age foetuses⁵⁹ The aim of this guideline is to make recommendations regarding the diagnosis and management of small-for-gestational-age (SGA) foetuses.

Reduced Foetal Movements⁶⁰

This guidance provides advice to guide clinicians regarding the management of women presenting with reduced foetal movements (RFM) during pregnancy. It reviews the risk factors for RFM in pregnancy and factors influencing maternal perception. It provides recommendations as to how women presenting in both the community and hospital settings should be managed.

Welsh Government guidance

A Strategic Vision for Maternity Services in Wales⁶¹ This document sets out the Government's expectations of NHS Wales in delivering safe, sustainable and high quality maternity services.

⁵⁶ National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB14 - Cwm Taf Health Board</u> p5 [accessed 17 January 2013]

⁵⁷ Ibid *RoP [para 225]* 28 June 2012 [accessed 17 January 2013]

⁵⁸ National Institute for Clinical Excellence (NICE), <u>Antenatal care: routine care for the health pregnant woman</u> CG62, March 2008 [accessed 17 January 2013]

⁵⁹ Royal College of Obstetricians and Gynaecologists <u>Investigations and management</u> of small for gestational age fetuses (Green top 31), November 2002 [accessed 17 January 2013]

⁶⁰ Royal College of Obstetricians and Gynaecologists <u>Reduced Fetal Movements</u> (Green top 57), February 2011 [accessed 17 January 2013]

⁶¹ Welsh Government <u>A Strategic Vision for Maternity Services in Wales</u> September 2011 [accessed 17 January 2013]

- 43. The BMA suggested that further work is needed to establish what obstacles prevent clinicians from implementing the guidance in its entirety.⁶² It told the Committee that clinicians sometimes query the usefulness of the guidance when it is based on what they perceive as limited evidence. Furthermore, it argued that clinicians may be disinclined to follow guidance, particularly in times of limited resources, which advises action where success is dependent on how likely the condition is to occur in the population.⁶³
- 44. Witnesses told the Committee that work is underway via the 1000 lives plus programme to build a consensus for Wales that overcomes these obstacles. The BMA told us that this work will begin by asking:
 - "...why people are not doing it [adhering to guidance] and whether there is a particular part of a particular guideline that is stopping them implementing the other 90% of the guideline."
- 45. Although we welcome efforts to build consensus and develop an all-Wales strategy aimed at reducing levels of stillbirths, detecting growth restriction and an agreed protocol on reduced foetal movements, we are convinced that more needs to be done, now, to deploy existing evidence-based guidance and to apply that guidance uniformly and consistently in practice. A lack of adherence to NICE guidance among clinicians is a theme that has arisen in inquiries prior to this one and continues to cause us concern.
- 46. We believe that existing and future guidance will only be as robust as the evidence on which it is based. Although questions have been raised about the efficacy of certain aspects of the current guidelines, we agree with Professor Gordon Smith that this is a two-step process: firstly, we need to ensure that our existing knowledge is implemented completely and consistently, and secondly, we need to work to generate the research that will transform the guidelines in five

⁶² National Assembly for Wales, Health and Social Care Committee Rop [para 226] 28 June 2012 [accessed 17 January 2013]

⁶³ Ibid *RoP [paras 221, 222 and 226]* 28 June 2012 [accessed 17 January 2013]

⁶⁴ Ibid *RoP [para 222]* 28 June 2012 [accessed 17 January 2013]

or ten years' time. 65 We address the issue of research and evidence relating to stillbirths and its underlying causes later in this report.

Standard and continuity of care

- 47. The relative failure of routine antenatal care to identify and assess babies at risk of stillbirth in Wales shocked us. Information provided by the Welsh Government noted that at least 1 in 3 stillbirths are associated with substandard care. 66 This is an unacceptable statistic that, if addressed, could reduce the number of unnecessary deaths in Wales by approximately 60 a year.
- 48. Gordon Smith, Professor of Obstetrics and Gynaecology at Cambridge University and a member of the Board of the International Stillbirth Alliance, highlighted that about a third of stillbirths occur among babies at term who are otherwise healthy. He told the Committee:

"These are babies that, if delivered prior to the event, would have had a normal life and normal survival. When we compare the numbers to other focuses of public health, we can see that there is demonstrable relative neglect."67

- 49. The variability of care standards across Wales was cited by a number of witnesses⁶⁸ and was acknowledged by the Welsh Government in its oral evidence. 69
- 50. The Royal College of Obstetricians and Gynaecologists' evidence to the Committee suggested that the establishment of a maternity network would help standardise care. Its written evidence stated that:

"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

27

⁶⁵ National Assembly for Wales, Health and Social Care Committee Rop [para 116] 28 June 2012 [accessed 17 January 2013]

⁶⁶ Ibid Additional information - Al 1 - National Stillbirth Working Group p2 [accessed] 23 January 2012]

Find the second s

⁶⁹ Ibid *RoP [paras 397]* 28 June 2012 [accessed 17 January 2013]

changes, all of which may be important factors in any attempt to reduce the number of stillbirths in Wales."⁷⁰

51. We were disappointed by the Welsh Government's comment in the January 2013 update on the work of the National Stillbirths Working Group that "there is no funding for an obstetric network". 71 Although we understand that resources are tight, we agree with the BMA that work should be done to scope the potential for establishing, at the very least, a virtual network.

Recommendation 4: We recommend that the Welsh Government scope the viability of establishing a maternity network to drive the standardisation of care across Wales. We believe that at least a virtual clinical network should be established within the next 12 months.

- 52. Written and oral evidence to this inquiry also highlighted the importance of ensuring continuity of care during pregnancy. 72 It was argued that this helps build a trusting relationship between expectant parents and health professionals, allowing more open conversations and potentially better detection and managements of possible risk factors in both those mothers deemed high risk and those deemed low risk.
- 53. Evidence provided by Sands, however, showed that expectant parents are often seen by numerous midwives at antenatal appointments. They argued that this means consistency is not maintained and important opportunities to identify and assess possible warning signs are missed.⁷³

National Assembly for Wales, Health and Social Care Committee <u>Consultation</u> <u>Response SB11 - Royal College of Obstetricians and Gynaecologists</u> p2 [accessed 17 January 2013]

⁷¹ Ibid <u>Additional information - Al 1 - National Stillbirth Working Group</u> p2 [accessed 23 January 2012]

National Childbirth Trust (<u>Consultation Response SB15</u>), Sands (<u>Consultation Response SB6</u>), and the Royal College of Midwives (<u>Consultation Response SB10</u>)
 National Assembly for Wales, Health and Social Care Committee <u>Consultation Response SB6 - Sands</u> p9 [accessed 17 January 2013]

4. Identifying and assessing the risk of stillbirth

Identifying high risk babies

54. Almost all witnesses to this inquiry commented that high risk mothers are readily identified but it is the identification of high risk babies in low risk mothers which is problematic. It is clear from the evidence we have gathered during this inquiry that a healthy mother does not necessarily equate to a healthy baby; the wellbeing of a baby cannot be monitored by looking solely at the mother. Witnesses told the Committee that there are two key issues to remember when considering the identification and assessment of the risks associated with stillbirth:

"One is that there is no such thing as a low risk until the baby is in the cot, and the second is that, therefore, we need to look at monitoring all pregnancies effectively and not just the highrisk ones. We know that when we monitor high-risk pregnancies, we get a good outcome, so it is not unreasonable to expect the same if we were to do the same for the low-risk pregnancies."⁷⁵

55. Professor Gordon Smith told the Committee:

"...when we look at the total number of stillbirths that occur, we see that most stillbirths occur to women who lack risk factors. So, if you are going to impact on the overall rate of stillbirths, you are going to have to reduce the number of stillbirths in those women who appear to be low risk. It is not that we should necessarily be intervening in the pregnancies of all of these women, but we should be doing something to try to better identify whether they are at risk of stillbirth and should be channelled towards the high-risk pattern of care...we need a better way of discriminating the low-risk women who have a high-risk placenta."⁷⁶

56. In oral evidence the Welsh Government acknowledged that "...we need to be much cleverer about identifying the women who are at

National Assembly for Wales, Health and Social Care Committee <u>RoP [para 195]</u> 28 June 2012 [accessed 17 January 2013]

⁷⁵ Ibid *RoP [para 176]* 28 June 2012 [accessed 17 January 2013]

⁷⁶ Ibid *RoP [para 99]* 28 June 2012 [accessed 17 January 2013]

risk".⁷⁷ The Chief Nursing Officer noted that the National Stillbirth Group has been asked to look at categorisation of pregnancies specifically. We welcome this development and urge the Group to progress this work as soon as possible.

Post-term delivery

57. As noted in paragraph 14 of this report, we were told that women who have passed their due date (i.e. have gone beyond 42 weeks of pregnancy) are at a higher risk of placental insufficiency and stillbirth. Representatives from the Royal College of Obstetricians and Gynaecologists suggested, however, that instances occur when the health service fails to provide an induced birth sufficiently early. Mr Bryan Beattie, Consultant in Foetal Medicine at the University Hospital Wales, said:

"Given pressures on maternity services, one problem is that women who may be scheduled for induction at 12 days past their due date may not be brought into hospital until 13 or 14 days past their due date, and because the ripening process to prepare the cervix before labour can take one or two days, you have some mums delivering 14, 15 or 16 days past their due date."⁷⁹

- 58. Mr Beattie's evidence also acknowledged, however, that, in addition to service pressures, some late inductions can be attributed to the preferences of the mother to avoid intervention:
 - "...it is an educational issue, in that there are some women who are reluctant to have any intervention. That is something that requires a lot of time and effort, not to force people to do something different to what they want to do, but to ensure that they really understand the significant increase in risk of declining that intervention."80
- 59. Mr Beattie suggested that it would be helpful to review on an ongoing basis the number of women in Wales who deliver more than 13 days after their due date, to look at the outcome for those pregnancies

_

⁷⁷ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 301]</u> 28 June 2012 [accessed 17 January 2013]

⁷⁸ Ibid *RoP [para 154]* 28 June 2012 [accessed 17 January 2013]

⁷⁹ Ihid

⁸⁰ Ibid Rop [para 155] 28 June 2012 [accessed 17 January 2013]

and whether it was a maternal choice issue or a resource issue that meant deliveries could not be made at a more appropriate time.⁸¹ He and other witnesses⁸² to the inquiry referred to recent research suggesting that inducing labour on and around the due date is not associated with an increased rate of caesarean section. He said:

"One of the reasons for avoiding intervention is that there was a concern that many people end up having unnecessary caesarean sections, but there is fairly good evidence now to suggest that that is not the case. For women with other risk factors, such as advanced maternal age, smoking or obesity, there may well be advantages in having a rethink and perhaps even inducing them around about their due date, rather than letting them go significantly past that point."

60. The Welsh Government told the Committee:

"We have done quite a lot to address the higher risk, that is, everybody now knows that you have to have active management after 40 weeks. You have to think about post-term delivery and anticipate it, and people are not left to go for 43 or 44 weeks and then suddenly have a stillbirth like in the old days."84

61. The Committee believes that post-term delivery is one of the few areas in the field of stillbirth which we know – and have the evidence to prove – leads to a definite higher risk. As such, we believe this is an area that merits further investigation and consideration to ensure that we are doing all we can, with the tools at our disposal, to ensure that the risk is avoided.

Recommendation 5: We recommend that the Welsh Government undertake a review of the number of women in Wales who deliver more than thirteen days after their due date. The outcome of those pregnancies and the factors that led to the decision not to induce within the recommended guideline time should be considered in every case. Further consideration ought to be given to whether

⁸¹ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 155]</u> 28 June 2012 [accessed 17 January 2013]

⁸² Dr Alexander Heazell Rop [para 95] 28 June 2012 [accessed 17 January 2013]

⁸³ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 156]</u> 28 June 2012 [accessed 17 January 2013]

⁸⁴ Ibid *RoP [para 304]* 28 June 2012 [accessed 17 January 2013]

women with other high risk factors such as advanced maternal age, smoking or weight should be induced closer to their due date.

Possible screening methods

- 62. We were told during the course of the inquiry that some European countries, which have lower stillbirth rates than Wales and the UK more widely, place a greater influence on ultrasound and serial ultrasound assessments for all pregnancies.85 The Committee heard, however, that even mothers who have been identified as high risk in the UK might not receive serial ultrasounds owing to shortages in resources 86
- 63. The Committee was told that an inquiry into antepartum⁸⁷ stillbirths in the UK found that 45 per cent had received sub optimal care, with the two most frequent problems identified being the recognition and management of foetal growth restriction and reduced foetal movements (RFM).88
- 64. With regard to reduced foetal movements, the Committee heard that there is significant variation in what clinicians define as RFM, with a high proportion being unsure of what constitutes RFM. We received evidence that RFM reported by mothers does not always receive a clear clinical response.89 This is particularly worrying when considered alongside evidence90 that suggests maternal perception is associated with a 2-3 times increased risk of stillbirth. Some witnesses to the inquiry did warn, however, that reliance on reduced foetal movements as a sign of possible stillbirth is risky given that this can often present itself very late in a pregnancy, when trouble may have already set in. One witness said relying on reduced foetal movements "...is almost like trying to prevent motor vehicle accidents by looking for the blue lights of the ambulance".91

⁸⁵ National Assembly for Wales, Health and Social Care Committee Rop [para 175] 28 **June 2012**

⁸⁶ Ibid <u>RoP [para 177]</u> 28 June 2012

⁸⁷ An antepartum stillbirth is the term that describes the death of a baby in the

⁸⁸ National Assembly for Wales, Health and Social Care Committee Consultation Response SB4 - Dr Alexander Heazell p1 [accessed 17 January 2013]

⁸⁹ Ibid Consultation Response SB6 - Sands p8; Consultation Response SB12 - British Medical Association p6 [accessed 17 January 2013]

⁹⁰ Ibid <u>Consultation Response SB4 - Dr Alexander Heazell</u> p1 [accessed 17 January

⁹¹ Ibid *RoP [para 199]* 28 June 2012 [accessed 17 January 2013]

- 65. In relation to restricted foetal growth, the variability in practice and quality of foetus growth monitoring from unit to unit was raised, and there were disagreements⁹² as to whether the use of a tape measure to monitor foetal growth was inaccurate and out-dated or a good method, if performed properly and subsequently managed effectively. Professor Jason Gardosi from the West Midlands Perinatal Institute told the Committee that 85 per cent of stillbirths (excluding those caused by or associated with congenital anomalies) are potentially avoidable if small for gestational age (SGA) foetuses are identified and managed. He suggested that significant improvements to stillbirth rates could be made through:
 - a concerted programme of improving the training of doctors and midwives in how to detect foetal growth problems among low risk pregnancies and monitor foetal growth better in high risk pregnancies; and
 - ensuring that clear referral pathways exist when foetal growth restriction is detected.⁹³
- 66. In its evidence to the Committee, the Welsh Government acknowledged the problems that exist in Wales with regard to the identification and assessment of known risks. When questioned on possible screening methods for stillbirth the Welsh Government's Chief Nursing Officer told the Committee that:
 - "...all of them have pros and cons and not all of them, I would say, are the answer; they have a variety of applications depending on how they are carried out. They do not all pick up those fetuses that are at risk."94
- 67. Welsh Government representatives explained that:

"The inconsistency is the thing that we need to look at...It is inevitable that, if you have 14 maternity units in Wales, they might be doing things differently. However, now that we have the national stillbirth committee, which is focusing on what we know works from places like Scandinavia, we can start dictating

⁹² See the Welsh Government's written evidence (<u>para 23</u>) which argues against the use of fundal height measurement; and Professor Jason Gardosi's oral evidence (<u>para 179</u>)

⁹³ National Assembly for Wales, Health and Social Care Committee *RoP [para 186]* 28 June 2012 [accessed 17 January 2013]

⁹⁴ Ibid *RoP [para 261]* 28 June 2012 [accessed 17 January 2013]

how those things should be done. We have to wait to see what works; we still do not really know."95

- 68. A written update on the work of the National Stillbirth Working Group, provided in January 2013, notes that the Welsh Government plans to:
 - standardise the management of reduced foetal movements by introducing a national minimum standard and all-Wales guidance for the management of reduced foetal movements;
 - work with the West Midlands Perinatal Unit to roll out the use of individualised growth charts, with a view to picking up more women with growth problems.⁹⁶
- 69. It is clear to the Committee that further research and improved perinatal review is needed to provide a more robust basis upon which to develop and implement effective screening methods for stillbirth. We believe that this will assist with the task of building a consensus amongst health professionals about how to identify, assess and monitor risk factors. It is clear to us that this consensus and the necessary evidence base upon which to base it has been lacking. We believe that this, in turn, has led to sub-standard care in some instances and has certainly limited the ability to reduce the rate of stillbirth in Wales. The need for more robust research and perinatal review is addressed in the next chapter.
- 70. Notwithstanding the need for further research and review, it strikes the Committee that careful consideration of the relatively small steps that have already been devised or can be devised relatively straightforwardly to make a difference to the rates of stillbirth in Wales is long overdue. We cannot expect one action to transform the whole picture it is clear that the nature of stillbirths is too complex to presume that a single solution exists. Yet we already know that certain things will work raising public awareness of risk factors for example, or improving professional awareness of stillbirth through training and the sharing of good practice. To refrain from doing things we already know can help, just because we cannot solve everything, is not acceptable.

⁹⁶ Ibid <u>Additional information - AI 1 - National Stillbirth Working Group</u> p2 [accessed 23 January 2012]

34

⁹⁵ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 264]</u> 28 June 2012 [accessed 17 January 2013]

Key conclusion: There is no single step which, if taken, would remedy the risk of stillbirths in Wales. Yet, we believe that progress towards that end has been held back by a frame of mind in which the search for the perfect has driven out the possible. Consideration of the relatively small steps that have already been devised – or can be devised relatively straightforwardly – to make a difference to the rates of stillbirth in Wales is long overdue. These steps need to be taken now.

Resources

- 71. During the course of our inquiry reference was made to the superior resourcing of maternity care in other countries. We were told of better staffing levels, higher levels of ultrasound scanning, better levels of post-mortem and better assessment and review of death.⁹⁷
- 72. In written evidence Sands highlighted that:

"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. Although 70% of babies are born at night maternity services are not run as a 24/7 service." 98

- 73. It was suggested that there is a lack of specialist doctors in Wales. According to the Royal College of Obstetricians and Gynaecologists there are currently two full sub-speciality trained foetal medicine consultants in the whole of Wales. We were told that both are based at the University Hospital of Wales in Cardiff so patients outside Cardiff either have to travel to the capital, travel to Liverpool in the case of those based in north Wales, or in east Wales, travel to Bristol. We were told that although the estimated costs of referring cross-border are considerably higher than providing the service in-house, to date the issue has not been addressed.
- 74. The Royal College of Obstetricians and Gynaecologists believes for a country of Wales's size, two more full time foetal medicine specialists are required. Furthermore, they suggested that

⁹⁷ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 39]</u> 28 June 2012 [accessed 17 January 2013]

⁹⁸ Ibid <u>Consultation Response SB6 - Sands</u> p10 [accessed 17 January 2013]

⁹⁹ Ibid *RoP [para 148]* 28 June 2012 [accessed 17 January 2013]

consideration ought to be given to commissioning such services at the tertiary rather than secondary level – as is the case in other areas of the UK – in order to ensure that the specialism does not have to compete with general obstetrics and gynaecology pressures.¹⁰⁰

75. Since our oral evidence session in June 2012 the Royal College of Midwives has noted its concerns about an alleged shortage of midwives in Wales. In its *State of Maternity Services Report 2012*¹⁰¹ published in January 2013, the College warned that this is the third year in a row that the numbers of midwives in Wales have dropped.¹⁰² Concerns about staffing levels were also expressed by the Assembly's Children and Young People Committee in its report on neonatal care in September 2012.¹⁰³

76. Local Health Board representatives acknowledged the challenges with regard to available medical staff in Wales, but praised the current tool used to assess how many midwives are necessary (the Birthrate Plus tool).¹⁰⁴ The Welsh Government's Chief Nursing Officer told the Committee:

"We are certainly monitoring very closely the compliance with particular standards around staffing levels. All health boards in Wales are required to meet Birthrate Plus, which is the number of midwives, and we keep a very close eye to ensure that they do not deviate from that. That includes the ratio of registered midwives to support staff as well as physical numbers employed. The same is true for the medical staff; we ensure that the health boards are monitoring that. There have been some challenges. I do not deny that. Some of the evidence we have recently given to the Wales Neonatal Network certainly illustrated some of the challenges of the medical vacancies we have at the moment in some of the training rotas. There are plans under way to address those issues. However, there are national problems with some of these things. We certainly commission and ensure that the right number of training

36

¹⁰⁰ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 147-148]</u> 28 June 2012 [accessed 17 January 2013]

¹⁰¹ Royal College of Midwives <u>State of Maternity Services Report 2012</u> 2

¹⁰² BBC News Online <u>Wales maternity care warning by Royal College of Midwives</u> 21 January 2013 [accessed 25 January 2013]

¹⁰³ National Assembly for Wales, Children and Young People Committee <u>Report on the inquiry into neonatal care</u> September 2012 [accessed 25 January 2013]

¹⁰⁴ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 400]</u> 28 June 2012 [accessed 17 January 2013]

places exists. It is about recruitment to and maintaining the training programmes."¹⁰⁵

77. The Chief Nursing Officer proceeded to note that close interest is being taken in the service reconfiguration process and how resources are being allocated within the respective health boards' plans. She told the Committee:

"Certainly, for maternity and neonatal services, we have been taking a very close look at this [reconfiguration] because some challenges have been identified, particularly with medical recruitment to paediatric and neonatal rotas and so on." 106

78. It is clear to us that matters of resource – particularly in the form of staffing – are crucial to the maintenance of high-standard care. We share the concerns regarding maternity and obstetric staffing levels in Wales that have been expressed by the Children and Young People's Committee in its report on neonatal care¹⁰⁷ and by the Public Accounts Committee in its report on maternity services¹⁰⁸.

Recommendation 6: We recommend that the Welsh Government investigate and report on evidence presented to the Committee that having to seek specialist foetal medicine consultations outside Wales now exceeds the cost of providing the service within Wales. The Welsh Government should also explore the proposal that specialist foetal medicine services should be commissioned at the tertiary rather than secondary level.

¹⁰⁷ National Assembly for Wales, Children and Young People Committee <u>Report on the inquiry into neonatal care</u> September 2012 [accessed 25 January 2013]

¹⁰⁵ National Assembly for Wales, Health and Social Care Committee *RoP [para 282]* 28 June 2012 [accessed 17 January 2013]

¹⁰⁶ Ibid *RoP [para 284]* 28 June 2012 [accessed 17 January 2013]

¹⁰⁸ National Assembly for Wales, Public Accounts Committee <u>Report on the inquiry</u> <u>into maternity services in Wales</u> February 2013 [accessed 15 February 2013]

5. Understanding the underlying causes of stillbirth

- 79. With nearly half of stillbirths currently classified as unexplained, there is clearly much work to be done to better understand its underlying causes. We were told during the course of our inquiry that, even if we take the steps to standardise care and improve our detection of at risk babies with the tools we already have, there is still too much that we do not know about stillbirth.
- 80. Despite this lack of knowledge, evidence we received suggested that learning more about the causes of stillbirth is not an impossible task. We were told that our lack of understanding of its underlying causes is not because we have looked for answers and failed to find them. Rather, our ignorance is due, in large part, to the relative neglect of this area of medicine in terms of review and research.¹⁰⁹
- 81. This chapter explores the practical steps suggested to us during the course of our inquiry that can be taken to improve our understanding of stillbirth. We hope that taking these steps to increase our understanding of its causes will, in turn, drive the stillbirth rate down in Wales.

Health inequalities

82. As noted by Public Health Wales in its written evidence to this inquiry:

"Rates of stillbirth are persistently higher in areas with high levels of deprivation. 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."

83. The link between stillbirths and the general health of the population was raised by the majority of witnesses to our inquiry. 111

¹⁰⁹National Assembly for Wales, Health and Social Care Committee <u>RoP [para 15]</u> 28 June 2012 [accessed 17 January 2013]

¹¹⁰ Ibid <u>Consultation Response SB5 - Public Health Wales</u> p3 [accessed 17 January 2013]

See evidence from Sands [RoP para 40], the Welsh Government [RoP para 278] and the BMA [Consultation Response SB12 - British Medical Association p2]

According to Cwm Taf Health Board, women living in the most deprived areas of Wales are 1.7 times more likely to suffer a stillbirth compared to women in the least deprived areas. Furthermore, Public Health Wales told the Committee that maternal smoking – a known risk factor for stillbirth – is more prevalent in areas of high deprivation.

Data and review

84. The Committee was told that all live births and stillbirths are required to be reported to the Welsh Government on a quarterly basis.¹¹⁴ All stillbirths are also reported to the All Wales Perinatal Survey (AWPS) which continuously collects data and reports on stillbirth in Wales annually.¹¹⁵ The AWPS is funded by the Welsh Government. In addition to this national collection of data, evidence provided by health boards suggests that a variety of methods are adopted from board to board to collect data, and review and report on stillbirths.

Perinatal review

- 85. A perinatal review is a process by which an individual case of perinatal death is considered by relevant health professionals. The process, done properly, will bring together a multi-disciplinary team that attempts to look at a particular case and the clinical circumstances leading up to the case. Specifically, the group will consider whether there were any areas where, if something had been done differently, it might have been avoidable.
- 86. Although evidence to our inquiry was clear in supporting the use of perinatal review to better understand the underlying causes of stillbirth, it was emphasised that the quality of review in Wales is variable. According to Sands:

"At the moment there is no standardised process, and the way in which perinatal reviews are carried out varies hugely from unit to unit. It depends on who is in charge and how much time

¹¹² National Assembly for Wales, Health and Social Care Committee <u>Consultation SB14</u> - <u>Cwm Taf Health Board</u> p1 [accessed 17 January 2013]

¹¹³ Ibid *RoP [para 347]* 28 June 2012 [accessed 17 January 2013]

¹¹⁴ Ibid <u>Consultation Response SB3 - Betsi Cadwaladr University Health Board</u> p5 [accessed 17 January 2013]

¹¹⁵ Ibid <u>Consultation Response SB1 - All Wales Perinatal Survey</u> p1 [accessed 17 January 2013]

they have. It is very hit and miss whether you get a really good investigation into what has happened for your baby."116

87. Dr Alexander Heazell also cited the variability of perinatal review across the UK as a hindrance to improving our understanding of stillbirths. He told the Committee:

"There is no compulsion on any institution to meet a minimum quality standard for their perinatal review, which I think is critical. The analogy that I would use is that many crimes would be unsolved if nobody ever looked for any fingerprints or evidence."

117

- 88. Cwm Taf Health Board, although conducting thorough perinatal reviews at the health board level, acknowledged the benefit that could be gleaned from standardising the approach to perinatal review across Wales. Giving evidence to the Committee, Cwm Taf's Director of Nursing said:
 - "...it would be helpful to have a national approach. Certainly, in my earlier career, I was a reviewer with the national confidential inquiry into stillbirths and deaths in infancy and, from a personal perspective, I would say that there is a great deal of learning to be done from those inquiries on an individual basis that you then take back into your service but also nationally."118
- 89. The All Wales Perinatal Survey and other witnesses claimed that a national perinatal audit (or confidential inquiry as it is often called) is central to understanding the causes of stillbirth. The AWPS told the Committee

"We are talking about looking at a consecutive series of stillbirths prospectively, so as they occur, you get a multidisciplinary team together including obstetricians, midwives and people who have been involved in the care, and you look at the case and the clinical circumstances leading up to the case and at whether there were any areas where, if something different had happened, it might have been avoidable. When you do that across a series of cases, you start

¹¹⁶ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 51]</u> 28 June 2012 [accessed 17 January 2013]

¹¹⁷ Ibid *RoP [para 114]* 28 June 2012 [accessed 17 January 2013]

¹¹⁸ Ibid *RoP [para 407]* 28 June 2012 [accessed 17 January 2013]

to come up with themes and then it becomes clear where things could be done differently or where there may be lessons learned that ought to be shared across organisations. What is happening at the moment is that individual health boards tend to do them locally, so you do not have the sharing of lessons."¹¹⁹

90. During oral evidence, the Chief Nursing Officer acknowledged the need to improve perinatal review. She stated:

"We know how many stillbirths occur, and where. We know the details of the individuals, and we are not talking about thousands [...] so we can analyse every one. What we are not very good at is learning the national lessons from that. An incident will happen, and the team will explore it, and perhaps it will share it within the health board, so it goes wider than the team, but it does not spread much further than that. We have identified a significant need for a much better national approach to learning lessons, and actually understanding what is going on. That is a key step change for us that we hope will take us forward." 120

91. The AWPS told the Committee that, subject to being given the necessary remit by the Welsh Government, it could undertake a perinatal audit in Wales. Representatives told the Committee:

"We are halfway there because we have the survey up and running. We are already collecting data, but it is about enhancing the data that we collect and bringing the panel together to do the systematic reviewing, and then starting to put together a strategy that can be implemented to actively reduce the stillbirth rate." 121

92. When asked if additional resource would be needed to undertake this work, AWPS told the Committee:

"We would need the team, so we would need some resource for the expert panel and some additional resource for the

41

¹¹⁹ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 358]</u> 28 June 2012 [accessed 17 January 2013]

¹²⁰ Ibid *RoP [para 313]* 28 June 2012 [accessed 17 January 2013]

¹²¹ Ibid *RoP [para 359]* 28 June 2012 [accessed 17 January 2013]

enhanced data collection. We could put a costing together for that."122

93. The Minister's written paper to the Committee in June 2012 noted that the National Stillbirth Working Group would be focusing part of its work on a stillbirth register and confidential enquiry for Wales.¹²³ It is a matter of great disappointment to us that the Welsh Government's written update on the Group's work – provided in January 2013 – notes that there is no resource to conduct detailed national confidential enquiries of stillbirths in Wales.¹²⁴

94. While we acknowledge that resources are tight in the current financial climate, we firmly believe that a dedicated national confidential enquiry could yield results that, in the long term, could save significant funds. Moreover, this work may help reduce the number of people who face such a tragic loss on too frequent a basis. We believe that a wider and more imaginative consideration of the budget provided by the Welsh Government for research and investigation in the medical field could assist with finding the necessary funding to conduct a national confidential enquiry. We remain to be convinced that the proposed collaboration within Wales and with the UK national enquiries will mitigate the need for a Walesbased survey.

Recommendation 7: We recommend that a national minimum standard for reviewing perinatal deaths should be developed and rolled out across Wales. We also recommend that a wider, more imaginative approach to Welsh Government funding for medical research and investigation is adopted, and that the Welsh Government seek detailed costings for a national perinatal audit for Wales from the All Wales Perinatal Survey. We believe that the initial investment in this audit could yield significant benefits in the future detection and prevention of stillbirth.

¹²² National Assembly for Wales, Health and Social Care Committee *RoP [para 363]* 28 June 2012 [accessed 17 January 2013]

¹²³ Ibid <u>HSC(4)-19-12 paper 10 - Evidence from the Welsh Government</u> p6, 28 June 2012 [accessed 17 January 2013]

¹²⁴ Ibid <u>Additional information - Al 1 - National Stillbirth Working Group</u> p2 [accessed 23 January 2012]

Post-mortem

- 95. The importance of post-mortem as a means by which to better understand the underlying causes of stillbirth was a strong theme in this inquiry. Witnesses told the Committee that because the reasons behind a large proportion of stillbirths are not known, they need to be looked at in more detail, most usefully through a post-mortem, to gather information and better understand why stillbirths occur.¹²⁵
- 96. Despite its importance, it is clear from evidence that the uptake of post-mortem is low across the UK. Figures provided in the All Wales Perinatal Survey's Annual Report for 2011 show that, of the number of cases of stillbirth in Wales in 2011 where parents were asked to consent to a post-mortem (159 out of 168 stillbirths), parents gave consent in only 40.5 per cent of those cases.¹²⁶
- 97. Sands told the Committee that part of the problem is an alleged lack of perinatal pathologists:

"The uptake of post-mortems in Wales is extremely low. That is partly because of the lack of perinatal pathologists to undertake them. People will turn away from having a post-mortem because they cannot lay their baby to rest in a timely manner. It is at least two weeks before their baby is returned to them for a funeral, and then they are looking at six to eight weeks or more before they get the results of the post-mortem. Whereas, for an adult, you are talking about a 24-hour turnaround."127

- 98. We were told that there is only the equivalent of 1.2 whole-time perinatal pathologists across Wales, with parents who consent to post-mortem facing both delays and the prospect of their baby being transported a significant distance.¹²⁸
- 99. In addition, evidence pointed to a lack of confidence and skills among health professionals to broach the subject of post-mortem. The Royal College of Midwives told the Committee:

¹²⁵ National Assembly for Wales, Health and Social Care Committee *RoP [para 344]* 28 June 2012 [accessed 17 January 2013]

¹²⁶ All Wales Perinatal Survey <u>Annual Report 2011 (v2</u>) p28, 10 December 2012 [accessed 17 January 2013]

¹²⁷ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 91]</u> 28 June 2012 [accessed 17 January 2013]

¹²⁸ Ibid <u>Consultation Response SB6 - Sands</u> p11 [accessed 17 January 2013]

"One area that is possibly lacking in Wales is bereavement support and the counselling that goes with it. It might increase the uptake of post-mortems if that was done properly. However, there is a shortage of bereavement support or specialised midwives in that area in Wales." 129

100. The Welsh Government's written evidence states that the main obstacle to understanding the causes of stillbirth is the "very low" rate of paediatric post-mortem. The Minister's evidence acknowledges that the low uptake is due to a number of factors, including the "bewildering" and "complex" questions that parents are asked when consent is sought for post-mortem. It also argues that the low uptake is partly influenced by the organ retention scandals of the late 1990s. The Welsh Government's written evidence goes on to recognise that:

"Many midwives and doctors are not trained about the value of post-mortems nor how to seek consent and parents are easily discouraged if staff lack confidence in the process." 131

101. We acknowledge the inherent difficulties associated with seeking consent for post-mortem. Grieving parents are vulnerable and understandably reticent to consent. However we firmly believe that without a higher rate of post-mortem in Wales, developing the evidence base to better understand the causes of stillbirth will remain a challenge that conquers us.

102. We are pleased to learn that the National Stillbirth Working Group has been tasked with undertaking work to increase consent for postmortem following stillbirth, and that improved training for health professionals in addressing the question of post-mortem with parents is an action the Welsh Government will now take forward. Detail on how these actions will be progressed was vague, however, and we would welcome further clarity on how the Welsh Government proposes to deliver an increased rate of post-mortem in the case of stillborn babies.

44

¹²⁹ National Assembly for Wales, Health and Social Care Committee <u>RoP [para 201]</u> 28 June 2012 [accessed 17 January 2013]

¹³⁰ Ibid <u>HSC(4)-19-12 paper 10 - Evidence from the Welsh Government</u> p4, 28 June 2012 [accessed 17 January 2013]

¹³¹ Ibid <u>HSC(4)-19-12 paper 10 - Evidence from the Welsh Government</u> p4, 28 June 2012 [accessed 17 January 2013]

Recommendation 8: We recommend that the Welsh Government publish a detailed plan of how it proposes to tackle the problem caused by the low rate of post-mortem for stillborn babies. The plan should include:

- details of how training will be delivered to health professionals in order that they are better equipped to raise this very difficult issue with grieving parents;
- details of what improved information will be developed for parents so that they are able to make more informed decisions; and
- an assessment of the actions needed to improve the provision of perinatal pathology.

Research

103. The need for more and better research into stillbirth was one of the resounding themes of our inquiry. The Committee was told of the relative neglect of stillbirths in terms of research, and the potential that further work could have in reducing its stubbornly static rate in Wales.

104. Professor Gordon Smith told the Committee:

"If you think about death in the first year of life—infant death—you are looking at all prematurity, sudden infant death syndrome, a proportion of abuse, infection, such as group B streptococcus and other infections acquired around the time of birth. If you put all those together, then you see a huge focus of research and public health interest. It is then difficult to see that there is a commensurate magnitude of interest in the problem of stillbirth. That is manifested in the essentially static rates of stillbirth over the last 20 to 30 years." 132

105. He went on to explain:

_

"What we really need is the research that identifies stillbirth, for example, a screening test for stillbirth, in the way that we have a highly effective screening test for Down's syndrome. We have a method of screening for Down's syndrome, where we can screen the whole population and identify less than 5% of them

 $^{^{132}}$ National Assembly for Wales, Health and Social Care Committee $\underline{\it RoP~[para~91]}$ 28 June 2012 [accessed 17 January 2013]

as being high risk and in that figure of less than 5%, we can identify 90% of cases of Down's syndrome. If we can do that for Down's syndrome, it would seem to me that there is potential of doing that for at least some types of stillbirth, but the reality is that we are not trying to do that through research because the funding is not there."133

106. The Committee was also alerted to the fact that, in the case of cot death, the numbers of babies dying has dropped by 70 per cent as a direct result of research. We were told that similar gains could be made for stillbirth if adequate attention was given to this area of medicine.134

107. As discussed in chapter 4, the need for research to better inform the use of scanning, measurement of reduced foetal movements and restricted foetal growth is hindering the ability of health professionals to use these tools effectively. For as many witnesses who supported a particular approach to screening women for stillbirth via a particular method, there seemed to be as many querying the evidence on which such approaches were based. As an example, although providing ultrasound scanning later in pregnancy is favoured by some as a means by which to monitor women for the risk of stillbirth, it was also noted that there is not much evidence in the literature about the oneoff third-trimester scan being beneficial in detecting risk. 135

108. The relative lack of research in this area was attributed by some to a lack of funding. Professor Gordon Smith noted that:

> "This is an area where there is no major charity. There is no British Heart Foundation or Cancer Research UK, which sponsor huge programmes of work in their areas. There is very little in the way of charitable funding for this area, so what is the Government doing to fund the research that will generate the tools for five to 10 years' time?"136

109. We were assured to learn that the National Stillbirth Working Group will be identifying and promoting further research within Wales

¹³³ National Assembly for Wales, Health and Social Care Committee Rop [para 95] 28 June 2012 [accessed 17 January 2013]

¹³⁴ Ibid <u>Consultation Response SB6 – Sands</u> p9 [accessed 17 January 2013]
135 Ibid <u>RoP [para 199]</u> 28 June 2012 [accessed 17 January 2013]

¹³⁶ Ibid *RoP [para 136]* 28 June 2012 [accessed 17 January 2013]

to improve understanding of why stillbirths occur. ¹³⁷ A recent update on the Group's work notes that some of those who gave evidence to this inquiry will work with a national research study being undertaken in Scotland to seek to better understand the causes of stillbirth. ¹³⁸ We remain concerned, however, that wider research is required in order to move forward in this area.

Recommendation 9: In the absence of the large charities and interested industry that fund the bulk of research for other health conditions, we recommend that the Welsh Government, through the National Institute for Social Care and Health Research's Clinical Research Centre, commission a comprehensive piece of work on the underlying causes of stillbirth. This work should be undertaken in cooperation with health professionals and academics with expertise in this field, and should draw on international knowledge of stillbirth. This work should be completed by the end of this Assembly.

_

¹³⁷ National Assembly for Wales, Health and Social Care Committee <u>HSC(4)-19-12</u> <u>paper 10 - Evidence from the Welsh Government</u> p6, 28 June 2012 [accessed 17 January 2013]

¹³⁸ Ibid <u>Additional information - Al 1 - National Stillbirth Working Group</u> p2 [accessed 23 January 2012]

Annex A - Witnesses

The following witnesses provided oral evidence to the Committee on 28 June 2012. Transcripts of the oral evidence sessions can be viewed, in full, at:

http://www.senedd.assemblywales.org/mglssueHistoryHome.aspx?lld= 1309

28 JUNE 2012		
Holly Martin Stillbirth Research Fund		
Sands		
Sands		
National Childbirth Trust		
National Childbirth Trust		
International Stillbirth Alliance		
Manchester Academic Health Science Centre		
Royal College of Obstetricians and Gynaecologists		
West Midlands Perinatal Institute		
Royal College of Midwives		
Royal College of Midwives		

Dr Mark Temple	British Medical Association Wales
Mr Phil Banfield	British Medical Association Wales
Session 5	
Dr Jean White	Chief Nursing Officer
Polly Ferguson	Welsh Government
Dr Heather Payne	Senior Medical Officer (Maternal & Child Health)
Session 6	
Dr Siobhan Jones	Public Health Wales
Dr Shantini Paranjothy	All Wales Perinatal Survey
Session 7	
Angela Hopkins	Cwm Taf Health Board
Fiona Giraud	Betsi Cadwaladr University Health Board

Annex B - Written evidence

The following people and organisations provided written evidence to the Committee. All written evidence can be viewed in full at http://www.senedd.assemblywales.org/mglssueHistoryHome.aspx?lld=3352

Organisation	Reference
All Wales Perinatal Survey	SB 1
OC Support	SB2
Betsi Cadwaladr University Health Board	SB 3
Dr Alexander Heazell	SB 4
Public Health Wales	SB 5
Sands	SB 6
International Stillbirth Alliance	SB 7
Holly Martin Stillbirth Research Fund	SB 8
Powys Teaching Health Board	SB 9
The Royal College of Midwives	SB 10
Royal College of Obstetricians and Gynaecologists	SB 11
BMA Cymru Wales	SB 12
West Midlands Perinatal Institute	SB 13
Cwm Taf Health Board	SB14
National Childbirth Trust	SB 15
National Stillbirth Working Group (additional written evidence)	SB - AI 1