Health and Social Care Committee

HSC(4)-19-12 paper 10

Inquiry into Stillbirths in Wales – Written Evidence from the Welsh Government

Purpose

1. This paper provides evidence for the Health and Social Care Committee's one-day inquiry into stillbirths in Wales and examines the awareness, implementation and effectiveness of current guidance and recommendations across the different sectors with regard to still birth prevention, especially in relation to management of poor fetal growth, reduced fetal movements, and post term delivery, and where potential improvements can be made.

2. The evidence paper:
    - Looks at the current position in relation to monitoring stillbirths in Wales.
    - Examines what we are doing to reduce the number of stillbirths in Wales.
    - Looks at the 1000 Lives Plus Transforming Maternity Services Mini Collaborative 'National Stillbirth Working Group', and its aim to transform the outcomes for women and their families.

Summary

3. The effectiveness and quality of NHS maternity services has a fundamental role to play in reducing the risk of stillbirths. Although the cause of the majority of stillbirths is unknown there is considerable information on the actions that could be taken to prevent stillbirths in Wales.

4. With the support of the 1000 Lives Plus Transforming Maternity Services Mini-Collaborative, a National Stillbirth Working Group has now been set up and is:

a. Developing a strategy aimed at reducing levels of stillbirth.

b. Identifying and promote further research within Wales to improve understanding of why stillbirths occur.

c. Working with women to optimise the balance between 'normality' and 'intervention'.

d. Facilitating the sharing and promulgation of best practice across Wales.

Still Births in Wales- current position

5. In 2010 there were 190 still births in Wales, the rate since 2000 fluctuating between 4.6 and 5.7 per 1,000 births. The most recently reported rates showed that the downward trend in Wales and the rest of the UK has stalled in the past ten years.

6. The main causes of perinatal mortality are prematurity and congenital anomaly, although for the large proportion of stillbirths (41.7%) the cause is unknown.

7. Known causes of stillbirth include congenital anomalies, certain infections, maternal high blood pressure (pre-eclampsia) and bleeding behind the placenta (placental abruption).

8. Lifestyle factors amenable to public health interventions, such as maternal smoking, obesity and drug and alcohol intake have also been identified as contributing to the risk of stillbirth.

Smoking

9. Women who smoke during pregnancy are about twice as likely to experience premature rupture of membranes and placental abruption during pregnancy, and have small babies (weighing on average 200 grams less than babies of mothers who do not smoke). Babies born to women who smoke are at greater risk of stillbirth, smoking estimated to account for 7% of the risk in the general population but up to 20% of the risk in disadvantaged populations.

10. The latest Infant Feeding Survey (2010) demonstrated that:

- A third of mothers (33%) in Wales smoked at some point in the 12 months immediately before or during pregnancy, more than in the other UK countries. Of mothers who smoked, about 50% gave up at some point before the birth, compared to 54% in the UK as a whole.
- One in six of all mothers (16%) in Wales continued to smoke throughout their pregnancy.
- The highest proportions of mothers who smoked before or during pregnancy were found among mothers in routine and manual occupations and among those aged 20-24.

Obesity

11. Data published in the Centre for Maternal and Child Care Health Enquiries (CMACE) report on maternal obesity shows that Wales has the highest prevalence of obesity in pregnancy in the UK at 6.5%.

12. Obesity in pregnancy is associated with an increased risk of a number of pregnancy-related complications and adverse outcomes and the babies of obese women have an increased risk of perinatal mortality compared with the general maternity population in the UK. In addition neonatal unit admissions (within 24 hours of birth) correlate directly with maternal obesity.

Alcohol and drugs

13. All women in Wales are asked about alcohol and drug intake at the beginning of their pregnancy and offered support in reducing dependence. Welsh Government

does not have accurate data on misuse of drugs during pregnancy but this is being developed as part of the implementation of the maternity strategy.

14. Drinking during pregnancy will have a significant impact on the physical and mental health of the woman and can result in Fetal Alcohol Syndrome (FAS). This disorder leads to lifelong intellectual and behavioural problems for the child. The diagnosis of FAS is difficult and requires a geneticist to confirm and it is probable that there is an under reporting. In Wales, the Congenital Anomaly Register and Information Service (CARIS) has been collecting data since 1998 and reports a rate of 0.07 per 1000 live births.

15. Key findings for the UK as a whole are:

a. Over half (54%) of mothers drank alcohol during pregnancy. However, among mothers who drank during pregnancy consumption levels were low. Only eight per cent of all mothers drank more than two units of alcohol per week on average.

b. Almost three-quarters of mothers (73%) who drank during pregnancy received advice about drinking, with midwives being the most common source.

Fetal Movements

16. Following a large trial on 'Kick Counting' approximately 20 years ago, which showed no difference to infant mortality, the practice of asking women to do this was phased out. There is now a wide variation in practice across UK and Europe.

17. The NICE Guidelines do not support formal fetal movement 'Kick Counting' but recommend that all women should report diminished fetal movements (DFM) and an assessment made for fetal wellbeing.

18. Evidence does suggest that a significant reduction or sudden change in movement is an important clinical sign. Reduced fetal movements usually does not indicate a problem with the pregnancy but can sometimes be an important warning sign that the foetus is not receiving enough oxygen from the mother, via the placenta.

19. The recent finding of a reduction in stillbirths in Norway indicated that implementation of clinical practice guidelines and information for women on fetal movement is encouraging and a larger study is now being carried out and UK participation is being encouraged.

20. The challenge is in how to define reduce movements and how to monitor women without increasing anxiety. The Royal College of Obstetricians and Gynaecologists (RCOG) produced guidelines last year, which looks at how women should be aware of their baby's movement patterns in the womb, gives advice to clinicians, reviews the risk factors and the factors influencing maternal perception. These guidelines are supported by the Stillbirth and Neonatal Death Society (SANDS).

21. Based on available evidence the National Stillbirth Working Group will be developing an all Wales protocol on reduced fetal movements (see item 36-38)

Growth

22. Growth restriction has a known association with stillbirth, but its identification is currently very poor.

23. Researchers have demonstrated there is no benefit in measuring the fundal height [measurement of uterine growth taken abdominally with a tape measure] in low risk population to detect poor growth, as it is inaccurate.

24. However, there is a continued need to draw on best practice from around Europe, internationally and the rest of the UK with a view to share and/or implement in Wales.

25. Both fetal movements and growth restriction are being discussed by the National Stillbirth Working Group being co-ordinated by 1000 Lives Plus.

Post –mortem

26. The main issue that affects the understanding of the causes of stillbirth is that there is a very low rate of paediatric post mortem.

27. The perinatal post-mortem rate in the UK remains low at around 42.4%, as a result of emotional distress and partly influenced by the organ retention scandals in the late 1990s. In Wales in 2010, 44.4% of women gave consent for post-mortem following stillbirth.

28. There are several reasons why post-mortem rates on babies are so low:

- In many cases bereaved parents are put off consenting to a post-mortem because the process for seeking consent is bewildering. Parents can be overwhelmed and confused by the complexity of the questions they are asked.
- In 2008, just 9% of parents whose baby was stillborn or died in the first week of life were not offered a post-mortem (ref CEMACE report 2008).
- 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.

What we are doing to reduce the number of stillbirths in Wales.

A. Strategic Vision for Maternity services in Wales

29. The Strategic Vision for Maternity Services in Wales was launched in September 2011, which focuses on improving the health of women and their families with an emphasis on cessation of smoking, healthy eating, diet and exercise, to help improve outcomes for babies.

30. The agreed population level desired outcome is ‘a healthy woman, a healthy baby and healthy pregnancy’ and the Chief Executive of NHS Wales will be issuing

by end of June a set of population level outcome indicators to track how well we achieve this. In addition, he will issue a set of national performance measures on which he will hold the NHS to account on in terms of how women and their babies are better off as a result of NHS maternity care.

31. While these will not exclusively track stillbirths these are recorded via the birth registration system and in detail by the All Wales Perinatal Survey and Local Health Boards are expected to report each stillbirth as a Serious Adverse Incident and to examine the causes and act on the findings.

B. Reducing the risks of still birth- positive lifestyle changes

The Pregnancy Book

32. The Pregnancy Book is currently provided by midwives to all prospective parents. It provides information on how to improve health and well-being, and maintain a healthy pregnancy.

Change4 life programme

33. Change4Life is a 'sister-brand' of the Department of Health's (DH) Start4Life programme. It encourages individuals, families and communities to make small changes to their lifestyle to improve long-term health, particularly in relation to diet, alcohol and exercise.

34. Start4Life is in the process of broadening its reach to incorporate a wider range of health issues and to widen the audience to include pregnant women, fathers and families with children under 5 (instead of aged 2). Welsh Government officials are liaising with DH to explore the opportunities for broadening its scope in Wales.

Maternal smoking

35. The Tobacco Control Action Plan for Wales makes a commitment for Public Health Wales to work with Local Health Boards to further strengthen referral pathways between maternity units and Stop Smoking Wales to increase pregnant smokers' access to smoking cessation; with the aim of reducing the prevalence of maternal smoking.

1000 Lives Plus Programme

36. The aim of the 1000 Lives Plus Transforming Maternity Services Mini-Collaborative, launched by the Chief Nursing Officer in March 2011, is to improve the experience and outcomes for women, babies and their families within Welsh maternity services. The current focus of work is on interventions relating to improved recognition and response to the acutely deteriorating woman and prevention of deep vein thrombosis. All Maternity units in Wales are involved in the programme and the programme is overseen by a National Steering Group.

37. The Mini-Collaborative has recently identified the area of stillbirths as their next priority and a first meeting of the National Still Birth Working Group has been held. The terms of reference are 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 Welsh Government with intelligence on local issues and progress with implementation.
- Work with SANDS and other appropriate groups to improve public awareness of these issues.

38. The Group has agreed that the initial focus of work will be to consider:

- A Stillbirth Register and Confidential Enquiry for Wales
- Increased scanning of pregnant women to correctly identify growth issues with their unborn babies
- Management of induction of labour for 'post dates' pregnancy
- All Wales review of the detection of intra uterine growth retardation
- All Wales agreed protocol on reduced fetal movements
- Increased consent for post mortem following stillbirth.

39. I will continue to monitor work being carried out to address and improve the safety and quality of maternity services.