

## **WELSH GOVERNMENT RESPONSE TO RECOMMENDATIONS FROM THE HEALTH & SOCIAL CARE COMMITTEE: ONE-DAY INQUIRY INTO STILLBIRTH IN WALES.**

**APRIL 2013**

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Welsh Government agrees with the conclusion of the Committee, this is a complex and multi-faceted issue and there is no single step which, if taken, would remedy the risk of stillbirth in Wales.

Setting up the National Stillbirth Group (NSG) in March 2012 has provided the momentum for Health Boards to come together to discuss and agree on the steps that will now be taken forward to reduce stillbirth rates in Wales. The work of the NSG is fully funded by 1000+ Lives for the financial year 2013/14. Please see the Terms of Reference and membership of the group at Annex 1.

In addition to supporting the implementation of recommendations 1,2,5 and 8 the NSG are leading work on the implementation of the following nationally agreed interventions:-

- Standardising the management of reduced fetal movements.
- Implementing customised growth charts.
- Increasing post-mortem consent.
- Local perinatal review.
- All Wales perinatal survey.

This work will be completed by end of March 2014.

### **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.**

### **Response: Accept**

This will form part of the work of the National Stillbirth Working Group

Working with SANDS, the National Stillbirth Working Group will develop public

health messages that will be given to women and their partners through written material and discussion at antenatal consultations. The aim is to roll this out across Wales from autumn 2013.

### **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.**

### **Response: Accept**

This will form part of the work of the National Stillbirth Working Group. The public health messages that will be given to women and their partners through written material and discussed at antenatal consultations will include standardising the information/advice on and management of reduced fetal movements. The aim is to roll this out across Wales from autumn 2013.

### **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.**

### **Response: Accept in Principle**

#### Midwives

The Welsh Government expects all midwives to receive supervision as required by the Nursing and Midwifery Council (NMC) and annual appraisal. Health Boards and the Local Supervising Authority ensure that this is in place and that regular monitoring is carried out.

The curriculum standards for pre-registration Midwifery education are set by the NMC. Standard 17 details the competencies required to register with the Council and includes providing care for women who have suffered pregnancy loss, stillbirth or neonatal death. The essential skills clusters set by the NMC include discussing with women local/national information to assist with making choices, including local and national voluntary agencies and websites.

The issue of its prominence in our current programmes will be discussed with CYNGOR – the all Wales advisory group on education and research for Nursing, Midwifery and Health Professions

### Obstetricians

At present there is no requirement to develop expertise/experience of counselling in relation to the risk of stillbirth. However, the UK RCOG Curriculum Committee is addressing this. Counselling will be included, as well as a video on how to break the bad news to patients and partners. Discussions are ongoing on the feasibility of a video on post-mortem following stillbirth. This will be in the curriculum by Aug 2014.

The National Specialist Advisory Group (NSAG) for Women's Health has been asked to consider this at their next meeting, in June 2013, and they will also be discussing this with the Medical Deanery in Wales.

The financial implications of amending the curricula are covered within the existing Higher Education and RCOG budgets.

The monitoring and review of training needs for staff is a matter for local health boards as part of statutory requirement to ensure they have the correct staff with the right skills to deliver their services and should be included in their annual training needs analysis.

Welsh Government's workforce and organisational development framework clearly states that we expect all staff to commit to an annual appraisal and personal development plan.

### **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.**

### **Response: Accept in Principle**

As part of the work of implementing the Strategic Vision for Maternity Services Welsh Government is in the process of scoping the viability of establishing a maternity network. The scoping will be completed by July 2013 and will include the financial implications of setting up and maintaining such a network. Based on the conclusions of the scoping exercise consideration will then be given on whether to set up a maternity network. This will include the possibility of setting up a virtual network.

### **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.**

**Response: Accept**

This will form part of the work of the National Stillbirth Working Group and will be completed by March 2014.

#### **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.**

**Response: Accept in Principle**

Health boards are responsible for the planning and commissioning of services through consideration of a range of factors in determining the best possible place for treatment.

David Sissling will write to the Chief Executives of the Health Boards to bring this recommendation to their attention. The expectation will be that they scope the options for the provision of specialist foetal medicine for the population of Wales. A progress report will be expected from each Health Board at the end of the first quarter of the financial year 2013/14.

#### **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.**

**Response: Accept**

**The development of a national minimum standard for reviewing perinatal deaths is being carried out as part of the work of the National Stillbirth Working Group.**

Discussions on developing a national perinatal audit for Wales from the All Wales Perinatal Survey are being taken forward through collaborative work with the Healthcare Quality Improvement Partnership (HQIP) and MBRRACE -UK (Mothers and Babies - Reducing Risk through Audits and Confidential Enquiries across the UK) The financial implications of all options will form part of the discussion on a way forward.

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

### **Response: Accept**

Through both work carried out by SANDS and on feedback from parents in Wales, the National Stillbirth Group are improving services.

An excellent example where sharing good practice is leading to the possibility of immediate improvements is in organising speedy access to services.

The group agreed the need to standardise the process for baby transfer to Cardiff for PM and improving the pathological examination of the placenta (to pick up placental pathology more reliably), by utilising the specialist perinatal pathologists at Cardiff. The ability to arrange a post-mortem on a specific date and to transport a baby to Cardiff and back on the same day helps parents to know where their baby is at all times.

### **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.**

**Response: Accept**

With the support of the National Institute for Social Care and Health Research (NISCHR), and in parallel with the work of the National Stillbirth Group, maternity units in Wales will be collaborating with the Scottish Research Study. This work involves a trial to test a package of care that may help reduce the risk of stillbirth when a woman reports reduced fetal movements. There will be no financial implications for Welsh Government.

The aim of the Scottish research study is to test the hypothesis that a protocol for detection and management of reduced fetal movements reduces rates of stillbirth. The study will test an intervention combining raising patient awareness of fetal movement counting, with a management plan for health professionals for women who present with reduced fetal movement. In parallel with the 1000 Lives work, a group of obstetricians and midwives are now developing Welsh involvement with the support of the NISCHR



1000 Lives Plus is the national improvement programme supporting organisations and individuals to deliver the highest quality and safest healthcare for the people of Wales.

## **National Stillbirth Working Group**

### **Terms of Reference**

**May 2012**

In the UK stillbirth is defined as fetal death from 24 weeks gestation. The stillbirth rate in Wales in 2010 was 5.3 per 1000 births - 190 babies.

Sweden has the lowest stillbirth rate in Europe at 3.5 per 1000 births. If Wales were to reduce their stillbirth rate to this figure, there would be an extra 64 babies alive each year. Although this is not directly transferable to Wales because of different population demographics (for example, there is an association between deprivation and increased stillbirth rates) this produces a figure that Wales can aspire to.

This work will be lead by Welsh maternity services and facilitated by the 1000 Lives Plus Mini-Collaborative along side the continuing work

#### **Transforming Maternity Services Mini-Collaborative**

The 1000 Lives Plus Transforming Maternity Services Mini-Collaborative was launched in March 2011 with an overall aim to improve the experience and outcomes for women, babies and their families within Welsh maternity services. The initial focus of work aimed at improving the recognition and response to the acutely deteriorating woman (including the recognition of and response to sepsis) and the prevention of deep vein thrombosis. All maternity units within Wales are involved in the programme.

A National Steering Group oversees this work. Health Board teams are supported in delivering the identified interventions using the 1000 Lives Plus Methodology. Effectiveness is ascertained by a series of outcome measures.

#### **The National Stillbirth Working Group will:**

- Review the available evidence base in relation to prevention of stillbirth.
- Develop a strategy aimed at reducing levels of stillbirth.
- Identify and promote further research within Wales to improve understanding of why stillbirths occur.
- Work with women to optimise the balance between 'normality' and 'intervention.
- Facilitate the sharing and promulgation of best practice across Wales.
- Identify constraints and solutions to specific clinical and operational issues.
- Provide WG with intelligence on local issues and progress with implementation.

- Work with charities with experience and expertise in this field, such as Sands, the Holly Martin Trust and other appropriate groups to improve public awareness of these issues.
- Work with Health Boards and Welsh Government to secure appropriate resources to implement interventions identified as being cost-effective.
- Facilitate work between different agencies and governmental departments who may be able to influence a reduction in risk demographics.
- Work with similar groups in the UK and abroad.

There is a strong health inequalities dimension to stillbirth and a number of the issues have been raised. For example:

- A definition and assessment of risk which includes social circumstances and lifestyle risks, with a particular focus on groups with known poorer comparative outcomes.
- Improved management of risk, through enhanced access to services and experience of services, with a particular focus on women with known poorer comparative outcomes.
- Identification of evidenced based interventions including tailored support for women with additional health and social needs.
- Improvements in data collection and performance management.
- Improvements in determining causes of stillbirth and information relevant to a successful future pregnancy.

WG has specifically requested the Stillbirth Working Group to consider the following issues:

- Increased scanning of pregnant women to correctly identify growth issues with their unborn babies.
- Management of reduced fetal movements.
- Management of induction of labour for 'post dates' pregnancy.

### **Membership Responsibilities**

Members are responsible for:

- Actively providing expert knowledge, advice and expertise.
- Proactively providing two-way communication between the Group and the body or service they are representing.
- Carrying out tasks as agreed and in the timescales required.

### **Group Meetings**

The Group will meet around 6 times a year, depending on need, with the option of more frequent meetings and some work being carried out in smaller groups to progress issues.

## Agenda and Papers

Members can suggest appropriate agenda items for discussion. Where possible, the agenda and any papers for discussion will be circulated at least one week prior to a scheduled meeting.

## Communication

Notes will be produced and circulated to the group; members of the group will, once notes have been approved, and where appropriate, share these with their respective organisation or bodies. All relevant papers, including notes and agendas, will be placed on the 1000 Lives maternity webpage:

[www.1000livesplus.wales.nhs.uk/maternity](http://www.1000livesplus.wales.nhs.uk/maternity)

## Governance

- The Group will provide regular updates to All Wales Maternity Services Implementation Group.
- Communicate and liaise with other stakeholders as appropriate.

## Group Membership

Name	Organisation
Bryan Beattie	Fetal Medicine Specialist
Catherine Roberts	1000 Lives Plus
Cate Langley	Heads of Midwives
Gordon Vujanic	Histopathology
Gwyneth Thomas	WG
Heather Payne	WG
Helen Rogers	RCM
Isobel Martin	Holly Martin Stillbirth Research Fund
Isobel Smith	WRP
Jackie Foster	Health Inspectorate Wales Lay Reviewer
Jan Davies	1000 Lives plus
Janet Scott	Sands
Julia Sanders	Consultant Midwife
Julie Richards/Vinny Ness	LSA
Nigel Davies	NSAG Maternity
Paul Clyburn	Anaesthetist
Philip Banfield	1000 Lives Plus
Polly Ferguson	WG
Shantini Paranjothy	All Wales Perinatal Survey
Shirley Gittoes	Sands
Tom Porter	PHW
Victoria Evans-Park	1000 Lives Pus