

Mark Drakeford AC / AM
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref: SF/MD/2849/14

David Rees AM
Chair
Health & Social Care Committee

22 September 2014

Dear David

Stillbirths in Wales – Progress Report

In response to your letter of 9 July, I enclose a progress report on implementation of the nine recommendations following the one-day inquiry into stillbirths in Wales in February 2013.

While there is still further work to be done to fully implement the recommendations, I am pleased to report the considerable progress made to date and the engagement of clinical professional staff across NHS Wales.

Best wishes

Mark Drakeford

Mark Drakeford AC / AM
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

**HSCC One Day Enquiry into stillbirths in Wales.
Welsh Government update against recommendations**

Recommendations	Welsh Government Response	Progress
<p>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.</p>	<p>Accept: This will form part of the work of the National Stillbirth Working Group</p> <p>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.</p>	<p>Outcome: As similar work was being proposed by Sands (the stillbirth and neonatal death charity), and the Department of Health (DH), there was agreement that the Welsh Government would collaborate in this work. The Public Health Messages Task and Finish Group was formed in early 2013 with midwifery representation from Wales.</p> <p>A complete list of risks associated with stillbirth was developed and the messages subsequently tested with focus groups of first time parents and midwives from across the UK. This produced useful feedback specifically that women were keen to hear about the risks but only about things they were able to do something about.</p> <p>A writing group is now in the process of creating a narrative for these messages. This group includes representation from the Royal Colleges, Public Health England and the Perinatal Institute. The draft narrative of public health information for women has now been tested with the Royal College of Obstetricians and Gynaecologists (RCOG) women’s panel. This resulted in further useful feedback and a further reworking of the narrative.</p>

Recommendations	Welsh Government Response	Progress
		<p>In summer 2014 an agency has been briefed to generate some creative ideas for producing a leaflet of key risks associated with stillbirth that women can actually do something about (stopping smoking, watching out for signs of infection, being aware of fetal movement etc). This work will be presented on 23 September 2014 to the Public Health Messaging Task and Finish Group for final comments and drafting prior to publication.</p>
<p>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.</p>	<p>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.</p>	<p>Outcome: Sands has been leading the national work to explore and agree messages that women and the wider public should know about stillbirth. (See recommendation 1). Sands also provided the content on fetal movements for the newly published all Wales pregnancy book, "Bump, Baby and Beyond" (April 2014). The publication is given to all women at the beginning of their pregnancy and contains information to support parents from the early stages of pregnancy through to toddler years.</p>
<p>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</p>	<p>Accept in principle: Welsh Government will raise these issues with those responsible for midwife and medical education.</p>	<p>Outcome: <u>Midwives</u> The curriculum standards for pre-registration midwifery education are set by the Nursing and Midwifery Council (NMC). Standard 17 details the competencies required for midwives to register with the Council and this includes providing care for women who have suffered</p>

Recommendations	Welsh Government Response	Progress
<p>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.</p>		<p>pregnancy loss, stillbirth or neonatal death.</p> <p>The issue of the prominence of stillbirths in current Welsh midwifery programmes was discussed with the all Wales Midwifery Education Group in early 2014. The curriculum content was reviewed and Welsh Government has received assurances that the content meets the NMC standard, is relevant, evidence based, up to date and appropriate.</p> <p><u>Obstetricians</u> Until now there has been no requirement to develop expertise/experience of counselling in relation to the risk of stillbirth. However, the UK RCOG Curriculum Committee has addressed this and counselling will now be included in the curriculum from August 2014.</p>
<p>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.</p>	<p>Accept: 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.</p>	<p>Outcome: Scoping the viability of establishing a maternity network was completed in July 2013 and included the financial implications of setting up and maintaining such a network.</p> <p>A Maternity Network has now been set up and managed by Public Health Wales, 1000 Lives service improvement programme. A senior Improvement Manager for maternity services has been appointed. Her role as the network manager is full time and is a permanent substantive role.</p> <p>An advert for a clinical lead for the network will</p>

Recommendations	Welsh Government Response	Progress
		<p>soon be advertised and this person should be in place by autumn 2014. The expectation is that this role will be filled by a consultant obstetrician. Once in place, the steering group of the network will be established. The aim is to undertake this by autumn 2014.</p> <p>The stillbirth work will be the first work-stream to be prioritised by the network.</p>
<p>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.</p>	<p>Accept This will form part of the work of the National Stillbirth Working Group and will be completed by March 2014.</p>	<p>Outcome: This work is proving to be challenging as it will involve time consuming manual data collection. Attempts have been made by two health boards to explore how information could be extracted through existing data collection systems but this has proved to be unachievable. This issue will take priority once the Maternity Network meets in autumn.</p>
<p>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</p>	<p>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.</p> <p>David Sissling will write to the Chief Executives of the</p>	<p>Outcome: Welsh Health Specialised Services Committee has been leading review of this provision. They are currently working with Cardiff & Vale University Health Board (C&V UHB) to confirm their proposals to provide more timely access</p>

Recommendations	Welsh Government Response	Progress
<p>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.</p>	<p>Health Boards to bring this recommendation to their attention. The expectation will be that they scope the options for the provision of specialist fetal 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</p>	<p>to fetal services (including fetal cardiac and specialist paediatric input). A draft service specification has been developed and has been shared with each of the leads, as well as Dr Orhan Uzun, fetal cardiologist, for comment and amendment by end of September 2014.</p> <p>WHSSC is also working with C&V UHB regarding access to Chorionic Villus Sampling, which is part of the combined screening test for Down's screening that health boards are implementing. Officials have asked C&V UHB to accept referrals from other health boards and have also suggested they re-train interested consultants in Abertawe Bro Morgannwg University Health Board and Aneurin Bevan University Health Board as a sustainable solution.</p> <p>A meeting with the leads from each of the health boards is planned for the end of October 2014 to agree arrangements.</p>
<p>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</p>	<p>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.</p> <p>Discussions on developing a national perinatal audit for Wales from the All Wales Perinatal Survey are being taken forward though collaborative work with the Healthcare Quality Improvement Partnership (HQIP) and MBRRACE -UK (Mothers and Babies - Reducing Risk through Audits and Confidential</p>	<p>Outcome: Wales is working in collaboration with DH and Sands in a UK Perinatal Mortality Review. The review group has reached consensus on what should be included in any review:</p> <p><i>'all perinatal losses, [from 22 weeks gestation until 28 days after birth], excluding terminations of pregnancy and those with a birth weight of less than 500 g'.</i></p>

Recommendations	Welsh Government Response	Progress
<p>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.</p>	<p>Enquiries across the UK) The financial implications of all options will form part of the discussion on a way forward.</p>	<p>The recommendation is that there will be one UK online tool for collection of data and the DH is in the process of carrying out a cost/benefit analysis of standardising perinatal review which should be completed in autumn 2014. Once this has been completed the UK group will consider how to take this forward.</p> <p>Officials conducting the All Wales Perinatal Survey (AWPS) have been kept informed of this work.</p>
<p>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:</p> <ul style="list-style-type: none"> • 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 	<p>Accept: Through both work carried out by SANDS and on feedback from parents in Wales, the National Stillbirth Group are improving services.</p> <p>An excellent example where sharing good practice is leading to the possibility of immediate improvements is in organising speedy access to services.</p> <p>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</p>	<p>In order to address this recommendation a Perinatal Pathology Sub-Group was set up to recommend actions to increase the uptake of post-mortems.</p> <p><u>Training for Health Professionals</u> An all Wales standardised training package has been developed, focussing on practical issues such as gaining consent and the legal requirements.</p> <p>Cardiff and Vale University Health Board has agreed to undertake a 'train the trainer' event regarding consent for post mortem and plan to undertake a training event with all health boards in mid September 2014.</p> <p><u>Improved information</u> Working with Sands, the all Wales Information for parents/consent package has been</p>

Recommendations	Welsh Government Response	Progress
<p>provision of perinatal pathology.</p>		<p>updated. The revised 'Guide to Post-Mortem Examination of a Fetus, Baby or Child' is currently in the process of being approved by the National Pathology Quality and Regulatory Compliance Group.</p> <p><u>Improved service provision</u> Because of current vacancies, pending retirements and a desire to increase the number of post-mortems a business case to WHSSC for additional funding of consultant perinatal pathology sessions is being prepared by Cardiff and Vale University Health Board. It is estimated that an additional 2.46 sessions per week by a consultant perinatal pathologist may be required.</p>
<p>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</p>	<p>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.</p> <p>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</p>	<p>Outcome: 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 are collaborating with the AFFIRM 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.</p> <p>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</p>

Recommendations	Welsh Government Response	Progress
end of this Assembly.	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	intervention combining raising patient awareness of fetal movement counting, with a management plan for health professionals for women who present with reduced fetal movement.