National Assembly for Wales / Cynulliad Cenedlaethol Cymru
Health and Social Care Committee / Y Pwyllgor Iechyd a Gofal Cymdeithasol
One-day inquiry into stillbirths in Wales: follow up / Ymchwiliad un-dydd i farw-enedigaethau yng Nghymru: gwaith dilynol
Evidence from Heads of Midwifery Advisory Group Wales / Tystiolaeth gan Pennaethiaid y Grŵp Cynghori ar Fydwreigiaeth – SB (F) 01

Health and Social Care Committee

Call for Evidence

Follow-up Work on the Inquiry into Stillbirths in Wales

Date: 27th November 2014

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1) INTRODUCTION

Heads of Midwifery Advisory Group – Wales (HOMAG)

The All Wales Heads of Midwifery Advisory Group is a forum which facilitates collaborative working and communication between the leaders of midwifery and maternity services across the principality with the Chief Nursing Office at the Welsh Assembly Government.

Its principle aims are to:-

- Be recognised as the body to provide advice to the CNO on all matters relating to maternity services.
- Ensure that the Group is consulted on and provides comments on All Wales Maternity issues and developments.
- Provide responses to reports/documents, which affect midwifery and maternity service.
- Ensure that all relevant strategic documents relating to maternity services are achieved by;
    - Raising the profile of Midwives in the maternity services within Wales.
    - Agreeing and developing an annual work programme identifying national priorities affecting maternity services.
    - Influencing the strategic development of midwifery practice.
- Provide advice on policy development and policy consultation.
- Promote the philosophy of All Wales Standards and practice where possible.
- Promote the development of the evidence base that supports delivery of Maternity Services and Midwifery Care.
- Share good practice.
- Link with national programmes and agendas i.e. 1000 Lives Initiatives.
- Working in collaboration on a multidisciplinary basis to address and promote issues relating to maternity care.

The Heads of Midwifery Advisory Group welcomes this opportunity to present evidence about the progress that has been made in implementing the Recommendations made by the Health and Social Care Committee on its One-Day Inquiry into Stillbirth in Wales (2013).

2) BACKGROUND

The Heads of Midwifery in Wales acknowledge that the stillbirth rate in Wales has remained steady over the last 5 years and that it remains higher than other European countries.

Of note the stillbirth rate in 2013 was 4.15 per 1,000 births (CI - 3.5, 4.9)[1] continuing the trend of a small decline in stillbirth rates since 2005- 2007.

Acknowledging that in the majority of cases the cause of stillbirth is unexplained we accept the evidence that maternal cigarette smoking, obesity linked to high levels of depravation and older age at child birth are major risks for stillbirths.

We acknowledge the work undertaken by the following bodies in Wales to reduce the stillbirth rate.

1000 Lives Plus Transforming Maternity Services Mini Collaborative – Stillbirth Work.

The Transforming Maternity Services Mini-Collaborative was launched in March 2011 with an overall aim to improve the experience and outcome for women, babies and their families within Welsh maternity services. Services in Wales have been actively engaged in all aspects of this work.

The National Stillbirth Working Group was set up within the maternity programme in April 2012. Its membership includes representation of key stakeholders identified within Welsh maternity services which includes a Heads of Midwifery Advisory Group representative. The overall aim of this group is to facilitate the 'Welsh Initiative for Stillbirth Reduction' – known as the 'WISR' – project. This group last meet in November 2013 and we've been informed that their work is to be carried forward by the newly established Maternity Network.

Public Health Wales

The Heads of Midwifery Advisory Group acknowledge all the work that Public Health Wales has undertaken, identify the modifiable risk factors for stillbirth in partnership with Health Boards and other stakeholders in Wales, especially around maternal smoking (MAMMS- Project) and obesity in pregnancy.

Local Authority Partnership Programmes

The Heads of Midwifery Advisory Group has, since their inception supported partnership programmes targeted at areas of high depravation; i.e. Flying Start and Families First ensuring midwives are a core element in the multidisciplinary approach in addressing maternal health and wellbeing.

SANDS

The Group also wishes to acknowledge the National work undertaken by the Stillbirth and Neonatal Death Society (SANDS) and their ongoing efforts to support Health Care Professionals and Women in the overall aim of reducing stillbirths in the UK.

The Heads of Midwifery Advisory Group welcomes the recommendations made by the Committee in response to the One Day Inquiry into Stillbirths in Wales and its ongoing commitment to reduce the rate of stillbirths in Wales by the ongoing monitoring of its recommendations.

3) ASSESSMENT

The Heads of Midwifery Advisory Group would like to offer the following comments and updates against the Committee's key conclusions and recommendations.

RECOMMENDATION 1

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

It is understood that the National Stillbirth Working Group last met in November 2013 and that their work is to be carried forward by the Maternity Network, which will be one of its priorities.

Whilst we absolutely support the development of the Maternity Network and welcome the recent appointment of the Clinical Lead and the Senior Improvements Manager for the Network, the delay in establishing these leads has seen a 'slow down' in the momentum of the overall WISR project on a national level. However, we can report that Health Board Leads for the Project have been progressing their local plans.

We can confirm that Health Boards have been approached by the Maternity Network via the Heads of Midwifery on the 14th November 2104 to confirm that the National Stillbirth Working Group is to be re-convened in the near future and have been requested to re-visit the membership list and their Health Board's Project Board representatives. We can confirm that the Heads of Midwifery Advisory Group will be represented on this Group.

In view of the progress that has been achieved to date with this initiative we can report the following in relation to this recommendation;

- **Standardising the management of women who present with reduced fetal movement (RFM).**

    - A Policy Exemplars Guide (PEG) is being developed to reflect the RCOG Green top guideline on Reduced Fetal Movements and Management of The Small for Gestation Age Baby which Cardiff and Vale University Health Board has been gathering baseline data, prior to testing the guidance nationally. Consequently, the national guidance for Health Boards is awaited. However, some Health Boards have developed their own guidance as an interim solution.

- **Implementing an all Wales Growth Assessment Programme (GAP)**

    - All Health Boards in Wales have agreed to implement or continue to use GAP and manage the associated costs and are now at varying stages of implementation of the GAP initiative.

- **Action to improve the provision of perinatal pathology in Wales and increase consent to post-mortem following stillbirths.**

    - We can confirm that the Maternity Network is to re-establish the Perinatal Pathology Sub-Group of the National Stillbirth Working Group and a meeting is scheduled for the 5th December 2014. The aim of this meeting will be to re-group the original members and secure an update on the ongoing post-mortem consent training being delivered within individual Health Boards.

In addition to the WISR work the Heads of Midwifery Advisory Group, acknowledging the key modifiable risk factors for stillbirths has commissioned a specific piece of work, led by the Consultant Midwife representative on the Group, to look specifically at the Public Health Role of the Midwife in delivering evidence based public health interventions with the aim to reduce the inequality that exists in maternal and neonatal outcomes. The paper will be presented to the Heads of Midwifery Advisory Group in December 2014

and the recommendations will be available in January 2015 to all stakeholders including the Maternity Network.

RECOMMNENDATION 2

We recommend that the Welsh Government work with professional bodies and health boards in Wales to ensure that all expectant parents received 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.

The Heads of Midwifery Group understand that in 2013 representatives from Wales were invited to join a group formed by SANDS and the DoH England. The group's aim was to explore and agree a list of messages that women and the wider public should know about stillbirth, including facts, risks/causes and preventive measures. The resulting list went through a market research series of focus groups for both women and midwives. As an update a meeting was held of this group on the 23rd of September 2014 and versions of the leaflet were circulated to the Heads of Midwifery Advisory Group for information and inviting comments.

Of note some Health Boards have developed their own patient information leaflets, which includes the importance of fetal movements and take all opportunities to discuss their relevance. This information is also held as key messages on some Health Boards' social media sites which include references to the New Pregnancy Book - 'Bump, Baby and Beyond' - which has information on fetal movements.

RECOMMENDATION 3

We recommended that the Welsh Government work with professional and regulatory bodies, and relevant academic institutes, 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 stillbirths.

The Heads of Midwifery Advisory Group advocate this approach and will ensure that our representative on the Heads of Midwifery Education Group keeps this as a priority on their agenda.

We can report that most Health Boards do have dedicated bereavement midwives/leads and that bereavement updates are available for staff to access in maternity services. Health Boards report good working relationship with local SANDS groups and some have Local Bereavement Groups established.

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.

As previously noted we welcome the establishment of the Network and the recent appointment of the Clinical Lead and the Maternity Improvement Manager. The Heads of Midwifery Advisory Group supports the Network's development and foresees that this will provide the national steer required to drive the standardisation of maternity care across Wales. We also welcome the Network's prioritisation of the Welsh Initiative for Stillbirth Reduction (WISR) work providing the drive and momentum to a National approach to reduce the rate of stillbirths in Wales.

RECOMMENDATION 5

We recommended that the Welsh Government undertake a review of the number of women in Wales who deliver more that 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 give to whether women with other high risk factors such as advanced maternal age, smoking or weight should be included closer to their due date.

The Heads of Midwifery Advisory Group are aware that two of the Health Boards are involved in collecting this data retrospectively. We assume that once the National Stillbirth Working Group is re-convened that there will be a clear plan for this requirement.

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.

The Head of Midwifery Advisory Group are aware that Mr David Sissling had written to the Chief Executives of all the Health Boards in Wales asking them to scope the options for the provision of specialist fetal medicine. We understand that Health Boards have contributed to this request. We are not aware of the outcome.

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 wider, more imaginative approach to Welsh Government funding for medical research and investigation is adopted, and that Welsh Government seek detailed costing for a 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 direction and prevention of stillbirth.

We are aware that the All Wales Perinatal Survey (AWPS), which collects perinatal and infant mortality data for Wales, has recently been granted an extension to their ethics submission from the South East Research Ethics Committee and from the Confidential Advisory Group for another five years as of 1st January 2015.

In addition the Heads of Midwifery Advisory Group welcomes the **RCOG - Each Baby Counts Initiative²,** which was launched in October 2014. This initiative seeks to reduce unavoidable deaths, including stillbirths, by 50% by 2020.

Form the 1st Januarys 2015, all units in the UK will be expected to report stillbirth and neonatal cases and the results of local serious incident investigations to the 'Each Baby Counts' project. The RCOG will then analyse the data in order to identify avoidable factors developing action plans suitable for local implementation with the aim of sharing the learning, advocating for national change where appropriate.

The data submitted will be cross checked against other national sources of data e.g. MBRRACE-UK data. It is also suggested that a national tool will be developed to standardise the review of all stillbirth cases. We understand that Wales has signed up to this initiative as one of the four counties in the UK.

RECOMMENDATION 8

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

We understand that Cardiff and Vale Health Board has agreed to undertake a train the trainer's event regarding consent for post mortem. The Post Mortem Train the Trainers Training we believe is scheduled for early Decembers 2014.

Health Board's have a register of the staff that have been trained in taking post-mortem consent. This is an ongoing process.

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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 undertake in co-operation with health or professionals and academics with expertise in the field, and should draw on international knowledge of stillbirth.

We understand that all the Health Boards in Wales were invited to take part in a large multi-centre Scottish stillbirth research study called AFFIRM. Of note we believe that two Health Boards actually participated (ABUHB and BCUHB). This is regretful but we appreciated the competing priorities within Health Boards. The Heads of Midwifery Group re-iterated their support for the RCOG-Each Baby Counts initiative and the extension of the All Wales Perinatal Survey, as positive steps in achieving this recommendation by available means.

4) CONCLUSION

In conclusion we would agree with the Minister for Health and Social Service's progress report to the Committee in September 2014 that despite the progress made on the engagement of clinical staff, further work remains to be done to fully implement the Committee's recommendations.

However, we are confident that the newly established Maternity Network, prioritising the WISR project in partnership with Health Boards, will drive the necessary change to reduce the rate of stillbirths in Wales.

The Heads of Midwifery Advisory Group would re-iterate their support and co-operation in this mission.

5) REFERENCES

1) Paranjothy, S et al 2010. All Wales Periantal Survey: Annual Report, Department of Child Health, School of Medicine, Cardiff University. http://www.ce.ac.uk//medic/andps//

2) RCOG (2014). Each Baby Counts – Conference Documentation. RCOG London