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

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1000 LIVES O FYWYDAU

Response to the Health and Social Care Committee follow-up from the Inquiry into Stillbirths in Wales

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Purpose and Summary of Document: To provide evidence to the Health and Social Care Committee on the progress made in relation to recommendations one, two, four, five and eight of the committee's one day Inquiry into Stillbirths in Wales.

1 Introduction

This paper is a response to the National Assembly for Wales Health and Social Care Committee's follow-up on its inquiry into stillbirths in Wales.

The response has been prepared by Public Health Wales' 1000 Lives Improvement Service.

Evidence is provided on recommendations one, two, four, five and eight of the "One day Inquiry into Stillbirths in Wales" (National Assembly for Wales, 2013) - the recommendations on which the 1000 Lives Improvement Service has some responsibility.

2 Background

The 1000 Lives Improvement Service used to host the Transforming Maternity Services Mini Collaborative. The Collaborative was established in March 2011 with the overall aim of improving the experience and outcomes for women, babies and their families within Welsh maternity services. The Collaborative came to an end on the 31 March 2104

The Collaborative, in turn, established the National Stillbirth Working Group (NSWG) in March 2012. The work of the NSWG was fully funded by 1000 Lives for the financial year 2013/14.

Following the Health and Social Care Committee's "One day inquiry into stillbirths in Wales" held in February 2013, the NSWG was tasked with supporting the implementation of recommendations one, two, five and eight of the report.

At the time, the NSWG was 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

At the time that the Transforming Maternity Services Programme came to an end, on 31 March 2014, the NSWG produced two reports summarising its work:

- Progress Report (March 2014)
- Increasing the Consent to post mortem following stillbirth in Wales (March 2014)

These reports are submitted to complement this response.

3 A Maternity Network for Wales (recommendation 4)

Following the Committee's recommendation that "the Welsh Government scope the viability of establishing a maternity network to drive the standardisation of care across Wales", the Welsh Government undertook the scoping.

In June 2013 the Quality and Safety Sub Group of the Welsh Government's Maternity Strategy Implementation Group recommended that the purpose of a maternity network in Wales should be:

- Ensuring similarly high quality standards across the whole of Wales with similar, but not necessarily identical, guidelines and pathways
- Collation of information across Wales for the purposes of audit, benchmarking and improvement of outcomes
- Sharing lessons learned widely across Welsh maternity services
- Enabling all those involved in women's health to interact more freely, learning from each other and supporting each other

In March 2014, the Health Minister wrote to the Director of the 1000 Lives Improvement Service requesting that the service set up and run the Maternity Network.

3.1 Network manager

The first task was to appoint a network manager. A full time, permanent manager, Claire Roche, was appointed and commenced in post on 21 July 2014. Claire is a midwife who has worked in three different health boards in South Wales, most recently as a Senior Midwifery Manager in Aneurin Bevan Health Board.

3.2 Clinical lead

A clinical lead post has been established to provide clinical leadership within the network. This post was aimed at consultant obstetricians. The clinical lead will work in partnership with the network manager. Claire Francis, a consultant obstetrician in Cardiff and Vale UHB has been appointed and wiill provide half a day per week to the network for a fixed term of one year (after which the role will be reviewed). She is due to start on 5 January 2015.

3.3 Steering group

A steering group is being convened and is scheduled to meet on 26 January 2015. The steering group will be multi-professional and aims to

represent all organisations involved in the provision of maternity services in Wales. It will include health boards, the educational sector, the Welsh Government and women who use the services. The steering group will have the responsibility of ensuring that the network has clear priorities and objectives, focusing on patient safety and quality as well as the experience of women and their families.

The themes of the Strategic Vision for Maternity Services in Wales (Welsh Government, 2011) will be a key driver for the work of the Maternity Network.

3.4 National Stillbirth Working Group (NSWG)

The National Stillbirth Working Group (NSWG) is being re-established as a sub group of the Network and will be the highest priority for 2015. The first meeting is planned for January 2015, as soon as the Clinical Lead commences her post. The group will meet quarterly during the year with an additional meeting planned for the first quarter to develop momentum.

Membership of the group has already been reviewed by the Network Manager and Clinical Lead with a particular focus on ensuring that there is representation from all health boards. The Heads of Midwifery and Clinical Directors for Obstetrics in each health board have been contacted and asked to identify who will represent their organisations.

There will also be representation on the NSWG from the Welsh Government, the All Wales Perinatal Survey and Paediatric Pathology. Women and families will be represented by the SANDS (Stillbirth and Neonatal Death Society) organisation.

The NSWG will be chaired by the Chief Nursing Officer for Wales, Professor Jean White. The Network Manager will meet with the CNO regularly during the period for which she chairs the group, ensuring that she is fully briefed and updated before meetings and during the intervening periods between meetings.

Prior to the meeting in January, all Heads of Midwifery and Clinical Directors for obstetrics will be asked to complete a self assessment for their organisations of the progress made against the interventions agreed nationally (Appendix 1). This will enable a thorough assessment to have been undertaken that will inform the NSWG.

4 Perinatal Pathology Sub–Group (recommendation 8)

The Perinatal Pathology Sub-Group of the NSWG has been reconvened to address the recommendation 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*
- *assessment of the actions needed to improve the provision of perinatal pathology."*

The sub-group will meet on Friday 5 December 2014 to assess progress in health boards with the consent training package.

All Heads of Midwifery and Clinical Directors for Obstetrics have been contacted and requested to nominate a representative from their Health Board to attend this meeting. The Cellular Pathology Services Manager of Cardiff and Vale UHB will attend in addition to representatives from SANDS.

5 Public awareness and information (recommendations 1 and 2)

The NSWG has ensured that there is a good representation of women (service users) in its membership. The views and opinions of those who have used the service and, in particular, have experienced the loss of their baby are essential to informing this work.

Since being in post, the Maternity Network Manager has had regular contact with the SANDS organisation. She attended the Stillbirth Public Health Messaging Task and Finish Group meeting in London on 23 September hosted by SANDS as the representative for Wales. Phillip Banfield, a consultant obstetrician from BCUHB, was also present. The aim of the meeting was to bring together representatives from across the UK so that feedback could be provided from SANDS on their project exploring public health messages relating to stillbirth.

The team shared the learning from their engagement with both women and midwives. Of particular interest were the messages that women felt were important depending on their experiences. Women who had

experienced a stillbirth wanted to be given as much information as possible. Women who had not had this experience were more reserved about the information they would want to receive. In particular, they did not want to be told anything that they did not have control over, for example being in a deprived or vulnerable group of women.

The proposed narrative and design of a patient information leaflet was shared with the group. It was reviewed and comments were made.

Since the meeting, communication has continued between the devolved nations of the United Kingdom. A draft consensus statement on reducing the risk of stillbirth was circulated in November 2014. The Maternity Network Manager shared it with the Welsh Government and the Heads of Midwifery and Clinical Directors for Obstetrics to coordinate a response from Wales. The response to the Department of Health was submitted on 23 November 2014.

The Maternity Network will continue to engage with this national work to develop public health messages as a matter of priority to ensure that all expectant parents receive adequate information about stillbirth and its associated risks.

The NSWG will also ensure that the key messages are shared with clinicians so that they can be given to women while the leaflet is being developed. Written information alone will not be as effective as well informed clinicians who are confident to deliver the messages.

6 Women who deliver more than thirteen days after their due date (recommendation 5)

The Transforming Maternity Services Mini-Collaborative Welsh Initiative for Stillbirth Reduction Progress Report (March 2014), acknowledged the challenge of reviewing women giving birth more than thirteen days after their expected date of delivery.

The collaborative identified that the numbers of women were very high and, through cross reference of data sets, found that information was inaccurate. The report explained that this was a reflection of the available maternity information in Wales and the lack of a Welsh national data set. It suggested that this would need to be explored further beyond the timeframe of the collaborative.

The issue will now be addressed by the NSWG. It will be a specific item for health board self assessments and will be on the agenda of the January 2015 meeting.

7 Conclusion and way forward

The Transforming Maternity Services Mini-Collaborative (March 2011 - March 2014) assisted health boards to agree interventions to be implemented with the aim of reducing stillbirth rates in Wales.

The Maternity Network will now take responsibility for facilitating and supporting health boards to work collaboratively to achieve this shared aim.

A permanent Maternity Network that is not time limited will strengthen partnerships between health boards, the Welsh Government, education providers, Royal Colleges, third sector and of course the women and families who use the services.

While the NSWG will specifically focus on the continued work required to progress the interventions in the Welsh Initiative for Stillbirth Reduction driver diagram (Appendix 1), other work streams of the network will also contribute to this work.

The network will address quality and patient safety. The Network Manager and Clinical Lead are keen to address the issue of having a national Maternity Dashboard and for each Health Board to have a dashboard that reports on the same parameters. Having a baseline in Wales that avoids variation in the way data is reported will be the first and crucial step to take forward a national approach to risk reporting, the identification and avoidance of harm, reduced variation and management in maternity services in Wales. The Network Steering Group will be asked to consider this issue when it meets in January 2015.

8 References:

Welsh Government (2011) "A Strategic Vision for Maternity Services in Wales" www.cymru.gov.uk

Welsh Government (June 2013) "Welsh Government Maternity Strategy: Report from Quality and Safety Sub-Group" www.cymru.gov.uk

Welsh Government (July 2013) "A Maternity Network for Wales: Scoping Paper" www.cymru.gov.uk

Appendix 1: Welsh Initiative for Stillbirth Reduction
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