Y Pwyllgor lechyd a Gofal Cymdeithasol Health and Social Care Committee

Cynulliad Cenedlaethol Cymru National Assembly for Wales



Mark Drakeford AM

Minister for Health and Social Services

26 February 2015

Dear Mark.

Follow-up inquiry into stillbirths in Wales: progress made to date

As you will be aware, the Health and Social Care Committee is committed to following up on the steps taken to implement recommendations arising from its scrutiny inquiries. To this end, the Committee recently turned its attention to the recommendations made in its 2013 report on stillbirths in Wales.

The Committee is grateful for the <u>update report</u> you provided in autumn 2014. Members acknowledge the progress that has been made in the last 18 months, not least in relation to the establishment of a Maternity Network to drive the standardisation of care across Wales. The Committee commends the work that has been done by service commissioners and front-line staff to address some of the concerns raised as part of our original inquiry.

While acknowledging the improvements outlined in your update report, the Committee noted your statement that "despite the progress made on the engagement of clinical staff, further work remains to be done to fully implement the Committee's recommendations". To inform the Committee's consideration of where recommendations were yet to be fully delivered, the Committee invited those who gave evidence to the original inquiry to provide their views on progress to date and on where further work may be needed to deliver improvements in this field. The Committee considered written

Bae Caerdydd Cardiff Bay CF99 1NA submissions during January 2015 and would like to note its thanks to those who took the time to contribute to this important piece of follow-up work.

The Committee's views on progress made in relation to each recommendation are listed in Annex A to this letter. The letter does not seek to make any further recommendations. Rather, its purpose is to ensure that:

- the momentum to reduce the number of stillbirths in Wales, as sought by the Committee in its original inquiry, is maintained; and
- the information collected as part of this follow-up inquiry informs the work of the National Stillbirth Working Group, to be established during 2015 as a sub group of the Maternity Network.

The Committee looks forward to receiving a response in due course.

Yours sincerely,

David Rees AM

Chair, Health and Social Care Committee

ANNEX A

This annex summarises the Committee's view on the progress made to date to implement its nine recommendations on stillbirths in Wales. It does not seek to summarise the evidence or Government responses received during the original or follow-up inquiry, all of which can be read in full on the Committee's website.

Recommendation 1: This recommendation raised the need to develop public health messages on stillbirth. The Welsh Government accepted this recommendation and has engaged in a process of developing relevant and appropriate public health messages. While the Committee acknowledges the progress already made in this area, particularly the work that has been undertaken by Sands and others to develop a consensus document which includes core messages on stillbirths, stakeholders noted that there was a lack of clarity about the Welsh Government's view on the document and its roll out in Wales. The Committee urges the Welsh Government to work with relevant partners to clarify the position.

Recommendation 2: This recommendation drew attention to the need to improve dissemination of public health messages and was accepted by the Welsh Government. While the importance of developing relevant books and literature to convey information was acknowledged, evidence received suggested that further work remains to ensure that discussion of stillbirth forms a routine part of the conversation between health professionals and expectant parents. Clarification of how the Welsh Government is working with professional bodies and health board managers to ensure stillbirth becomes a normal part of discussions with prospective parents would be welcomed.

Recommendation 3: This recommendation was agreed in principle and sought to achieve two things:

- first, a more prominent place for stillbirth in Welsh midwifery and obstetric training curricula; and
- secondly, arrangements to monitor and review the competence and training needs of health professionals in relation to stillbirth.

While the Government's update report outlines what has been done to address the first aspect of this recommendation, it does not refer to the second point. There was also some uncertainty among respondents to the Committee's follow-up work regarding progress on this recommendation. The Welsh Government may wish to provide further clarification on how it is working with

health boards to review the training needs and competence of health professionals in relation to stillbirth.

Recommendation 4: This recommendation called on the Welsh Government to scope the viability of establishing a maternity network to drive the standardisation of care in Wales and was agreed in principle. The Committee commends the significant progress that has been made on this recommendation and welcomes the appointment of a network manager and clinical lead. The Committee notes that the Maternity Network is expected to take on a significant workload in its first year and seeks assurance that the Network will be sufficiently equipped to drive forward improvements, both in terms of the support it receives from the Welsh Government and from research institutions in Wales. The Committee would welcome further information about:

- when the National Stillbirth Working Group will meet;
- how its progress will be monitored; whether its minutes will be published; and
- whether one of its functions will be to collect data on stillbirths.

Recommendation 5: The Committee's original report, and this recommendation, highlighted the increased risk of stillbirth in women who have passed 42 weeks of pregnancy. While the Welsh Government accepted the recommendation that the number of women in Wales who deliver more than 13 days after their due date should be reviewed, its update report acknowledged the difficulty encountered when seeking to collect the relevant data. The Committee remains concerned about the link between late delivery and increased risk of stillbirth. The Committee acknowledges that the Maternity Network will prioritise work on the recommended review. It urges the Welsh Government to ensure that this work is monitored closely to ensure that progress is made as soon as possible.

Recommendation 6: Concern that the cost of seeking specialist foetal medicine consultations outside Wales exceeded the cost of providing the service within Wales was raised during the Committee's original inquiry. The Welsh Government agreed in principle to the recommendation that this claim ought to be investigated and that the proposal to commission specialist foetal medicine services at a tertiary rather than secondary level should be explored. The Committee welcomes the steps that have been taken to: develop a service specification; ensure that Cardiff and Vale University Health Board accepts referrals from other health boards; and re-train interested consultants in

Abertawe Bro Morgannwg and Aneurin Bevan University Health Boards. However, further information about how these developments address the needs of pregnant women living in north or mid Wales would be welcomed.

Recommendation 7: The first aspect of the Committee's original recommendation called for the adoption of a national minimum standard for reviewing perinatal deaths in Wales. The Committee commends the significant amount of work undertaken by Sands and the Department of Health to develop a tool for UK-wide use, and welcomes the fact that this will be taken forward as part of the National Stillbirth Working Group's programme. The second aspect of this recommendation urged the Government to cost a national perinatal audit and find a wider, more imaginative approach to funding medical research and investigation of this kind. The Committee welcomes Wales' participation in the UK-wide perinatal mortality review.

Recommendation 8: The low rate of post mortem for stillborn babies was a clear theme in the Committee's original inquiry. The Committee recommended that: better training be given to health professionals about how to discuss post mortems with grieving families; improved information be developed for parents to allow them to make informed decisions; and that an assessment was made of the adequacy of the perinatal pathology service in Wales. The Committee welcomes the evidence that work has been undertaken to address each of these areas. Nevertheless, evidence suggests that further work remains to reduce the delays parents face when waiting for their babies' post mortem reports. The Committee acknowledges that the bid for additional funding for consultant perinatal pathology sessions may help address this delay. The Committee urges the Welsh Government to keep this under close surveillance. If improved timescales are not achieved over the next six months, the Committee believes that the remit of the Perinatal Pathology Sub Group should be extended to include work on how post mortem reports are returned to parents.

Recommendation 9: The evidence submitted to the Committee's original inquiry demonstrated clearly that little research had been funded or undertaken to establish the underlying causes of stillbirth. Although the Committee welcomes the participation of some health boards in the AFFIRM Scottish Research Study, it notes that not all health boards are participating. Furthermore, it notes that the Study concentrates on how one of the risk factors for stillbirth – reduced foetal movements – can be reduced, rather than

what its underlying causes are. The Committee continues to believe that further research is needed in this field.