

# The Pregnancy Loss Review: Care and Support when Baby Loss Occurs Before 24 Weeks Gestation

Terms of Reference

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# **Background**

- 1.1. Many of the care considerations for parents experiencing a stillbirth (when a baby is born without signs of life after 24 weeks gestation) will be similar for those experiencing a miscarriage. Local policies, however, may affect the type and place of care offered or available depending on the gestation when baby loss occurs.
- 1.2. In particular, registration certificates are often greatly valued by some parents as a way of recognising and naming their baby. Currently, parents whose babies are stillborn after 24 weeks gestation can register the baby's name and receive a certificate of registration of stillbirth. When a pregnancy ends before 24 weeks gestation however, there is no formal process for parents to legally register the loss. Some expectant parents find this to be particularly distressing, whilst other parents would find it equally distressing if they were required to register the loss when they did not want to.

# Purpose of the review

- 1.3. The purpose of the review is to consider:
  - The impact on families of the current threshold of 24 weeks gestation before being able, formally, to register a miscarriage if they so wish.
  - Whether it would, on balance, be beneficial to look at legislative options to amend existing primary legislation to allow parents to register a miscarriage if they so wish.
  - Options to improve NHS gynaecology and maternity care practice for parents who experience a miscarriage and other causes of baby loss.
- 1.4. The review will not consider changing the existing laws on abortion. However, the review's recommendations for improving care and support for those experiencing a pre-24 week gestation baby loss may be relevant to women and families who choose to terminate a much wanted pregnancy, for example due to congenital anomalies.
- 1.5. The review will work with key partners to make recommendations to government. The recommendations will be aimed at improving the care and support women and families receive when experiencing a pre-24 week gestation baby loss.
- 1.6. Some of the solutions are likely to lie in practice rather than in legislation. The review should consider practice-based solutions wherever possible.
- 1.7. The review will help government create a forward-looking approach to improve the support and experience of care for women and families who have a pre-24 week gestation baby loss.

## **Leadership and Governance**

- 1.8. The co-leads for the review are:
  - Zoe Clark-Coates, Founder & CEO, The Mariposa Trust; and
  - Samantha Collinge, Specialist Midwife and Maternity Bereavement Service Manager, University Hospitals Coventry and Warwickshire NHS Trust.

- 1.9. The co-leads have overall responsibility for the review and its outputs.
- 1.10. An advisory panel will be appointed to ensure that service users, service providers and the full range of stakeholders directly shape the recommendations.
- 1.11. The Department of Health and Social Care will support the co-leads to deliver their responsibilities by providing administrative, research and analytical support.
- 1.12. The review will report to the Secretary of State for Health and Social Care.

# **Co-production**

- 1.13. The review will be undertaken in consultation with the General Register Office.
- 1.14. The review should closely involve service users and service providers in all aspects of its work. It should:
  - seek to understand existing practice across different local areas;
  - · engage widely with stakeholders; and
  - make recommendations that have broad support among service users, providers, relevant professionals, and organisations affected.
- 1.15. The review period should be used to air differences and find shared solutions.

### **Outputs**

1.16. The review will prepare a report that identifies priorities and makes detailed recommendations for improvement.

### **Devolution**

- 1.17. The review is commissioned by and will report to the Department of Health and Social Care in England. Recommendations will extend to England in relation to matters that are devolved in Wales (including health), and England and Wales in relation to non-devolved matters (including registration).
- 1.18. The review should engage with the Welsh Government and stakeholders in Wales, where appropriate, to consider interfaces with Welsh legislation and practice.