

Dr Sarah Seaton, Prof Elaine Boyle, Prof Samantha Johnson, Prof Brad Manktelow - Written evidence (PRT0027)

WHO WE ARE

The Infant Mortality and Morbidity Studies ([TIMMS](#)) research group is a multi-disciplinary, internationally recognised group, whose core aim is to improve maternity, neonatal and paediatric services to improve the lives of babies, children, young people and families. We undertake national and international research with a particular focus on the short- and long-term impact of preterm birth. This submission is made by the following experts, on behalf of the TIMMS research group:

- Professor Elaine Boyle: Professor of Neonatal Medicine
- Professor Samantha Johnson: Professor of Child Development
- Professor Brad Manktelow: Professor of Medical Statistics, Head of TIMMS research group, Perinatal Lead of MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquires across the UK)
- Dr Sarah Seaton: Lecturer in Perinatal and Paediatric Research, NIHR Advanced Fellow, Co-Principal Investigator of the Paediatric Intensive Care Audit Network (PICANet)
- Professor Lucy Smith: Professor of Perinatal Health, NIHR Advanced Fellow, Co-Investigator of MBRRACE-UK

In this submission we focus on the impact of prematurity across both the gestational age spectrum and from birth through to the care needs of surviving children in early life. We provide key research findings from our work, suggest recommendations and highlight potential positive outcomes for babies, children and families.

BIRTHS BEFORE 24 WEEKS GESTATION

What is known:

- Wide variation in clinical decision making exists in the UK as to whether signs of life are reported in preterm babies born before 24 weeks of pregnancy.¹ This leads to inconsistencies as to whether these babies' deaths are reported as a miscarriage or registered as a live birth and subsequent neonatal death.
- This variation impacts families² as it leads to unequal access to birth and death certification to validate their baby's life, parental leave and pay, and paid dental care and prescriptions.
- Additionally, variation has existed in the provision of survival focused care for babies born at 22- and 23-weeks gestational age but our recent evaluation³ has highlighted that recent national guidance from the British Association of Perinatal Medicine (BAPM)⁴ has led to a more consistent approach to care.
- This variation in both birth and death registration and provision of survival focused care leads to biased comparisons of preterm birth rates and associated perinatal mortality outcomes. For example, organisations that rarely report signs of life in babies born before 24 weeks gestation have artifactually lower estimates of neonatal mortality of up to 30% compared to those organisations who report signs of life in these babies more frequently, preventing fair comparisons of the quality of care.⁵ Similarly, survival rates for babies born at 22 weeks vary markedly across countries before adjustment for differences in registration practice.⁶

Recommendations:

1. Ensure consistent death registration of births before 24 weeks gestation by mandating implementation of guidance regarding

¹ Smith et al. [Variability in the management and outcomes of extremely preterm births across five European countries.](#)

² Smith et al. [Parents' experiences of care following the loss of a baby at the margins between miscarriage, stillbirth and neonatal death](#)

³ Smith et al. [Effect of national guidance on survival for babies born at 22 weeks' gestation in England and Wales](#)

⁴ BAPM. [Perinatal management of extreme preterm birth before 27 weeks of gestation](#)

⁵ Smith et al. [Comparing regional infant death rates: the influence of preterm births <24 weeks of gestation](#)

⁶ Smith et al. [An International Comparison of Death Classification at 22 to 25 Weeks' Gestational Age](#)

assessment of signs of life⁷ across all gynaecology and maternity services.

2. Ensure consistent reporting practices when making comparisons of gestation-specific survival rates for preterm births and overall survival rates across organisations, regions or countries such as those implemented by MBRRACE-UK.
3. Encourage healthcare professionals and trainee healthcare professionals involved in the care of babies born before 24 weeks to make use of the Healthtalk learning resources⁸ to improve care for parents experiencing extremely preterm baby loss. Also ensure parents are aware of the Baby loss certificates launched in Scotland⁹ and England¹⁰ to support parents who have experienced a loss of pregnancy before 24 weeks.

Positive outcomes:

- Reduced distress and confusion experienced by parents relating to inconsistent practice
- Equitable access for parents to birth certification to validate their baby's life, provision of parental leave and pay to allow time to grieve, and access to paid dental care and prescriptions.
- Recognition for parents and families of the full burden of baby loss from 22 weeks and facilitation of evaluation of care provision and outcomes at early gestational ages through reliable monitoring of perinatal birth outcomes from 22 weeks gestational age

⁷ [The MBRRACE-UK Guidance on the determination of signs of life following spontaneous birth before 24+0 weeks of gestation where, following discussion with the parents, active survival-focused care is not appropriate](#) was developed in collaboration with the [Royal Colleges, national Government, parent advocacy groups and health care professionals](#). A [visual summary](#) of the guidance and [videos](#) for healthcare professionals and parents are available. Elements of the guidance have now been included in [WHO ICD-10 Causes of Disease](#) to promote international consistency of birth and death registration regarding fleeting reflex activity observed after birth.

⁸ Through accessing Parents' stories of loss featured in the Healthtalk module entitled "[Losing a baby at 20 to 24 weeks](#)"

⁹ National Records of Scotland. [Memorial book of pregnancy and baby loss prior to 24 weeks](#)

¹⁰ Gov.uk. [Request a baby loss certificate](#)

- Provision of reliable information for parents and families on gestation-specific survival of extremely preterm births for informed decision making
- Robust identification of organisations providing high- or low-quality care through valid comparisons of rates of survival of preterm birth between organisations, regions and countries

IMPROVING PERINATAL MORTALITY OUTCOMES AMONG PRETERM BIRTHS

What is known:

- The burden of perinatal mortality is high among preterm births, with births before 37 completed weeks' gestational age accounting for 75% of stillbirths and late fetal losses, and 73% of neonatal deaths.¹¹
- Poor survival outcomes increase exponentially with decreasing gestational age, with extremely preterm births at the highest risk
- Over recent years, MBRRACE-UK perinatal mortality surveillance has highlighted decreasing stillbirth rates for term born babies. In contrast, stillbirth rates have remained static for preterm births. Furthermore, in 2021 stillbirth rates increased in preterm births, with the greatest increase at 28 to 31 completed weeks of gestation.

Similar patterns have been seen for neonatal mortality with notable increases in neonatal mortality rates for babies born between 24 to 27 completed weeks' gestational age.

Recommendations:

1. Ensure healthcare providers adopt and use the BAPM Perinatal Optimisation Pathway,¹² to improve preterm outcomes

¹¹ MBRRACE-UK. [Perinatal Mortality Surveillance: Report for births in 2021](#)

¹² BAPM. [Perinatal Optimisation Pathway](#)

2. Ensure increased provision of perinatal pathology services as a national priority to allow equity of access to all modalities of post-mortem examination for babies born extremely preterm.
3. Ensure continued evaluation and implementation of national initiatives to reduce stillbirth and neonatal deaths with a focus on monitoring their impact on reducing preterm birth, particularly the most extreme preterm group.
4. Use up-to-date survival information¹³ for discussions with parents to determine decisions around survival focused care

Positive outcomes:

- Improvements in care to consistently and progressively reduce perinatal mortality outcomes for babies born preterm and achieve reductions in total perinatal mortality
- Improved knowledge of the aetiology of extremely preterm birth to focus initiatives to reduce perinatal mortality
- Key knowledge and explanation for parents on aetiology for informed discussions around prevention of preterm loss in future pregnancies
- Provision of reliable information for parents and families on gestation-specific survival of preterm births for informed decision making

NEONATAL LENGTH OF STAY

What is known:

- Separation of families during a neonatal stay is traumatic and can be lengthy, particularly for babies born very preterm

¹³ Seaton et al. [Estimated neonatal survival of very preterm births across the care pathway.](#)

- Anecdotally, it was thought that many very preterm babies who survived neonatal care stayed in hospital until around their due date, but our research has shown that particularly for babies born at 29-31 weeks gestational age,¹⁴ discharge can be earlier and families are not always prepared

Recommendations:

- Clear communication to families about neonatal length of stay using evidence-based estimates
- A need for clear evidence for what is a safe neonatal length of stay which minimises readmissions to other healthcare settings

LATE PRETERM AND EARLY TERM BIRTHS

What is known:

- A gradient of risk of mortality and poor outcomes extends across the whole range of gestational age at birth from 22 weeks to full term (39-40 weeks) with the most immature having the worst outcomes.
- Early term birth (37-38 weeks) carries an increased risk of adverse short- and long-term health, developmental, and educational outcomes, when compared to full term birth (39-41 weeks).¹⁵
- Late preterm (34-36 weeks) births comprise around 5% of all live births and 70% of preterm births in England and Wales; early term births comprise around 25% of all live births.
- Very preterm birth (<32 weeks) carries the highest risk of severe disability but affects a minority (around 1%) of births.
- Although less severely affected at the individual level, very large numbers of individuals born late preterm and early term contribute

¹⁴ Seaton et al. [Estimating neonatal length of stay for babies born very preterm.](#)

¹⁵ Alterman et al. [Gestational age at birth and academic achievement in primary and secondary school in England.](#)

the greatest burden of adverse outcomes associated with gestational age at birth at the population level.

- There is no routine data collection for births at >34 weeks.

Recommendations

- Consider gestational age at birth as a continuum rather than a dichotomy of “term” and “preterm” birth.
- Institute routine pregnancy, perinatal and neonatal data collection for all births.
- Support research to better understand the risks, outcomes, and costs associated with late preterm and early term births, and to develop interventions to improve outcomes for these groups.
- Ensure implementation of the NICE Guideline¹⁶ for the developmental follow-up of children and young people born preterm to ensure that all preterm born children at highest risk of developmental problems and disorders receive appropriate monitoring.

INCREASED RISK OF NEEDING INTENSIVE CARE IN THE FIRST TWO YEARS OF LIFE

What is known:

- Following discharge from neonatal care, risk of admission to a paediatric intensive care unit (PICU) is highly related to prematurity and is substantially higher among children born at <32 weeks than the general population.¹⁷
- Most of these PICU admissions are an emergency and the primary diagnosis is due to respiratory conditions, indicating their ongoing lung problems.

¹⁶ NICE. [Developmental follow-up of children and young people born preterm.](#)

¹⁷ van Hasselt et al. [Paediatric intensive care admissions of preterm children born <32 weeks gestation](#)

- Of the preterm-born children admitted to PICU, approximately a fifth are admitted again at least once before their second birthday.
- Risk of PICU is highest in the initial days after discharge from neonatal care and the highest risk is for children discharged in Autumn and Winter (upcoming, as yet unpublished, research).
- Children born preterm (<37 weeks of gestation) are over-represented when considering children with a long-stay (≥28 days) in PICU¹⁸

Recommendations

1. Clear and consistent communication to families, with advice and measures to minimise the risk of serious respiratory disease
2. Expanding the respiratory syncytial virus vaccination programme to cover all children. The Royal College of Paediatrics and Child Health have written to the government asking them to consider introducing a full vaccination programme, as recommended by the Joint Committee on Vaccinations and Immunisations.¹⁹ This would protect all children, particularly those born very preterm and susceptible to respiratory conditions, as there would be less RSV in circulation during the autumn and winter months.
3. A review of all children admitted as an emergency to PICU before their due date but after discharge home from neonatal care to explore if there were any safety issues
4. Consider the full continuum of prematurity and explore if children born late or early term are also at elevated risk of needing critical care

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¹⁸ van Hasselt et al. [Impact of prematurity on long-stay paediatric intensive care unit admissions in England 2008-2018](#)

¹⁹ [RCPCH launches campaign on RSV vaccination](#)