

Twins Trust - Written evidence (PRT0030)

Twins Trust appreciates the opportunity to submit evidence to the Preterm Birth Inquiry. As a charity dedicated to supporting families of multiples, we understand the profound impact preterm birth can have on infants, parents and their wider families.

There are around 10,000 sets of twins and 100 -150 sets of triplets born each year across the UK making up 1.4% of all pregnancies. In England, the incidence of preterm birth among twins and triplets is significantly higher compared to singleton pregnancies. Statistics from the Office for National Statistics (ONS) show that approximately 60% of twin pregnancies result in birth before 37 weeks (spontaneous or induced) and over 75% of triplets are born preterm before 35 weeks.

Multiple pregnancies account for 6.4% of stillbirths, posing a significantly higher risk compared to singleton pregnancies, with a 2.4 times greater likelihood of stillbirth occurrence. Similarly, neonatal deaths in multiple pregnancies constitute 13.5% of all instances, reflecting a staggering 5.5 times higher risk compared to singleton pregnancies.

Preterm birth presents a significant concern for expectant parents of multiples, often addressed during initial medical consultations. The prospect of preterm delivery looms as a prevalent topic throughout pregnancy, compelling parents to brace themselves for its potential occurrence. Statistics underscore the likelihood of preterm birth in multiple pregnancies, overshadowing the likelihood of carrying to full term.

Variation in care and health inequalities

- The implementation of existing NICE and NHS guidance on preterm birth

Twins Trust advocates for adherence to the NICE guidelines. Since 2017, our organisation has collaborated with 36 maternity units to enhance outcomes for twin and multiple pregnancies through our Maternity Engagement Project. Our focus is on ensuring that multiple pregnancy care aligns with NICE Guideline 137 (NG137) and NICE Quality Standard 46 (QS46). By following NICE guidelines, particularly NG137, research has demonstrated notable improvements in pregnancy outcomes for families with multiple births.

We fully recognise the importance of implementing existing NICE and NHS guidance on preterm birth to ensure consistent, evidence-based care across all healthcare settings. We recommend that all units follow the guidance and would welcome the chance to discuss our Maternity Engagement Project and our findings further. Our 'Nice Works II' report builds on our original 'NICE Works' report (2019), which highlighted that maternity units provide better, safer care for multiple pregnancies when following NICE guidelines. The report can be viewed here: <https://twinstrust.org/static/2e482d62-238c-4181-8a6e47b1eed09d2d/NICE-Works-II.pdf>

Prevention

Effective prediction of preterm birth is essential for early intervention and improved outcomes. Twins Trust supports investment in screening programmes and innovative technologies to identify high risk pregnancies and implement preventive measures. We emphasise the importance of both primary and secondary prevention strategies, including prenatal education, lifestyle interventions and medical interventions when indicated, to reduce the incidence of preterm birth.

Neonatal and longer-term care and support

The neonatal intensive care unit is a place where many parents of multiples find themselves, navigating a landscape fraught with emotion and complexity. While NICU can be challenging for any family with a newborn, the journey is often intensified for parents of twins, triplets, or even quadruplets, each requiring specialised care. These families are frequently faced with the unique circumstance of having babies with varying needs and conditions, a circumstance that can tug at the heartstrings as they divide their attention between multiple wards or hospitals. Some may experience the heart wrenching reality of losing one baby while another fights for survival, leaving them with the overwhelming burden of grief and hope intertwined. In such instances, the ability to process emotions may feel insurmountable as parents navigate the delicate balance between mourning the loss of one life and clinging to hope for the others. The toll of these experiences often lingers, potentially leading to long term emotional challenges for parents as they navigate the complexities of parenthood in the NICU.

Enhancing neonatal care is paramount in optimising outcomes for preterm babies. Twins Trust advocates for comprehensive postnatal care and psychological support for parents, recognising the emotional toll of preterm birth. Integration of neonatal and postnatal services promotes continuity of care and ensures holistic support for families throughout their preterm journey. Additionally, we emphasise the need for long-term support services addressing the unique challenges faced by preterm babies and their families beyond the neonatal period.

Other topics

Improving data collection and monitoring practices is essential for understanding preterm birth and identifying areas for intervention. Twins Trust supports research initiatives focused on preventing preterm birth and improving care outcomes, with an emphasis on evidence-based practices tailored to diverse populations. We encourage learning from

international experiences and collaboration with devolved administrations to inform best practices and drive continuous improvement in preterm care.

In conclusion, Twins Trust urges policymakers to prioritise the prevention of preterm birth, address health inequalities and enhance support services for families affected by preterm birth. We appreciate the Committee's efforts in addressing this critical issue and stand ready to support ongoing initiatives aimed at improving outcomes for preterm babies and their families.

26 March 2024