Pregnancy & Baby Charities Network

Manifesto 2021 With Background Information

Our Aims

The Pregnancy & Baby Charities Network (PBCN) is committed to improving outcomes and reducing inequalities for new and expectant parents and their babies.

We work to:

1. Make the UK the safest place in the world in which to have a baby, regardless of ethnicity, income, or circumstances.
2. Give all sick and premature babies the best chance of survival and quality of life.
3. Provide every family with the bereavement care they need after pregnancy or baby loss.

We know that to reach our goals, everyone must have unhindered access to the care they need, when they need it, across the pregnancy and baby journey.

Who we represent

This manifesto represents the views of the national charities who form the PBCN representing many different individuals and groups. For simplicity of language, we use the term 'woman' or 'mother' in the context of pregnancy and childbirth and this should be taken to include people who do not identify as women but who are or have been pregnant or have given birth. Similarly, where the term ‘family’ is used, this should be taken to include anyone who is the baby’s primary caregiver, including single and LGBTQ+ parents. We make no judgement on who makes a family.

Our Aims with Background Information

1. Make the UK the safest place in the world in which to have a baby, regardless of ethnicity, income, or circumstances by:

1.1 Achieving the Government's National Ambition[1] to halve stillbirths, neonatal deaths, maternal deaths, and brain injuries by 2025 through:

- Publishing an annual report through the Department of Health and Social Care on implementation, milestones, and achievements, to support ongoing transparency about areas of progress and areas where work still needs to be done
- Improving quality of care in line with NICE guidelines and reducing variation in service delivery
- Establishing an expert maternity task force in every region of the country to work with services which are identified as performing poorly by clinical audit or the Care Quality Commission (CQC)
- Including neonatal deaths below 24 weeks within reporting figures and a plan to reduce late miscarriage losses
- Setting an ambitious target to achieve continuity of carer throughout pregnancy, birth, and beyond by prioritising those with a higher risk of poor outcomes
- Implementing the Smoking in Pregnancy Challenge Group recommendations[2] to ensure smoking in pregnancy is reduced to 6% by 2022 in line with the Government's 2017 ambition.

1.2 Expanding the National Ambition to include other areas of avoidable and preventable pregnancy loss:

Reducing twin stillbirths and neonatal deaths by 50% is key to delivering between 5-7% of the total number of baby deaths that need to be avoided to achieve the National Ambition.

The latest Confidential Enquiry into Stillbirths and Neonatal Deaths in Twin Pregnancies found that 'in around 1 in 2 baby deaths, the care was poor. If care had been better it may have prevented the baby from dying'[3].

Miscarriage care should be improved in line with recently published recommendations[4].

The PBCN therefore calls for an expansion of the National Ambition to:

- Reduce avoidable and preventable losses in multiple pregnancies
- Introduce a graded model of care giving parity to mental and physical health and care after each miscarriage
- Make emergency miscarriage care available to all 24/7
- Ensure specialist recurrent miscarriage services are available no more than one-hour drive from home

1.3 Tackling inequalities:

Inequalities in outcomes exist for women during pregnancy and childbirth and their babies. Women from Black, Asian or other minority ethnic groups, those who live in deprived areas and those with severe and multiple disadvantage have poorer pregnancy outcomes and higher maternal death rates. The 2020 MBRRACE Saving Lives Improving Mothers' Care report[5] shows that risk of maternal death in 2016-18 continued to be more than four times higher among women from Black ethnic minority backgrounds compared with white women. Women from Asian backgrounds have a higher risk than white women.

The Office for National Statistics (ONS) highlighted that there are substantial inequalities in infant mortality rates between white and other ethnic minority groups[6]. Pakistani, Black Caribbean, and Black African babies were highlighted as having the highest mortality rates, which could be explained by other areas of inequality including deprivation. The association between social deprivation and child mortality is clear, and we also know that there are modifiable factors that can make a difference.

The PBCN therefore:

- Calls for the publication of specific, national targets before the end of 2022 that reflect a bold commitment to action on inequalities due to ethnicity and deprivation, underpinned by specialist pathways and workstreams in every Local Maternity System. These should be developed in partnership with those who have relevant lived experience and build on the knowledge and expertise of specialist agencies in each area.
- Supports the Royal College of Obstetricians and Gynaecologists and FiveXMore's 5 steps for health professionals to help reduce inequalities[7].

1.4 Enhancing data collection and sharing to identify groups whose outcomes are worse than the average and set targets for improvement through:

- Collecting and publishing data on loss during pregnancy pre-24 weeks' gestation including early pregnancy loss
- Ensuring Maternity Safety Action 24-hour notification of all perinatal deaths
- Ensuring data is consistently collected on ethnicity and complex social factors in pregnancy and the postnatal period so mothers' needs and outcomes can be better understood and such data to be publicly available in a form that is accessible
- Ensuring data are consistently collected on other adverse perinatal outcomes, including brain injury

1.5 Enabling families to have full digital access to health notes and information through:

- An NHS-supported, user-driven and user-friendly, plain English app that equips families with the knowledge and information to look after themselves, helps them identify pregnancy risks, and signposts them to relevant services
- Recognising groups who need additional support to access and input into digital information, and acknowledging and addressing issues related to digital poverty to ensure equal access

2. Give all sick and premature babies the best chance of survival and quality of life by:

2.1 Fully implementing the neonatal transformation review by 2025, ensuring that all parents are at the heart of caring for their babies

Over 100,000 babies are born premature or sick and admitted to neonatal care each year across the UK. NHS England's 2018 review of neonatal care[8] highlighted significant variation in neonatal resources and outcomes across England and set out a comprehensive programme of transformation needed to deliver consistent services across the country.

The PBCN therefore calls for:

- This implementation plan to continue to be fully resourced, supported and delivered over the coming years to make progress in reducing neonatal mortality.
- NHS Trusts, networks and national bodies to do more to understand and address the factors underpinning the higher risks of mortality faced by some babies to reduce the unacceptable levels of inequality in these babies' chances of survival. Particular focus should be given to those born in deprived areas, to younger mothers, and from specific ethnic backgrounds

2.2 Ensuring that there is a trained specialist nurse for every baby in neonatal intensive care

Evidence is clear that consistent provision of 1:1 nursing for babies in neonatal intensive care correlates with improved survival[9], and 1:1 neonatal intensive care nurse staffing ratios are recommended in both the British Association of Perinatal Medicine Service standards[10] and the Department of Health Toolkit for Commissioning Neonatal Care[8].

However, reviews against this standard routinely show it is not consistently met, in part because of a significant shortage of neonatal nurses[11] [12].

The PBCN therefore calls for:

- Investment commitments to develop the neonatal nursing workforce, including through the recruitment, training and retention strategies, to be upheld throughout the period of neonatal transformation to ensure a sustainable neonatal nursing workforce now and into the future.

3. Provide every family with the bereavement care they need after pregnancy or baby loss by:

3.1 All NHS Trusts fully implementing the National Bereavement Care Pathway by 2025

The National Bereavement Care Pathway (NBCP)[13] has been developed to ensure that every parent is offered the same excellent standard of bereavement care after pregnancy or baby loss. It covers five bereavement experiences: miscarriage, ectopic and molar pregnancies; termination of pregnancy for fetal anomaly; stillbirth; neonatal death; and sudden unexpected death in infancy. The NBCP includes nine core standards[14] and provides the framework and tools to ensure that all health professionals are adequately equipped to provide excellent bereavement care in the aftermath of pregnancy or baby loss. The Care Quality Commission (CQC) inspection framework for maternity services[15] covers the quality of bereavement care for parents following pregnancy loss or the death of a baby and is closely linked to the standards in the NBCP. Many NHS Trusts that have implemented the NBCP therefore see this reflected positively in their inspection reports.

The PBCN therefore calls on:

- Every NHS Trust to fully implement the National Bereavement Care Pathway by 2025, as recommended in the Ockenden Report[16] and to ensure that the nine core standards are met.

3.2 Specialist support for mothers and families experiencing the loss of a baby as a result of separation or removal

The rate of newborn care proceedings has increased exponentially in recent years[12], yet support for women undergoing pre-birth assessments, infant child protection proceedings, or dealing with the removal of their baby is woefully inadequate.

The loss of a baby as a result of social services' involvement must be recognised as a trauma. Often these removals are related to experiences of abuse and ill health suffered by the mother[17].

The PBCN is therefore calling for:

- A national care pathway for women at risk of or experiencing infant removal to be developed along the same lines as the National Bereavement Care Pathway by 2023. This pathway should be developed in partnership with women with lived-experience and delivered at local levels by specialist midwives and perinatal mental health services working in close partnership with local authority children's social care teams.

3.3 Guaranteeing that everyone who has experienced baby loss during pregnancy, at birth or up to their child's first birthday, receives enhanced support and access to high-risk care during subsequent pregnancies

For most types of baby and pregnancy loss, the risks present in the initial loss will remain for subsequent pregnancies and a previous baby loss should therefore be one of the indicators of increased risk. It is therefore crucial that those who have experienced a loss in a previous pregnancy are offered support and, in some cases, access to high-risk care in subsequent pregnancies.

The Royal College of Obstetricians and Gynecologists (RCOG) recommends offering investigations and, in some cases, specialist care only after a woman has had three consecutive miscarriages or one second trimester miscarriage[18]. This is in contrast to European guidelines produced by the European Society of Human Reproduction and Embryology (ESHRE) [19] which recommends referring women to specialist care after two miscarriages, not necessarily consecutive.

Obstetricians recommend specialist care for a woman in her next pregnancy after one late miscarriage or pre-term birth. Outcomes for these women are very good; fewer babies die and fewer have lifelong health complications if they are cared for in expert pre-term birth clinics (linked to neonatal services) of which there are over 30 in the UK. Only some women are referred to expert pre-term birth clinics; most women are cared for by obstetric generalists in district general hospitals and their outcomes are not as good as for those who receive care in specialist services[20].

Previous obstetric history is a good risk indicator for subsequent pregnancies. All specialist services should care for the wellbeing and physical and mental health of parents who have additional care needs to those who have not experienced pregnancy loss or the death of a baby.

The PBCN therefore calls for:
A guarantee that all subsequent pregnancies after two early miscarriages, one late miscarriage, ectopic pregnancy, a stillbirth, termination of pregnancy for foetal anomaly or for medical reasons, preterm birth or a neonatal death are offered high-risk care and given enhanced support, and that this is also offered to families who have experienced the death of a baby, this includes:

- Care for both the physical and mental health and the wellbeing of parents who often have additional care needs and inequalities to those who have not experienced pregnancy loss
- Referral to support from specialist charities or organisations relevant to the type of loss they have experienced, to help them access peer support
- An understanding of the inequalities in pregnancy and baby loss and how to give families better access to support that is right for them
- Care that can be accessed by families in the form and time that they need
- Ensuring both parents' history is taken and support is not given based solely on mothers' obstetric history
- Ensuring multi-disciplinary data sharing to ensure families do not need to repeat their history

Definitions and statistics

1. **Health inequalities**
   The Marmot Review[21] stated that to tackle health inequalities, it is important to take a universal approach but with an intensity that is 'proportionate to the level of disadvantage'. Known as "proportionate universalism", it is this standard that must be applied to health inequalities across the pregnancy and baby journey. In 2020, the Institute of Health Equity's Marmot Review 10 Years On[22] showed that health inequalities have increased overall and reiterated the importance of supporting maternity/early years to tackle this.

2. **Early miscarriage**
   Pregnancy loss before 12 weeks' gestation

3. **Late miscarriage**
   A baby delivered between 13^{+0} and 23^{+6} weeks' gestation showing no signs of life, irrespective of when the death occurred

4. **Stillbirth**
   Stillbirth normally means a baby delivered at or after 24+0 weeks gestational age showing no signs of life, irrespective of when the death occurred.
   The most recent Euro-Peristat report[23] looks at births across all 28 current EU member states plus Norway, Iceland and Switzerland. To accommodate the different stillbirth definitions, only stillbirth rates at or after 28 weeks of pregnancy are included. The best among these countries have rates below 2.3 per 1,000 babies born and includes Cyprus, Iceland, Denmark, Finland and the Netherlands. The comparative rate in England and Wales for the same period was 3.1 per 1,000.

5. **Neonatal Death**
   A liveborn baby (born at 20^{+0} weeks' gestational age or later), who died before 28 completed days after birth.

6. **Sudden Infant Death Syndrome (SIDS)**
   Sudden infant death syndrome (SIDS) is the sudden and unexplained death of an infant where no cause is found after detailed post mortem.
   230 unexplained infant deaths occurred in the UK in 2018, a rate of 0.30 deaths per 1,000 live births. As a comparison, in Germany (2015), the rate was 0.17 per 1,000 live births.

7. **Pre-term birth**
   Pre-term birth means the delivery of a baby prior to 37+0 weeks gestation.
   According to the March of Dimes (2010)(2), Norway, Sweden, Finland, Japan, Latvia, Estonia, and Lithuania see only 6% of pregnancies result in a pre-term birth. In contrast, the UK rate is 8%. On the assumption there are 750,000 births per year, it would require a reduction of 15,000 babies being born pre-term each year to reduce the rate to 6% in the UK.

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All of the above charities have contributed to our four priorities and all have expertise in the field. If you would like any further information please get in touch and we'll ensure that the correct person gets back to you. Thank you for your interest and support.