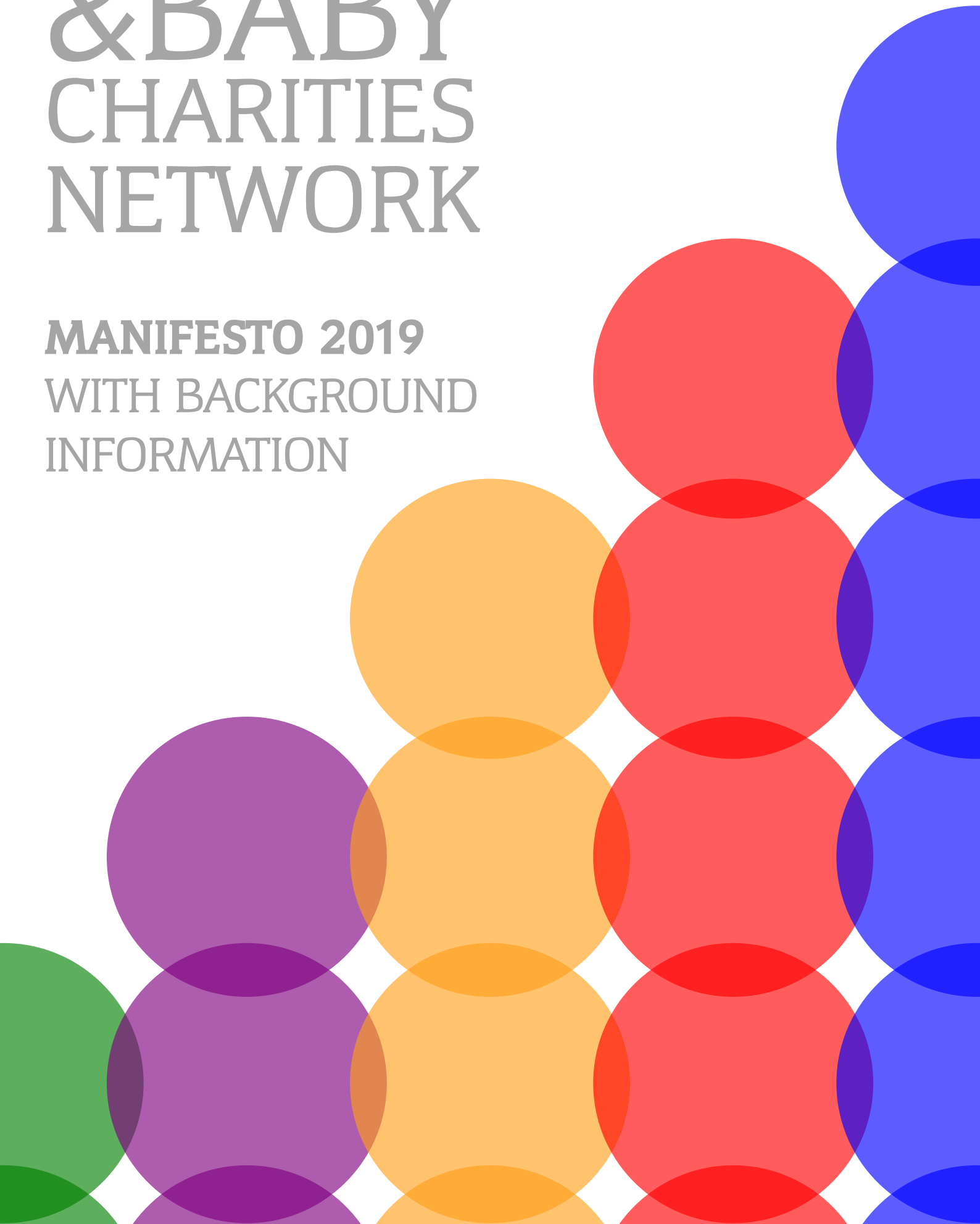
PREGNANCY &BABY CHARITIES NETWORK

MANIFESTO 2019
WITH BACKGROUND INFORMATION



PREGNANCY &BABY CHARITIES NETWORK

OUR TOP 4 PRIORITIES

1. Make England the safest country in the world in which to have a baby.

2. Give women a maternity guarantee that their pregnancy and birth journey will be personalised and will meet their needs.

3. Give sick and premature babies the best chance of survival and quality of life.

4. Provide every family with the bereavement care they need after pregnancy or baby loss.

Our four priorities with background information

1 Make England the safest country in the world in which to have a baby.

- Reducing stillbirths, neonatal deaths, maternal deaths, brain injuries, sudden infant deaths and pre-term births to match the best in the world by 2025.

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 (2015)[1] 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.

A neonatal death is a baby born at any time during pregnancy who lives, even briefly, but subsequently dies within four weeks of birth. The best rates are achieved in Denmark, Estonia, Spain, Cyprus, Luxembourg, and Austria at 2.0 per 1,000. The rate for England and Wales is 2.2 per 1,000.

Sudden infant death syndrome (SIDS) is the sudden and unexplained death of an infant where no cause is found after detailed post mortem. Two hundred and forty unexplained infant deaths occurred in the UK in 2016, a rate of 0.31 deaths per 1,000 live births. As a comparison, in Germany (2015), the rate was 0.17 per 1,000 live births.

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.

- 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.

While it is right that services identified as poorly performing are recognised as needing improvement, the support available to teams to help them make improvements is variable.

There is growing evidence to show that providing practical support and advice from peers can enable improvements to be enacted more quickly. Each region should have a team in place so that local services, in need of support, get the help they require.

2 Give women a maternity guarantee that their pregnancy and birth journey will be personalised and will meet their needs.

- Giving all women a single maternity health professional who gives them continuity of care throughout their pregnancy and birth, prioritising those with a higher risk of poor outcomes by 2025.

The national review of maternity care in England, entitled Better Births[3], defines continuity of carer (Page 9), as:

"*i. Every woman should have a midwife, who is part of a small team of 4 to 6 midwives, based in the community who knows the women and family, and can provide continuity throughout the pregnancy, birth and postnatally.*

ii. Each team of midwives should have an identified obstetrician who can get to know and understand their service and can advise on issues as appropriate.

iii. The woman's midwife should liaise closely with obstetric, neonatal and other services ensuring that she gets the care she needs and that it is joined up with the care she is receiving in the community."

We would like to see women at higher risk of poor outcomes (as set out in the national maternity, neonatal and perinatal death audits), prioritised for the roll out of this model of care.

- Enabling full digital access to health notes and information, through a secure app with signposting to each level of care that might be required.

The same report states that "the sharing of data and information between professionals and organisations, use of an electronic maternity record should be rolled out nationally. Providers should ensure the woman shares and can input the information that is important to her" (page 11). We believe this is best delivered via an NHS-supported app that is tailored to detect risks in pregnancy and signposts to relevant services that might be required.

- Providing a personal budget to enable access to resources and services delivered by public, private and not-for-profit organisations.

Again, this report confirmed that "NHS Personal Maternity Care Budgets would give impetus to choice by giving a woman control of the money used to buy her care" (page 92). How this can be delivered is currently being tested in a number of pilot sites. Based on the success of this test, we would like to see it rolled out more widely and the choice of potential providers increased considerably.

3 Give sick and premature babies the best chance of survival and quality of life.

- Fully implementing the neonatal transformation review by 2025, ensuring that 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 has recently (2018) completed a comprehensive review[4] of neonatal care across England, which highlighted significant variation in neonatal resources and outcomes across England, and the need to implement a comprehensive programme of transformation to deliver consistent services across the country. It is vital that this implementation plan is properly resourced, supported and delivered over the next five years especially if we are going to make progress in reducing neonatal mortality.

- 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[5], and 1:1 neonatal intensive care nurse staffing ratios are recommended in both the British Association of Perinatal Medicine Service standards[6] and the DH Toolkit for Commissioning Neonatal Care[7]. However, reviews against this standard routinely show it is not consistently met, in part because of a significant shortage of the neonatal nurses (e.g. Bliss Baby Report 2015[8] / Neonatal Review 2018). It is therefore vital that investment and focus is applied to the recruitment, training and retention of sufficient neonatal nurses to meet this standard.

4 Provide every family with the bereavement care they need after pregnancy or baby loss.

- All NHS trusts fully implementing the National Bereavement Care Pathway by 2025.

The National Bereavement Care Pathway (NBCP)[9] 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 programme was established during 2017 with an initial eleven pilot sites and expanded in 2018 to a further 21 pilot sites. Nine core standards encapsulate the activity and behaviour required in order for an NHS Trust to be said to be fully implementing the NBCP.

To support successful roll out of the NBCP to all the NHS Trusts by 2025, five major areas of activity are planned and should be supported. These are:

1. Embedding the standards
2. Audit and validation
3. Engagement networks and champions
4. Training
5. Continuous improvement

- Guaranteeing that all women with subsequent pregnancies after two early miscarriages, one late miscarriage, an ectopic pregnancy, a termination after fetal anomaly, a stillbirth, pre-term birth or a neonatal death are offered high-risk care and given enhanced support.

A miscarriage is defined as losing a pregnancy before 24 weeks gestation. The causes of late miscarriage (after 14 weeks) have more in common with pre-term birth than early miscarriage. Early pregnancy loss (pre-12 weeks gestation) has a high morbidity rate with around one in four pregnancies ending in miscarriage and one in eighty pregnancies ending through ectopic pregnancy.

In the UK, a woman having had three recurrent miscarriages (NICE Guidelines[10]) would be referred to high-risk care. This is in contrast to European guidelines[11]. ESHRE (the European Society of Human Reproduction and Embryology) recommends referring women to specialist care after two early miscarriages.

Obstetricians recommend seeing a women in her next pregnancy after one late miscarriage or pre-term birth. Outcomes for these women are very good. Fewer babies die and fewer leave with 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.

Not all women are referred to expert pre-term birth clinics, being cared for by obstetric generalists in district general hospitals and their outcomes are not as good as for those who received care in specialist services.

Previous obstetric history (i.e. stillbirth, pre-term birth, two or more miscarriages or ectopic pregnancy) is a good risk indicator for subsequent pregnancies. Women who are pregnant for the first time have a higher risk of losing their pregnancy than mothers who have had a previous healthy baby because assessment and action on risk in first time pregnant women is insufficient to identify those women who are at greatest risk.

All specialist services should care for the physical and mental health and the wellbeing of parents who often have additional care needs to those who have not experienced pregnancy loss.

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PREGNANCY &BABY CHARITIES NETWORK

See the list of charities signed up to the network so far (overleaf)

PREGNANCY &BABY CHARITIES NETWORK

Charities signed up to the network so far

ACTION ON PRE-ECLAMPSIA
PROMOTING SAFER PREGNANCY
www.apec.org.uk

ARC
Antenatal Results & Choices

best beginnings
working to give every child the best start in life

birth companions

Bliss
for babies born premature or sick

Borne
Research to prevent premature birth

Child Bereavement UK
REBUILDING LIVES TOGETHER

CMV Action
EDUCATE • VACCINATE • ERADICATE

The Ectopic Pregnancy Trust
Registered Charity No. 1071811

Group B Strep Support
www.gbss.org.uk

WORKING TO **STOP** GBS INFECTION IN BABIES.

genesis research trust

ICP Support

the lullaby trust
safer sleep for babies – support for families

MAMA Academy
Helping Babies Arrive Safely

Continued...

THE MULTIPLE BIRTHS FOUNDATION
MBF

MISCARRIAGE ASSOCIATION
The knowledge to help

nct 1ST 1,000 DAYS NEW PARENT SUPPORT

Pelvic Partnership
Supporting you

PS Pregnancy Sickness Support

Sands
Stillbirth & neonatal death charity

Tommy's
Funding research
Saving babies' lives

Twins trust. We support twins, triplets and more...

PREGNANCY &BABY CHARITIES NETWORK

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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.