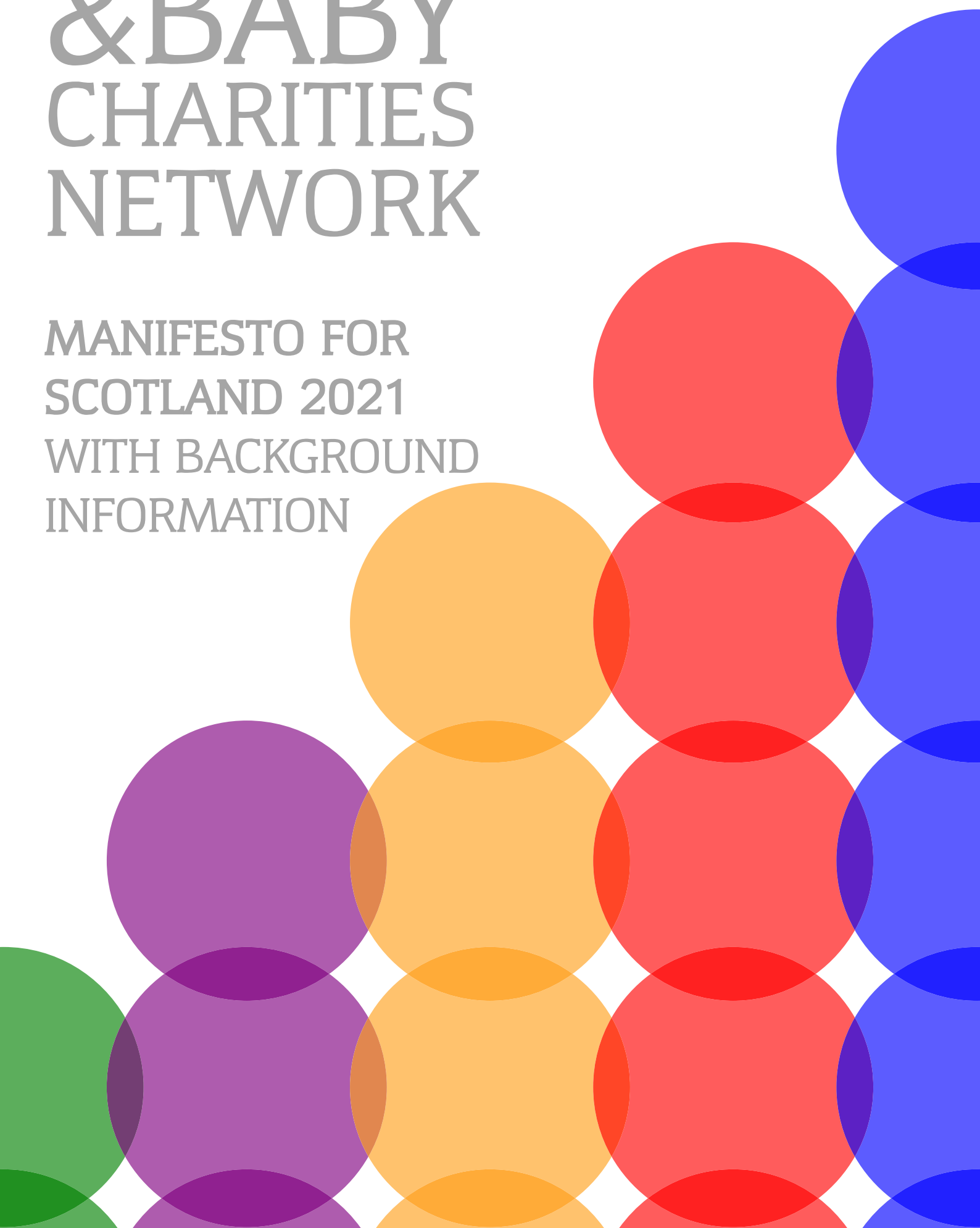


# PREGNANCY & BABY CHARITIES NETWORK

MANIFESTO FOR  
SCOTLAND 2021  
WITH BACKGROUND  
INFORMATION



OUR

TOP

4

PRIORITIES

1

Make Scotland the safest place in the world in which to have a baby.

2

Give all families a maternity guarantee of a personalised care journey that best fits their needs.

3

Give all sick and premature babies the best chance of survival.

4

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

# Our four priorities with background information

1

## Make Scotland the safest place in the world in which to have a baby.

- Reaffirming and ensuring resources are available to reduce stillbirths by 35 per cent and neonatal deaths by 15 per cent, in line with existing targets

Stillbirth normally means a baby delivered at or after 24+0 weeks gestational age showing no signs of life, irrespective of when death occurred. Since 2014, there has been a 22.5% improvement in the rate of stillbirth across Scotland, largely due to targeted interventions supported by the Scottish Patient Safety Programme (SPSP) and the Maternity and Children Quality Improvement Collaborative (MCQIC).<sup>1</sup>

Neonatal death is a baby born at any time during pregnancy who lives, even briefly, but dies within four weeks of birth. While Scotland has the lowest neonatal mortality rate in the UK at 1.36 per 1,000 births<sup>2</sup> this decline has not kept pace with the decline of stillbirth nationally.

In November 2018, MCQIC published their revised Maternity Care Core Measurement Plan which set out a stretch target to reduce stillbirth by 35 per cent and reduce the neonatal mortality rate by 15 per cent.<sup>3</sup>

- Introducing targets to reduce maternal deaths, brain injury and sudden infant deaths

Sudden Infant Death Syndrome (SIDS) is the sudden and unexplained death of an infant where no cause is found after detailed post-mortem. There were two hundred unexplained infant deaths in the UK – 24 of whom died in Scotland – in 2018, a rate of 0.31 per 1,000 live births.<sup>4</sup>

Perinatal and infant mortality is consistently higher in Scotland when compared to Scandinavian countries, and, while a rare outcome, the maternal mortality rate in the UK is slightly higher compared to other Western European countries.<sup>5</sup>

Pre-eclampsia, a serious and potentially fatal pregnancy complication – for both mother and babies – occurs in around 5% of UK pregnancies. Adopting Placental Growth Factor Testing (PGFT), which is a reliable test of whether mother and baby are at risk, as well as reliably indicating which women will need to deliver, will ensure at risk-mothers and babies receive optimal

treatment for their needs before the condition progresses.<sup>6</sup>

For Scotland to be the safest country in the world to have a baby, targeted interventions which focus on reducing death and poor outcomes among babies and mothers across the whole perinatal period and within the first year of life are needed.

## ● Committing to identifying and reducing inequalities in the risk of perinatal death

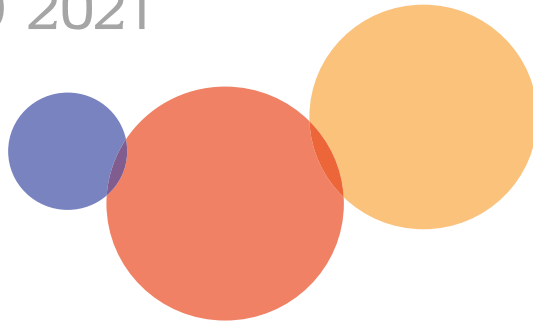
The *Best Start* – a national review of maternity and neonatal services in Scotland – recognised the need to address health inequality to ensure the best outcomes for women and their babies throughout the perinatal period. The review noted that “health inequalities persist, with higher rates of obesity, alcohol-related mortality, smoking, alongside lower participation in physical exercise, in Scotland’s most deprived communities” and set out that the new models of care must improve outcomes for all women and babies, with a particular focus on the most vulnerable families.<sup>7</sup>

Resources for ongoing continuing professional development (CPD) training for frontline maternity professionals need to be made available and prioritised, particularly in significant areas of avoidable harm. Training should focus on national and local trends in data and be assessed for impact.

The Scottish Government must ensure that the latest national guidelines from the relevant professional bodies are introduced in a timely way, and followed.

Compared with White babies, stillbirth rates for Black/Black British babies are twice as high and for Asian/Asian British babies they are 1.6 times as high. For babies from the most deprived families, stillbirth rates are 1.7 times higher than from the least deprived.

Compared with White babies, neonatal mortality rates for Black/Black British babies and for Asian/Asian British babies are 1.7 times as high. The difference in neonatal death rates between Black/Asian babies and white babies appears to be increasing. For babies from the most deprived families, neonatal death rates are 1.6 times higher than from the least deprived.



2

## Give all families a maternity guarantee of a personalised care Journey that best fits their needs by:

- Giving all families a single maternity health professional who looks after them throughout their pregnancy and birth, prioritising those with a higher risk of poor outcomes

The *Best Start* sets out that the new model of maternity care will allow: "Women [to] experience real continuity of carer, across the whole maternity journey, with vulnerable families being offered any additional tailored support they may require."<sup>8</sup>

The *Best Start* sets out that the model for continuity of carer will vary across settings and population groups, highlighting that those with particular social vulnerability may receive additional support, and that all different models should be audited and evaluated.

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 this model of care as it is embedded across Scotland.

While some *Best Start* programme work continued throughout the COVID-19 pandemic, many of the elements of the programme paused throughout 2020. To ensure these targets are met, additional resourcing must be provided to ensure completion of the programme.

- Working with every woman to develop a birth plan tailored to her individual needs

The same report sets out that "every woman will have a clear birth plan, developed for her needs, which is updated regularly throughout her maternity journey."

Women should have the opportunity to discuss their preferred birth plan with all professionals involved in their care, including their primary midwife

and obstetrician, and should have sufficient opportunity to discuss their preferences and be given all the information they need to make informed choices. Additionally, women should have discussions about their expectations for care in the post-natal period as part of the birth-plan process.<sup>9</sup>

- Developing a digital maternity record that all women, and the professionals involved in their care, can easily access

Again, the same report established that “a Scottish electronic women’s maternity record should be developed, that is readily accessible to women, and all professionals involved in her care.”<sup>10</sup>

We welcome this recommendation and would like to see it fully

implemented. The importance of being able to share electronically planning, demographic and assessment information across boundaries for vulnerable women and their children is recognised as a core component of the Getting it Right for Every Child programme.<sup>11</sup>

## 3

### Give all sick and premature babies the best chance of survival, by:

- Fully implementing the *Best Start* review, including full implementation of the new model of neonatal care, ensuring that parents are at the heart of caring for their babies.

Over 5,000 babies are born needing neonatal care in Scotland every year.<sup>12</sup> The *Best Start* made a series of recommendations (43–52) to transform the model of neonatal care delivered in Scotland. Evidence established that significant service change was required to ensure intensive care services can be provided in line with national standards of best practices, and to ensure services supported positive parent and baby relationships through enabling parents to be present on the unit, providing hands-on care to their baby.<sup>13</sup>

It is vital that the full implementation of these recommendations is properly resourced and supported if they are to be fully embedded. Due to COVID-19 there has been an extended pause to some aspects of the *Best Start* programme which has affected progress towards embedding service change. There must be a commitment to extend and resource the *Best Start* programme accordingly to ensure these recommendations are achieved.

- **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, provided by teams of highly skilled nurses with sufficient skill mix, correlates with improved survival.<sup>14</sup> The requirement for 1:1 neonatal intensive care staffing ratios are recommended in both the British Association of Perinatal Medicine Services Standards<sup>15</sup> and the Neonatal Care in Scotland: A Quality Framework.<sup>16</sup>

However, reviews against this standard routinely show it is not consistently met, in part because of the shortage of neonatal nurses. The latest National Neonatal Audit Programme shows in 2019 that just over half (52%) of shifts in Scotland had enough Qualified in Specialty nurses working on them, and 22% of shifts did not have enough staff to meet staffing ratios.<sup>17</sup> 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 Health Boards fully implementing the Scottish Bereavement Care Pathway by 2023**

In response to evidence showing that bereavement services are not universally available or accessible, The Best Start also recommended that improvements be made to bereavement care:

“In every case [families]...should be offered access to appropriate bereavement support before they leave the unit, and each maternity and neonatal unit should have access to staff members trained in bereavement care”<sup>18</sup>

In April 2018, the Scottish Government announced funding would be available to develop the Scottish National Bereavement Care Pathway (NBCP), with Early Adopter Sites going live in 2020. This pathway sets out core standards and guidance detailing what high-quality, compassionate and consistent bereavement care looks like in all settings where pregnancy and baby loss occurs.



We are delighted that the Government continues to value the impact that high-quality bereavement care for all families

who experience pregnancy and baby loss has, by extending their funding commitment for the roll out of the National Bereavement Care Pathway Scotland.

- **Guaranteeing that all subsequent pregnancies after two early miscarriages, one late miscarriage, a stillbirth, a termination for fetal anomaly, preterm 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-14 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.

The Royal College of Obstetricians and Gynaecologists (RCOG) recommends offering investigations and in some cases specialist care only after a woman has had three consecutive miscarriages or one second trimester miscarriage.<sup>19</sup> This is in contrast to the European guidelines<sup>20</sup> produced by ESHRE (the European Society of Human Reproduction and Embryology) which recommend referring women to specialist care after two early miscarriages, not necessarily consecutive.

Obstetricians recommend specialist care for a women in her next pregnancy after one late miscarriage

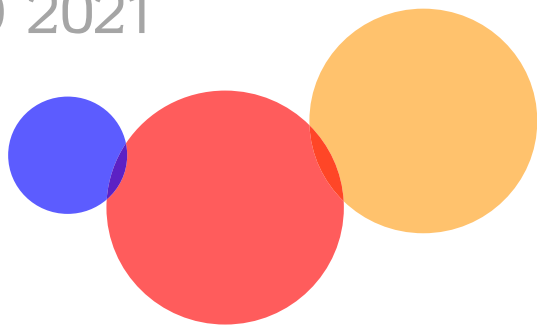
or pre-term birth. Outcomes for these women are very good. Fewer babies die and fewer have with lifelong health complications if they are cared for in expert pre-term birth clinics (linked to neonatal services) of which there are over 30 in the UK.

Only some women are referred to expert pre-term birth clinics; others are 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. being previously diagnosed with pre-eclampsia, experiencing a stillbirth, pre-term birth, two or more miscarriages or ectopic pregnancy) is a good risk indicator for subsequent pregnancies.

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.

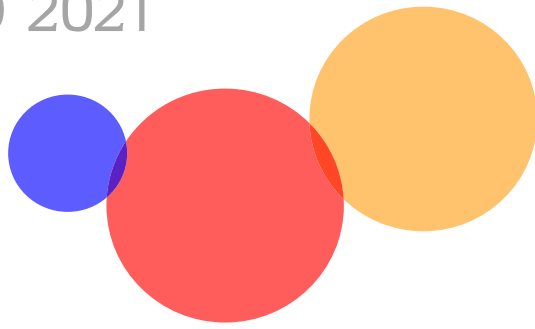




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PREGNANCY  
& BABY  
CHARITIES  
NETWORK

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



The Ectopic Pregnancy Trust



Registered Charity No. 1071811



Group B Strep Support

genesis research trust



Continued...



Pelvic Partnership  
Supporting you



Pregnancy Sickness Support



# 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.