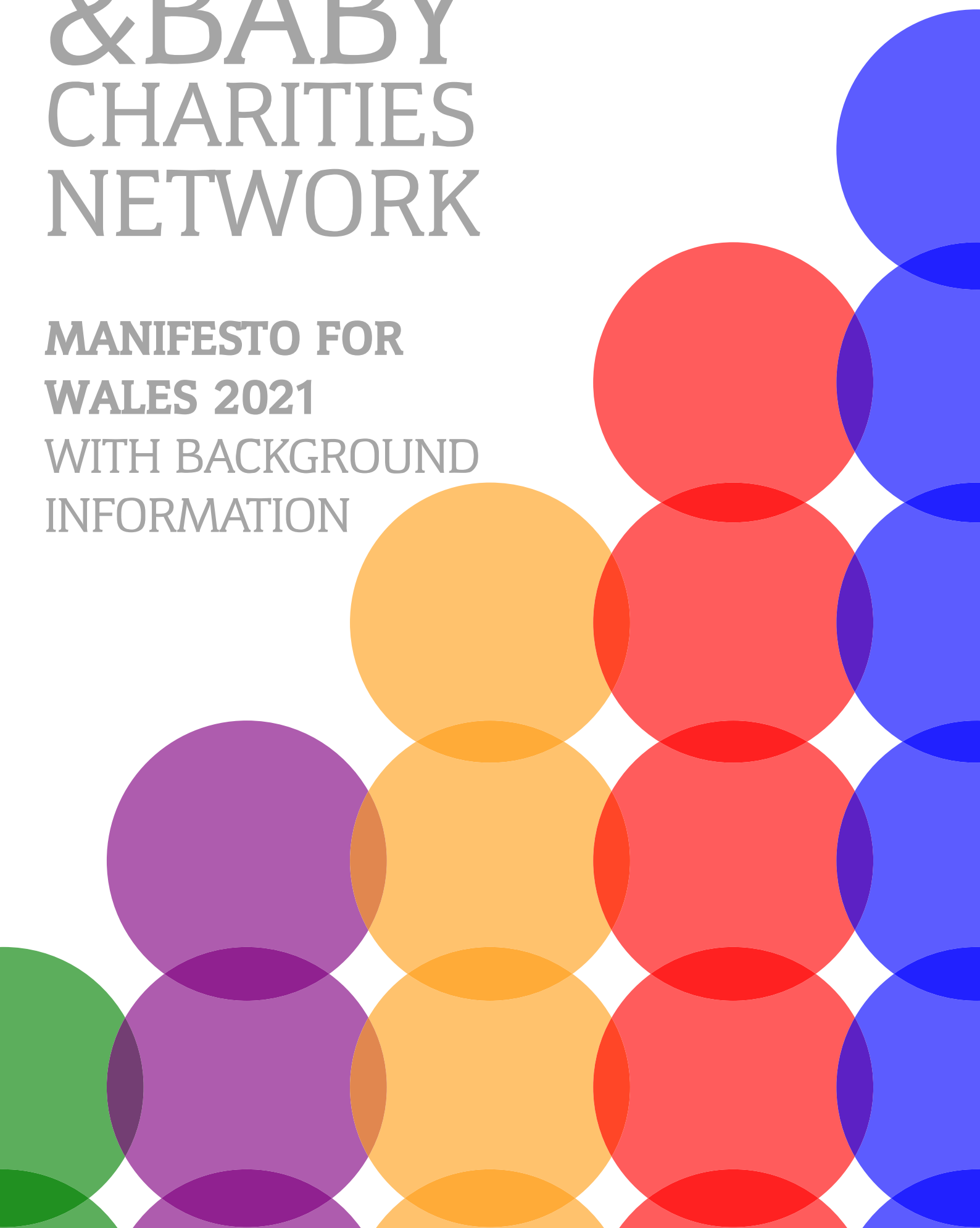


PREGNANCY & BABY CHARITIES NETWORK

**MANIFESTO FOR
WALES 2021**
WITH BACKGROUND
INFORMATION



OUR

TOP

4

PRIORITIES

1

Make Wales 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 fits their needs.

3

Give all 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 Wales the safest place in the world in which to have a baby, by:

- Introducing targets to reduce maternal deaths, stillbirths, neonatal deaths and preterm births.

For Wales to be the safest place 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.

Perinatal and infant mortality is consistently higher in Wales when compared to Scandinavian countries, and, whilst a rare outcome, the maternal mortality rate in the UK is slightly higher compared to other Western European countries¹.

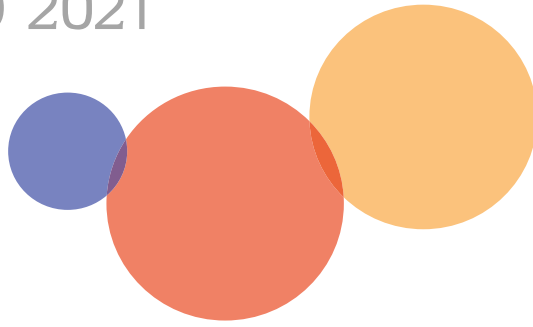
Political focus and accountability is necessary to stop Wales continuing to fall behind the rest of the UK.

Stillbirth normally means a baby delivered at or after 24+0 weeks gestational age showing no signs of life, irrespective of when death occurred. The trend over time for the stillbirth rate in Wales since 2013 has not reduced, as it has in other parts of the UK. In 2019, the stillbirth rate for England fell to a record low for the third consecutive year to 3.8 stillbirths per 1,000 total births, while the stillbirth rate for Wales increased to 4.6 stillbirths per 1,000 total births².

A neonatal death is a baby born at any time during pregnancy who lives, even briefly, but dies within four weeks of birth. As in other parts of the UK, the neonatal death rate in Wales has not significantly reduced since 2013 and was 3.3 per 1,000 total births in 2019³.

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 198 unexplained infant deaths in England and Wales in 2018, a rate of 0.30 deaths per 1,000 live births: an increase from 0.28 deaths per 1,000 live births in 2017⁴.

We have seen in England and Scotland what a high profile target can do to drive meaningful activity to reduce the rate of baby deaths. This requires political oversight and championing at the highest level. While the Welsh Government are committed to reducing the rate of babies dying, they have previously resisted calls for a target, saying the population is too



small. However, with smaller cohorts, it is still possible to track trends over time, which is already happening. Comparisons are in the public domain at Health Board level in Wales, and Office for National Statistics data are broken down nationally. These clearly show the lack of a target and concerted efforts to reduce the rate of babies dying in Wales is resulting in poorer outcomes for babies and families there.

The Welsh Government's *Maternity Care in Wales – A Five Year Vision for*

the Future 2019 – 2024⁵ (the Vision) states "Quality assurance of maternity service delivery across Wales will be led by Welsh Government performance board review in conjunction with Healthcare Inspectorate Wales (HIW) assessment. This will be informed by the All Wales Maternity Performance outcome indicators."

The All Wales Maternity Performance Indicator dataset must include a target to reduce stillbirth and neonatal death rates, which is reported against annually.

- Ensuring strategies and resources are available to deliver the services to achieve these targets, and to report on progress annually

The Vision states that an: "All Wales Maternity Performance Indicator dataset will be developed by a national multi-professional working group by 2020. This will be supported by NSAG, HOMAG, the Maternity and Neonatal network and Public Health Wales to ensure the same dataset supports population surveillance. The dataset will include measures that reflect quality, safety and women/families and staff reported indicators (e.g. surveys). Specifically we will reduce: stillbirth, neonatal death, hypoxic ischaemic encephalopathy; (moderate/severe) and maternal level 3 admission to critical care; Public Health - Smoking cessation; obesity in pregnancy."

While the development of this data set is to be welcomed and urgently needs to be completed, it will be of little use unless targets to go alongside it, and strategies and resources to meet them, are introduced.

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

- **Commit to identifying and reducing inequalities in the risk of perinatal death**

Inequity in the provision of maternity services in Wales remains. For example, people in North Wales are referred to Liverpool for recurrent miscarriage care, but there is no such referral policy in mid or South Wales. There are no specialised miscarriage services in Wales. Similarly, preterm clinics are not available to everyone in Wales and there is no specialist provision for families who have experienced a stillbirth. We call on Wales to develop their own specialist maternity services, or to allow and fund access to services in England for those who want them.

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 every family a maternity guarantee of a personalised care journey that best fits their needs.

- Giving all families a lead maternity health professional who looks after them throughout their pregnancy and birth, prioritising those with a higher risk of poor outcomes, by 2025.

● Working with every woman and birthing person to develop a birth plan tailored to their individual needs.

In his foreword to the Vision, The Minister for Health and Social Services, Vaughn Gething stated, *"Person-centred, safe and high quality care for mothers and babies throughout pregnancy, birth and following birth can have a positive impact on the health and life chances of women and babies and on the healthy development of children throughout their life."*

The Vision also makes commitments that:

- All women will be provided with evidence-based information and have the opportunity to enter into discussions about their maternity care putting them, their unborn baby and family at the centre of any decisions.
- To develop all Wales clinical pathways including models for delivery of continuity of care.
- All women will receive continuity of carer across their maternity

journey with seamless links to specialist care when required.

- All women will have a named midwife; some may also need a named obstetrician who is responsible for planning care in partnership with the woman and her family.
- All women will receive antenatal and postnatal continuity of carer by no more than two midwives and two obstetric teams.

An action has been identified by the Government to set up an all Wales multi professional working group to support the implementation of continuity of carer models across Wales, and to explore and develop a feasibility model of continuity of carer for intrapartum care. We are calling for these commitments to be delivered and for a timetable to set out when they will be achieved.

● Delivering a digital maternity record that all women and birthing people, and the professionals involved in their care, can easily access

The Vision states: *"We will provide electronic maternity records for all pregnant women in Wales, enhancing effective communication between health care professionals."*

We will undertake a scoping of proposed national information systems and develop an All Wales electronic maternity record that will be accessible to individual mothers and across Health Boards.

Maternity information systems will link data across Wales to ensure electronic

maternity records can be accessed by all professionals providing care. This access will include specialists in different geographical locations and primary care providers. Historical birth records will be also accessible electronically."

We are calling for this to be implemented as soon as possible, and no later than 2024 as set out in the Vision.

3

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

- Ensuring that parents are at the heart of caring for their babies

Around 3,000 babies are born each year needing neonatal care in Wales⁶.

The Vision also states that, *"Health Boards will aim to support families staying together wherever possible, particularly where circumstances necessitate care away from home. This will include dedicated accommodation for families near to neonatal units or facilities to accommodate partners in postnatal care."*

The All Wales Neonatal Standard Domain 1⁷ sets out that services should embed Family Centred Care, an approach that *"places parents at the centre of their baby's care and is hugely beneficial to babies and parents...It puts the physical,*

psychological and social needs of the baby and family at the heart of all care given." Delivery of care should take place *"as close to home as possible, with ease of access to specialist centres when this care is required."*

It is vital that the implementation of these recommendations is properly resourced and supported if they are to be fully embedded by 2024. In the wake of the COVID-19 pandemic, visiting guidance in Wales only mandates that one parent can be present at a time⁸, which is not in line with RCPCH guidance⁹. We are calling for an urgent focus on safely returning to unrestricted parent access, for both parents, as soon as possible.

- 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, by highly skilled nurses with the appropriate skill mix¹⁰, correlates with improved survival¹¹. The requirement for 1:1 neonatal intensive care staffing ratios are recommended in the British Association of Perinatal Medicine Services Standards¹².

Wales performs well compared to other areas when it comes to shifts meeting ratios (81.2%) but it's level of meeting QIS (Qualified in Speciality training) standards on shifts is low (37.9%)¹³.

We are calling for urgent action to ensure there is an appropriate plan & resource to ensure nurse staff have access to QIS now and longer term.

4

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

- Committing to developing a Welsh Bereavement Care Pathway that covers all forms of pregnancy and baby loss – Miscarriage, ectopic and molar pregnancy; Termination of Pregnancy due to Fetal Anomaly; Stillbirth; Neonatal death; Sudden Unexpected Death in Infancy.

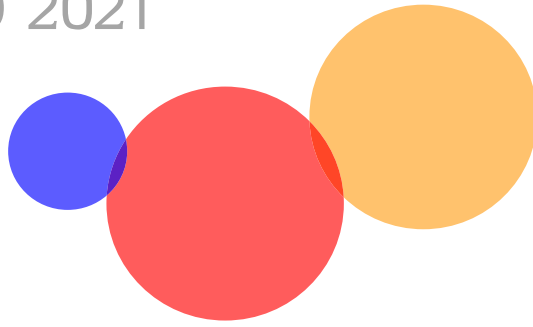
There is no National Bereavement Care Pathway¹⁴ (NBCP) in Wales as in other parts of the UK. The Wales Maternity Network - All Wales Clinical and Bereavement Care Standards which were previously developed, do not cover all five experiences of pregnancy, baby loss and baby deaths, and they do not go as far as the NBCP Standards being rolled out in England, or those currently being piloted in Scotland. They only cover maternity services and not the other settings in which a pregnancy loss or the death of a baby can occur.

There is clearly a need for such a pathway in Wales, with the *Independent Maternity Services Oversight Panel: Thematic maternal category report*¹⁵ (from the review of maternal care at the former Cwm Taf University Health Board between 2016 and 2018) identifying four key themes as contributing to the poor quality and safety of care of pregnant women and birthing people:

- *“a lack of relevant and timely information to inform their choices*
- *a failure to understand and cater for their individual needs*
- *a failure to monitor and escalate their treatment when things changed*
- *poor communication with and between those providing their care.”*

The NBCP programme in England has received a number of inquiries from individual hospitals in Wales wishing to follow the Pathway and its nine standards, as staff there see the benefits for bereaved families.

We are calling for the Welsh Government to support the development of a NBCP Wales to ensure that all parents experiencing pregnancy and baby loss receive the standards of bereavement care they need and deserve.



- **Guaranteeing that all subsequent pregnancies after two early miscarriages, one late miscarriage, a termination of pregnancy due to fetal anomaly, a stillbirth, preterm birth or 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) sometimes 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 miscarriage¹⁶. This is in contrast to the European guidelines¹⁷ 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.

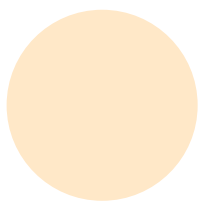
Obstetricians recommend specialist care for a women in her next pregnancy after one late miscarriage

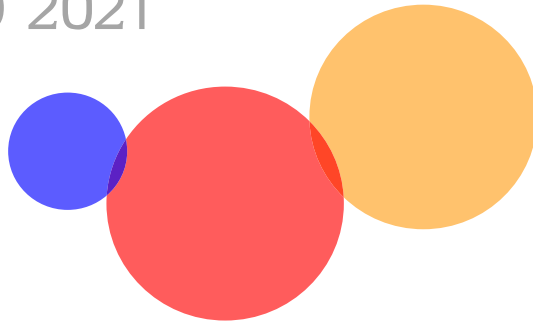
or pre-term birth. Outcomes for these women are very good. Fewer babies die and fewer have lifelong health complications if they are cared for in expert pre-term birth clinics (linked to neonatal services) of which there are over 30 in the UK.

Only some women are referred to expert pre-term birth clinics, many 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. previous diagnosis of pre-eclampsia, experiencing a stillbirth, pre-term birth, two or more miscarriages, a termination of pregnancy due to fetal anomaly, or ectopic pregnancy) is a good risk indicator for subsequent pregnancies.

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





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



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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.