

Maternal, Newborn and Infant Clinical Outcome Review Programme

# MBRRACE-UK Supplementary report on survival up to one year of age for babies born before 27 weeks gestational age

For Births in Great Britain from January to December 2016

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#### **Definitions used in this report**

Late fetal loss A baby delivered between 22+0 and 23+6 weeks gestational age showing no

signs of life, irrespective of when the death occurred.

Stillbirth A baby delivered at or after 24<sup>+0</sup> weeks gestational age showing no signs of

life, irrespective of when the death occurred.

Antepartum stillbirth A baby delivered at or after 24<sup>+0</sup> weeks gestational age showing no signs of

life and known to have died before the onset of care in labour.

Intrapartum stillbirth A baby delivered at or after 24+0 weeks gestational age showing no signs of

life and known to have been alive at the onset of care in labour.

**Neonatal death** A liveborn baby (born at 22<sup>+0</sup> weeks gestational age or later, who died before

28 completed days after birth.

Early neonatal death A liveborn baby (born at 22+0 weeks gestational age or later, who died before

7 completed days after birth.

Late neonatal death A liveborn baby (born at 22+0 weeks gestational age or later who died after 7

completed days but before 28 completed days after birth.

**Post neonatal death** A liveborn baby (born at 22<sup>+0</sup> weeks gestational age or later, who died before

365 completed days after birth.

**Perinatal death** A stillbirth or early neonatal death.

**Extended perinatal death** A stillbirth or neonatal death.

**Infant death** A neonatal or post neonatal death.

**Termination of pregnancy** The deliberate ending of a pregnancy, normally carried out before the embryo

or fetus is capable of independent life.

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#### **Abbreviations**

CI Confidence Interval

HQIP Healthcare Quality Improvement Partnership

ISD Information Services Division (Scotland)

MBRRACE-UK Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK

MNI-CORP Maternal, Newborn and Infant Clinical Outcome Review Programme

NHS National Health Service

NICU Neonatal Intensive Care Unit

NIMACH Northern Ireland Maternal and Child Health

NIMATS Northern Ireland Maternity System

NISRA Northern Ireland Statistics and Research Agency

NRS National Records of Scotland
ONS Office for National Statistics

PDS Personal Demographics Service

SMR02 Maternity Inpatient and Day Case Dataset (Scotland)

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#### 1. Introduction

This MBRRACE-UK Supplementary report on outcomes of babies born before 27<sup>+0</sup> weeks gestational age provides information on deaths up to one year of age in Great Britain arising from births between 1<sup>st</sup> January 2016 and 31<sup>st</sup> December 2016.

MBRRACE-UK are commissioned by the Healthcare Quality Improvement Partnership (HQIP) to undertake the Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) on behalf of NHS England, the Welsh Government, the Scottish Government Health and Social Care Directorate, the Northern Ireland Department of Health, the States of Guernsey, the States of Jersey, and the Isle of Man Government. The aims of the MNI-CORP are to collect, analyse and report national surveillance data and conduct national confidential enquiries in order to stimulate and evaluate improvements in health care for mothers and babies.

This supplementary report summarised here focuses on the surveillance of all births between 22<sup>+0</sup> to 26<sup>+6</sup> weeks gestational age with data presented by gestational week of birth for Great Britain. The availability of data for England, Scotland and Wales has permitted an exploration of:

- The proportion of total births that are live born at extremely preterm gestations
- The proportion of babies receiving active neonatal care by gestational age
- The proportion of babies surviving to admission to a neonatal intensive care unit by gestational age
- Survival rates up to one year of age by gestational age using a range of denominators which take
  into account variation in how births at early gestational ages are reported as live born or stillborn to
  enable international comparisons and monitor UK trends over time.

#### 1.1 Overview of this report

This supplementary report is divided into four chapters. Following this introduction Chapter 2 describes the methods used for reporting mortality. The national survival rates for babies born between 22<sup>+0</sup> to 26<sup>+6</sup> weeks gestational age (excluding terminations of pregnancy) are presented in Chapter 3. In Chapter 4 these findings are compared with UK rates of survival over time.

The full version of this report will only be available as a downloadable document, available from the MBRRACE-UK website (<a href="www.npeu.ox.ac.uk/mbrrace-uk/reports">www.npeu.ox.ac.uk/mbrrace-uk/reports</a>).

#### 1.2 Survival of babies born before 27 weeks gestational age

As shown in the MBRRACE-UK Perinatal Mortality Report, stillbirth and neonatal mortality rates are increased for babies born preterm. Mortality is particularly high for those born before 27 weeks gestational age [1-3]. Information on survival is vital for clinicians to be able to discuss clinical decisions and counsel parents who baby is born or who are at risk of giving birth at extreme early gestations. It also offers health care providers valuable information for service planning. It is vital that survival estimates are up-to-date and take into account recent changes in health care practice.

Improvements in perinatal care have led to improved outcomes for babies born extremely preterm admitted to neonatal intensive care units (NICUs) in the UK over the last two decades. The national EPICure and EPICure-2 studies [2] reported survival outcomes of extremely preterm babies from 1995 to 2006 and more recently the Medicines for Neonates Investigators Group have reported further improved survival based on the National Neonatal Research Database [3] for England over the period 2008-2014 (Table 1). These three studies show increases at all gestational ages in the survival of babies born between 22 and 25 weeks gestational age admitted to neonatal care. Over the period 1995 to 2014 survival of babies admitted to neonatal care has increased from 14% to 18% for babies at 22 weeks gestational age and from 59% to 74% for babies born at 25

weeks gestational age. International research also confirms increasing survival and improving long term neurodevelopmental outcome for babies born before 27 weeks of gestation [4, 5].

Table 1: Percentage of births surviving to discharge from hospital by gestational age reported in UK national studies 1995-2014

Study (Voor)	Coography	Population	Gestational age at birth (weeks)					
Study (Year)	Geography		22 <sup>+0</sup> -22 <sup>+6</sup>	23 <sup>+0</sup> -23 <sup>+6</sup>	24 <sup>+0</sup> -24 <sup>+6</sup>	25 <sup>+0</sup> -25 <sup>+6</sup>	26 <sup>+0</sup> -26 <sup>+6</sup>	
EPICure [2] (1995)	e [2] (1995) UK and Ireland		14%	29%	43%	59%	-	
EPICure 2[2] (2006)	England	Live births	2%	19%	40%	66%	77%	
11(11)		Admissions to neonatal care	16%	30%	47%	69%	78%	
Santhakumaran et al[3] (2008-2014)	England	Admissions to neonatal care	18%	36%	59%	74%	83%	

Improvements in neonatal care and changing attitudes towards initiation of active care at the threshold of survival mean up-to-date information is needed to ensure reliable data for counselling and service provision. It is important to remember that attitudes towards the initiation of active interventions before and after birth [6] impact greatly on observed survival rates. In assessing survival rates it is important to remember that reported outcomes are impacted by the population used for the calculation of mortality rates [6]. While the UK studies have shown improvements over time in the survival to discharge from hospital of babies admitted to neonatal care, only the EPICure 2 study collected information on all births including stillbirths and live births dying before admission to neonatal care. Estimates of survival of live born babies in 2006 ranged from 2% (n=3) for those born at 22 weeks gestation, to 77% (n=448) at 26 weeks. It is vital that up-to-date survival information is available on all extremely preterm births in addition to admissions to neonatal care in order to be able to provide appropriate counselling for parents about all potential outcomes. Previous studies have also only focused on survival to discharge from neonatal care which does not include deaths following discharge from hospital.

In this report, survival outcomes are reported for babies born at 22<sup>+0</sup>-26<sup>+6</sup> weeks gestational age in Great Britain in 2016. Linked information on survival up to 1 year of age offers up-to-date information on longer term survival including deaths following discharge from neonatal care. A range of population denominators are presented to aid counselling for parents.

#### 2. Methods for reporting survival rates

#### 2.1 MBRRACE-UK linked data on births and deaths

MBRRACE-UK link detailed information on deaths reported to them with individual level information on all births in the UK and Crown Dependencies [1]. Deaths reported to MBRRACE-UK are:

- late fetal losses: a baby delivered between 22<sup>+0</sup> and 23<sup>+6</sup> weeks gestational age showing no signs of life, irrespective of when the death occurred;
- stillbirths: a baby delivered at or after 24<sup>+0</sup> weeks gestational age showing no signs of life, irrespective of when the death occurred;
- neonatal deaths: a live born baby (born at 20<sup>+0</sup> weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died before 28 completed days after birth.

These definitions also include any late fetal loss, stillbirth, or neonatal death resulting from a termination of pregnancy. MBRRACE-UK received stillbirth, neonatal and post neonatal death registrations from statutory sources for babies born in 2016 which were used to ensure complete ascertainment of deaths. These data were matched to the detailed MBRRACE-UK death notifications. Since deaths of babies born showing no signs of life before 24+0 weeks gestational age are not officially registered in the UK, ascertainment for late fetal losses at 22+0-23+6 weeks gestational age cannot be verified in the same way. MBRRACE-UK have implemented a system of repeated verification checks with each individual Trust and Health Board in the UK to maximise ascertainment of these deaths.

The MBRRACE-UK data on deaths are linked to information on all births for England, Wales and the Isle of Man (Personal Demographics Service (PDS) and ONS birth registration data), Scotland (NRS and Information Services Division; ISD), Northern Ireland (NIMATS), Bailiwick of Guernsey (Health and Social Services Department) and the Bailiwick of Jersey (Health Intelligence Unit) to give a single dataset of births for the whole UK and Crown Dependencies. The data are also linked to routine information on all post neonatal deaths (a live born baby who died before 28 and 365 completed days after birth) for England, Wales (ONS death registration data), and Scotland (NRS and Information Services Division; ISD). Details of the generation of the births dataset are provided elsewhere [1].

#### 2.2 Births and deaths included in this report

This supplementary report focuses on survival up to one year of age of all babies born at 22<sup>+0</sup>-26<sup>+6</sup> weeks gestational age for births from 1 January 2016 to 31 December 2016 in Great Britain. Since information on post neonatal deaths was not available for Northern Ireland and the Crown Dependencies, this report includes only babies born to mothers resident in Great Britain, i.e. England, Scotland and Wales. The reporting of mortality for a birth cohort for a calendar year is in contrast to statutory publications, which are based on deaths in a calendar year. This method of reporting allows more accurate estimates of mortality rates to be produced as appropriate denominators are available.

To facilitate the comparability of mortality rates, deaths following termination of pregnancy have been excluded. This avoids the influence of the known variation in the rate of termination of pregnancy for congenital anomaly across the UK. The number of deaths of babies born in 2016 in Great Britain reported here will differ from that of statutorily registered deaths published by ONS (England and Wales) and NRS (Scotland) because of the inclusion of late fetal losses and the exclusion of terminations of pregnancy in this report to ensure comparability of mortality rates[1].

#### 2.3 Outcome measures used in this supplementary report

Outcomes by weeks gestational age are presented for births from 1 January 2016 to 31 December 2016. Outcome percentages are provided with 95 % confidence intervals.

A range of outcomes are reported for each gestational age:

- 1. Percentage of live births
- 2. Percentage of delivery room deaths
- 3. Percentage of babies receiving active care
- 4. Percentage of babies admitted to a neonatal intensive care unit
- 5. Percentage of babies surviving to 1 year.

**Live births:** The percentage of live births is calculated based on *all births alive at onset of care in labour*. Stillbirths and late fetal losses are categorised as an antepartum death where the death was confirmed before onset of care in labour and an intrapartum death where the fetus was known to be alive before onset of care in labour but died before birth. Stillbirths and fetal losses of unknown timing are classified as antepartum stillbirths in this report.

**Delivery room deaths**: A delivery room death is defined as a baby that is live born but is not admitted to a neonatal intensive care unit prior to death. The percentage of delivery room deaths is calculated based on *all live births*. Admission to a neonatal intensive care unit is categorised based on information reported to MBRRACE-UK for all deaths. For those births between 22<sup>+0</sup>-26<sup>+6</sup> weeks gestational age where this information was missing it is assumed that all babies surviving beyond 24 hours would have been admitted for neonatal care.

**Babies receiving active care:** The percentage of babies receiving active respiratory care is based on *all live births*. Recording of provision of active respiratory care on the MBRRACE-UK database commenced during 2016, and thus rates for births in 2016 are inferred from recording of a total of only 292 deaths. Future reports on babies born from 2017 onwards will include full data on provision of active care for all births.

**Babies admitted to a neonatal intensive care unit:** The percentage of births admitted to a neonatal intensive care unit is based on *births receiving active care*. As detailed above, admission to a neonatal intensive care unit is categorised based on information reported to MBRRACE-UK for all deaths. For those births between 22<sup>+0</sup>-26<sup>+6</sup> weeks gestational age where this information was missing it is assumed that all babies surviving beyond 24 hours would have been admitted for neonatal care.

**Babies surviving to 1 year**: This report includes deaths of babies born in 2016 including information on infant deaths occurring up to 31<sup>st</sup> December 2017. The percentage of babies surviving to 1 year is given in terms of four different denominators to allow interpretation of survival at different stages of the care pathway:

- a) All births alive at onset of care in labour
- b) All live births
- c) All live births receiving active respiratory care
- d) All births admitted to neonatal intensive care

This range of different denominators offers a variety of information for counselling parents. Survival estimates using the denominator all births alive at the onset of care in labour and all live births can assist counselling parents whose baby's birth is imminent. Following birth and assessment of the baby and decisions about whether to initiate care, survival based on babies receiving active care and babies admitted to a neonatal intensive care unit can provide more specific information for clinicians and parents on longer term survival following active care. These different outcomes allow comparisons with survival rates in other countries where there is variation in approaches to reporting of births at the threshold of survival as live born and with other UK cohorts based solely on admissions to neonatal care.

# 3. Survival of babies born at 22<sup>+0</sup>-26<sup>+6</sup> weeks gestational age

The data in this chapter relate to the information available for Great Britain about the outcomes for births in 2016 at 22<sup>+0</sup>-26<sup>+6</sup> weeks gestational age. The data shown in Table 2 details outcomes by gestational age. In total 3,148 births were born between 22<sup>+0</sup>-26<sup>+6</sup> weeks gestational age in 2016. This represents an incidence of 4.2 per 1000 total births (based on 753,315 total births to residents of Great Britain). The number of births increased with gestational age from 486 at 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age to 832 at 26<sup>+0</sup>-26<sup>+6</sup> weeks gestational age.

#### 3.1 Live births and provision of active care in the delivery room

Table 1 shows that there were 2,088 live births out of 2,331 births confirmed alive at the onset of care in labour. The percentage of live births ranged from 63% at 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age to 98% at 26<sup>+0</sup>-26<sup>+6</sup> weeks gestational age. Of those babies born alive, the percentage of babies dying with no admission to neonatal care ranged from 85% at 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age to 2% at 24<sup>+0</sup>-26<sup>+6</sup> weeks gestational age. Active respiratory care provision increased significantly with increasing gestational age from 23% of live births at 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age to 88% at 23<sup>+0</sup>-23<sup>+6</sup> weeks gestational age, 98% at 24<sup>+0</sup>-24<sup>+6</sup> and 100% at 25<sup>+0</sup>-26<sup>+6</sup> weeks gestational age.

#### 3.2 Admissions to neonatal care

There were 1,794 admissions to neonatal care representing 86% of births provided with active care at these gestations. The number of births admitted to neonatal care of those expected to have been provided with active care increased dramatically with increasing gestation. Of the 1,794 neonatal admissions, the proportion of babies born at 22+0-22+6 weeks gestational age was 1.6% (n=28) compared to 36.0% (n=646) born at 26+0-26+6 weeks gestational age. The percentage of births provided with active respiratory care that were admitted to neonatal care was substantially lower for babies born at 22+0-22+6 weeks gestational age (65%) and 23+0-23+6 weeks gestational age (85%) than at 24+0-25+6 weeks gestational age (96%) and 26+0-26+6 weeks gestational age (98%).

#### 3.3 Survival to 1 year

At 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age, only 15 babies survived to 1 year. Survival rates varied greatly when based on the four different denominators. This was due to the high numbers of intrapartum deaths and low numbers of admissions to neonatal care. Survival at 1 year ranged from 5% of births alive at the onset of care in labour, 8% of live births, 35% of births receiving active care and 54% of admissions to neonatal care. Since the number of survivors at 1 year is extremely small (3% of all births), these estimates should be treated with caution.

For babies born at 23<sup>+0</sup>-23<sup>+6</sup> weeks gestational age, survival at 1 year ranged from 26% of births alive at the onset of care in labour, 34% of live births, 38% of births provided with active care and 45% of admissions to neonatal care. This range in survival with denominator was less varied than for births at 22 weeks gestational age. Compared to babies born at 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age, survival was increased for all denominators except survival based on admissions to neonatal care which was lower. However survival based on admissions is based on considerably higher numbers of admissions (223 at 23<sup>+0</sup>-23<sup>+6</sup> weeks gestational age compared to 28 at 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age).

Survival to 1 year continued to increase with increasing gestational age. The difference between survival based on births alive at onset of labour, live births, births provided with active care and admissions to neonatal care was considerably reduced at these higher gestations. Survival based on births alive at onset of labour ranged from 54% at 24<sup>+0</sup>-24<sup>+6</sup> weeks gestational age to 80% at 26<sup>+0</sup>-26<sup>+6</sup> weeks gestational age. Survival of live births ranged from 59% at 24<sup>+0</sup>-24<sup>+6</sup> weeks gestational age to 82% at 26<sup>+0</sup>-26<sup>+6</sup> weeks gestational age. The rates of

survival of those receiving active respiratory care ranged from 60% % at 24<sup>+0</sup>-24<sup>+6</sup> weeks gestational age to 82% at 26<sup>+0</sup>-26<sup>+6</sup> weeks gestational age. For neonatal care admissions, survival at 1 year ranged from 63% at 24<sup>+0</sup>-24<sup>+6</sup> weeks gestational age to 84% at 26<sup>+0</sup>-26<sup>+6</sup> weeks gestational age.

Table 2: Number and percentage (with 95% confidence intervals) of total births, births alive at onset of care in labour, live births, delivery room deaths, live births receiving active care, admissions to neonatal care and survival to 1 year of age by gestational week at birth, 22<sup>+0</sup> to 26<sup>+6</sup>, based on different denominators: England, Scotland and Wales, for births in 2016

Percentage <sup>§</sup>	Gestational age at birth (weeks)							
	22 <sup>+0</sup> -22 <sup>+6</sup>	23+0-23+6	24+0-24+6	25 <sup>+0</sup> -25 <sup>+6</sup>	26 <sup>+0</sup> -26 <sup>+6</sup>	22+0-26+6		
Total births	486	510	656	664	832	3148		
Births alive at onset of labour care	290	362	497	508	674	2331		
Live births	183	301	456	486	662	2088		
% live born of births alive onset labour care	<i>63%</i> 57 to 69	<i>83%</i> 79 to 87	<i>92%</i> 90 to 94	<i>96%</i> 94 to 98	<i>98%</i> 97 to 99	<i>90%</i> 89 to 91		
Delivery room deaths	155	78	26	19	16	294		
% delivery room deaths of live births	85% 80 to 90	26% 21 to 31	6% 4 to 8	4% 2 to 6	2% 1 to 3	14% 13 to 15		
Babies receiving active care*	43	264	449	486	662	2088		
% babies receiving active care* of live births	23% 17 to 29	88% 84 to 92	98% 97 to 99	100%	100%	90% 89 to 91		
Babies admitted to NICU	28	223	430	467	646	1794		
% admitted to NICU of babies receiving active care*	65% 51 to 79	85% 81 to 89	96% 94 to 98	96% 94 to 98	98% 97 to 99	86% 85 to 87		
Survivors to 1 year	15	101	270	359	540	1285		
% surviving to 1 year of babies alive in labour	5% 2 to 8	28% 23 to 33	54% 50 to 58	71% 67 to 75	80% 77 to 83	55% 53 to 57		
% surviving to 1 year of all live births	8% 4 to 12	34% 28 to 39	59% 55 to 64	74% 70 to 78	82% 79 to 85	62% 60 to 64		
% surviving to 1 year of babies receiving active care*	35% 21 to 49	38% 32 to 44	60% 55 to 65	74% 70 to 78	82% 79 to 85	62% 60 to 64		
% surviving to 1 year of admissions to NICU	54% 36 to 72	45% 38 to 52	63% 58 to 68	77% 73 to 81	84% 81 to 87	72% 70 to 74		

<sup>§</sup> excluding terminations of pregnancy

<sup>\*</sup> Recording of active care on the MBRRACE-UK database commenced during 2016. Rates are inferred from data on 292 deaths Data sources: MBRRACE-UK, ONS, PDS, NRS, ISD. PDS © 2016, re-used with the permission of NHS Digital. All rights reserved.

#### 4. Discussion

#### 4.1 Main findings

This supplementary report provides national data on babies born in Great Britain in 2016 before 27 weeks gestational age. Comparison of the findings with those of the EPICure studies and the work using the National Neonatal Research Database highlights the changing picture of survival for these babies.

Outcomes for babies at 22 weeks gestational age have shown changes over the last 10 years. For babies alive at the onset of care in labour, a considerably higher percentage are reported now as live born than in 2006 [2] increasing from 56% in 2006 to 63% in 2016. This is likely to suggest a change in attitudes over the past decade towards reporting of babies at earlier gestations as live born. However the percentage of live births at this gestational age admitted for neonatal care has remained relatively static since 2006 (13% in 2006 versus 15% in 2016). Survival rates for live births were extremely low but increased from 2006 to 2016 from 2% to 8%. For those admitted for neonatal care survival showed a large increase but the numbers are extremely small and should be treated with caution. Survival rates clearly depend at this early gestation on whether there is a decision to provide comfort care or initiate resuscitation and intensive neonatal care.

For babies born at 23 weeks gestational age there has been little change in babies alive at the onset of care in labour being reported as live born between 2006 and 2016 (81% to 83%). However the percentage of live births admitted for neonatal care has increased since 2006 from 52% to 74% and their survival has improved. In terms of live births, 3 out of 10 births (34%) survived to 1 year in 2016 compared to 2 out of 10 (19%) surviving to hospital discharge in 2006. For babies admitted for neonatal care survival has increased consistently over time from 29% in 1995, 30% in 2006, 36% in 2008-2014 to 45% in 2016 (based on survival to discharge from 1995-2014 and survival to 1 year in 2016).

For babies born at 24 weeks gestational age over 92% of births alive at onset of care in labour survive to live birth. Neonatal care admissions as a percentage of live births have increased since 2006 from 86% to 94%. Survival of live births improved from 40% surviving to hospital discharge in 2006 compared to 59% surviving to 1 year in 2016. For those admitted for neonatal care survival has increased from 43% in 1995, 47% in 2006, 59% in 2008-2014 to 63% in 2016.

Survival increases with increasing gestational age with 77% and 84% of live births at 25 and 26 weeks gestational age surviving to one year. Improvements over time have been less marked, (66% at 25 weeks gestational age and 77% at 26 weeks gestational age in 2006). Now 77% of babies born at 25 weeks gestational age and 84% of babies born at 26 weeks gestational age admitted to neonatal care admissions survive to 1 year which shows a small improvement to reported data for 2008-2014 (74% and 83% respectively).

#### 4.2 Strengths and limitations

This supplementary report offers many strengths regarding the estimation of outcomes of babies born extremely preterm. While many other studies only provide outcomes for babies admitted to neonatal care, these data include outcomes of the whole population of extremely preterm births comprising antepartum deaths, intrapartum deaths and deaths in the delivery room. This offers the opportunity to provide more comprehensive information for parents regarding outcomes when counselling before birth.

Furthermore this report also includes survival up to one year after birth providing higher ascertainment of deaths compared to other hospital based national studies that measure survival to discharge from hospital which may slightly overestimate survival due to the exclusion of babies that are discharged home for palliative care from the number of deaths. Therefore when comparing longer term survival rates over time, it is important to note that improvements in survival seen in this report may be slightly underestimated.

It is possible that the increase in live born infants at 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age compared to 2006 may be partially due to an underestimation of the number of babies born showing no signs of life as MBRRACE-UK are unable to verify 100% ascertainment of late fetal losses at 22<sup>+0</sup>-23<sup>+6</sup> weeks gestational age using routine sources. However the overall percentage of babies born at 22<sup>+0</sup>-22<sup>+6</sup> weeks gestational age as a proportion of all births 22<sup>+0</sup>-26<sup>+6</sup> weeks gestational age has increased since 2016 from 15% to 16%. Also there was no change in the percentage of live births at 23<sup>+0</sup>-23<sup>+6</sup> weeks gestational age. Together with the extensive checking system MBRRACE-UK has in place to ensure ascertainment of late fetal losses, this suggests that the ascertainment of these babies is similar for 2006 and 2016 and that changes in live births are likely to be due to changes in views on viability.

#### 4.3 Conclusions

The data presented in this supplementary report offer clinicians and parents with up-to-date data on survival of babies born before 27 weeks gestational age gestational age. The use of a range of denominators support decision-making and counselling throughout the pathway from suspected onset of extremely preterm labour through to birth and admission to neonatal care.

Since January 2017 MBRRACE-UK have been collecting detailed information on stabilisation and resuscitation following birth, including information on whether a decision to not resuscitate the baby was made before or after birth. These additional data will allow survival rates to be calculated rather than estimated for those births where care is initiated following delivery as opposed to those where comfort care is provided which will provide a more complete picture of survival for parents and clinicians to aid decision-making before and after birth.

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