

## Infant Mortality and Stillbirth in the UK



Stillbirth and infant mortality rates are higher in the UK than several European countries, including Germany and Sweden. This POSTnote reviews recent UK data and examines the factors contributing to increased risk. It then looks at the policy options that may help to improve health outcomes for infants and their families.

### Background

Data on stillbirth and infant mortality is reported in national statistics.<sup>1</sup> In the UK the following definitions apply:<sup>2</sup>

- **Stillbirth** applies to babies born after 24 weeks of pregnancy, who did not breathe or show signs of life.
- **Miscarriage** is a pregnancy lost before 24 weeks.
- **Infant mortality** is the death of a child in the first year of life, including babies born at any stage of pregnancy who show signs of life after birth.
- Infant mortality is further defined as either **neonatal** (in the first 28 days) or **post-neonatal** (28 days to 1 year).
- **Perinatal mortality** includes stillbirths and deaths in the first 28 days of life.

Absolute numbers are collected, but data are often expressed as a rate: the number of deaths per 1,000 births a year for stillbirths, and per 1,000 *live* births for infant mortality. This allows comparisons to be made between populations and over time. Figure 1 shows how stillbirth and infant mortality rates have declined, largely due to improved healthcare.

The impact on a family of losing a baby is profound. Many parents report symptoms of anxiety and depression which can last for years after their baby's death.<sup>3</sup> The care of bereaved families is discussed in detail in a forthcoming POSTbrief on Bereavement Care.

### Overview

- Stillbirth and infant mortality rates have fallen in the UK since the early 1900s, but in the last two decades progress has slowed.
- Stillbirths and infant deaths are linked to a number of complex and interacting risk factors, many of which can be addressed. These include obesity, smoking, maternal age and inequalities across different socioeconomic and ethnic groups.
- Improvements in care received during pregnancy, labour and early infancy could also improve mortality rates.
- Studies show that many existing guidelines to improve care in the UK are not being followed, such as those relating to testing and monitoring of women with an increased risk of complications during pregnancy.

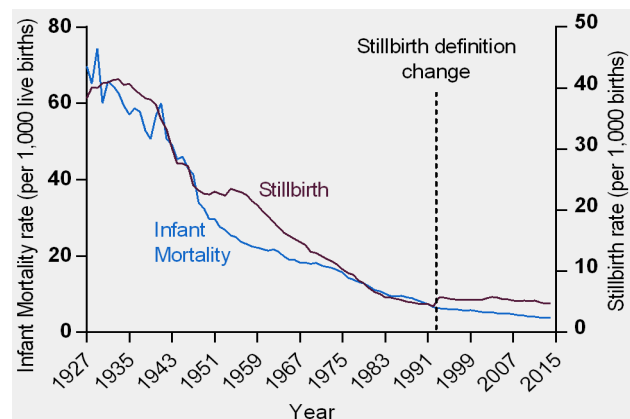


Figure 1. Stillbirth and infant mortality rates in England and Wales 1927-2014 (Office for National Statistics).<sup>1,2</sup>

### Infant Mortality in the UK

In 2014, 3,014 babies died before 1 year of age, 2,103 of them (around 70%) in the first 28 days of life (the neonatal period).<sup>6</sup> Infant mortality has more than halved since 1990, as has neonatal mortality.<sup>7</sup> The main causes of infant mortality in England and Wales are:<sup>8</sup>

- complications from being born prematurely (44%)
- congenital anomalies (see Box 3) (28%)
- lack of oxygen or trauma just before/during birth (7%)
- sudden infant deaths (6%)
- infections (4%)

All infant mortality can be affected by the care that mothers and infants receive. Post-neonatal mortality is more closely associated with conditions at home, due to risk factors (for example, smoking) that are discussed later.

### Stillbirth in the UK

Stillbirth rates have not decreased significantly since the 1980s. There were 3,245 stillbirths in England and Wales (4.7 per 1,000 births).<sup>9</sup> In 1992, the definition of stillbirth was changed from a death after 28 weeks to the current definition of after 24 weeks of pregnancy. The lowest rate since the 24 week definition was introduced in 1992 was 4.4 per 1,000 in the same year, rising to 5.7 per 1,000 in 2003 (England and Wales). Since 2003 the rate has been largely stable, although rates have declined since 2012;<sup>11</sup> it is not yet clear whether this will continue. Around nine in ten stillbirths occur before the onset of labour. One in three stillbirths occur in babies who have reached term and seem to be completely healthy. In England and Wales, half (52%) of stillbirths are unexplained, with the remainder resulting from lack of oxygen or trauma just before or during birth (25%), congenital anomalies (15%) or infections (<10%).<sup>12</sup> Data are also available for Scotland<sup>4</sup> and Northern Ireland.<sup>5</sup> International comparisons are described in Box 1.

### Risk Factors

An increased risk of infant mortality and stillbirth is in turn linked to several complex and interacting factors ('risk factors') many of which could be addressed. Risk factors for stillbirth include: social inequality; maternal obesity, age and ethnicity; smoking in pregnancy; having experienced a previous stillbirth; and contracting infections during pregnancy.<sup>13</sup> In the first year of life risk factors for mortality include low birth weight<sup>14</sup> and prematurity<sup>15</sup> (which are closely linked), which are also risk factors for stillbirth. Tackling the risk factors for stillbirth could thus reduce both the stillbirth and infant mortality rate (discussed below).

### Tobacco Smoking

If no women smoked during pregnancy, an estimated 7.1% of stillbirths could be avoided.<sup>18</sup> Smoking and passive smoking in pregnancy (see Box 2) increase the risk of infant mortality by an estimated 40%.<sup>19</sup> Smoking in pregnancy increases the risk of low birth weight and premature birth, which in turn increase the risk of infant mortality.<sup>20,21</sup> Smoking and passive smoking in pregnancy increase the risk of Sudden Infant Death Syndrome (SIDS), the unexplained death of an apparently healthy baby. A baby living in a household in which one or more people smoke has more than double the risk of SIDS.<sup>22</sup> National clinical guidelines from NICE (the National Institute of Health and Care Excellence) advise that women who smoke during pregnancy should be referred to NHS stop smoking services, and that partners and other household members who smoke should also be advised to quit.<sup>23</sup> While there is no data on how NICE guidelines are used<sup>24</sup> only 15% of pregnant women who smoke use stop smoking services, and of these just under half succeed in quitting.<sup>25</sup>

#### Box 1. International Comparisons

International comparisons are complicated by the fact that countries have different definitions of stillbirth. For instance, some do not register deaths as stillbirths until later in pregnancy. By including only babies stillborn from 28 weeks, researchers found that the UK has a higher stillbirth rate (2.9 per 1,000 births) than Germany (2.4), Poland (2.3), Sweden (1.9), the Netherlands (1.8) and Denmark (1.7). The stillbirth rate in the UK is falling more slowly than elsewhere in Europe. Stillbirth rates declined by 1.4% per year between 2000 and 2015 in the UK, compared with the Netherlands (6.8%), Denmark (4.4%) and Poland (4.5%).<sup>16</sup> The World Health Organisation reported that the UK has a higher infant mortality rate (3.5 per 1,000 live births) than several countries including Germany (3.1), Croatia (2.6), Sweden (1.6) and Finland (1.3).<sup>17</sup> Lower rates in other European countries suggest that further improvements are possible in the UK. However, international comparisons do not account for factors such as the prevalence of obesity, ethnic demographics and smoking, all of which affect rates. Data collection and recording standards also vary between countries, further complicating international comparisons.

### Overweight and Obesity in Pregnancy

Statistics on obesity in pregnancy are not routinely reported in England. However, obesity data are available for women aged 16-44, which is broadly representative of child-bearing age. Between 1994 and 2014, the proportion of this group who were overweight (Body Mass Index or BMI 25-29) rose from 19.5% to 21.2% and the proportion who were obese (BMI >30) from 7.8% to 12.9%.<sup>36</sup> Being overweight or obese in pregnancy increases the risk of both stillbirth and death in infancy, although the biological mechanism is unknown.<sup>26</sup> One study estimated that 12.2% of UK stillbirths could be prevented if no mothers were overweight or obese.<sup>13</sup>

Obesity increases the risk of conditions such as gestational diabetes (diabetes in pregnancy) and pre-eclampsia (high blood pressure in pregnancy). Both conditions increase the risk of stillbirth. Diabetes also increases the risk of congenital anomalies,<sup>27</sup> a major cause of infant mortality in the UK.<sup>28-30</sup> Obese women are more likely to have complications that require early delivery, and to have babies of lower birth weights,<sup>31,32</sup> which are both risk factors for infant mortality.<sup>20,21</sup> Obese women are also more likely to be older and live in areas of higher deprivation than non-obese women. Both of these are risk factors for infant mortality.<sup>40</sup>

#### Box 2. Smoking in Pregnancy

Smoking in pregnancy exposes the fetus to chemicals such as nicotine and carbon monoxide, and narrows blood vessels in the placenta. This reduces nutrient and oxygen availability<sup>33</sup> and interferes with fetal development. Smoking rates in pregnancy, recorded at the time of delivery, fell from 15.1% in 2006/7<sup>34</sup> to 11.4% of women by 2014/2015 (England). This varies across the country: from 19.9% in Durham, Darlington and Tees to 4.9% in London (2015).<sup>35</sup> Women aged under 20 have significantly higher smoking rates in pregnancy (57%) than the national average, as do women in routine and manual occupations (40%).<sup>36</sup> Smoking in pregnancy is likely to be higher than the recorded rate,<sup>37</sup> because :

- self-reported data is used, so smoking is often under-reported.<sup>38</sup>
- these rates do not include women who had a miscarriage or a stillborn baby, both of which are more likely to occur in women who smoke during pregnancy.<sup>39</sup>

NICE guidelines advise that obese women are helped to lose weight before becoming pregnant, as dieting in pregnancy may harm the baby. During pregnancy, NICE advises that obese women should exercise, eat healthily, and be assessed for conditions such as gestational diabetes and pre-eclampsia<sup>41</sup> Some health care workers say they have difficulties discussing obesity in pregnancy with women, and women report being distressed by the critical approach of some health workers when discussing their weight.<sup>42,43</sup> To help improve diet, women receiving benefits or under 18 are eligible for vouchers to spend on items such as fruit, vegetables and milk from early pregnancy.<sup>44</sup>

### Social Inequality

Stillbirth rates in the most socio-economically deprived areas of the UK are twice as high as those in the least deprived.<sup>40</sup> Infant mortality is also higher in deprived areas. One analysis divided parents into 5 groups based on level of deprivation, and found that babies born to parents in the most deprived group were 1.6 times more likely to die during the first year of life than those in the least deprived group.<sup>45</sup> Infants in the lowest socio-economic groups are also twice as likely to die in the neonatal period due to a congenital anomaly (see Box 3) than infants in higher socio-economic groups.<sup>46</sup> It is not fully understood why babies from deprived families are at higher risk of death. One explanation could be that women from lower socioeconomic groups have higher rates of other risk factors such as smoking,<sup>47</sup> obesity,<sup>48</sup> teenage pregnancy,<sup>49</sup> are less likely to quit smoking during pregnancy<sup>37</sup> and are more likely to have stillbirths or an infant death caused by infection.<sup>50</sup>

### Ethnicity

South Asian women are 60% more likely, and black women twice as likely to have a stillbirth than white women, in England and Wales. Infant mortality is twice as common for babies born to Caribbean and Pakistani women than to white women.<sup>51</sup> Some of this increased risk is due to higher rates of obesity, diabetes and deprivation in minority ethnic groups, but these do not explain the full extent of the increased risk. Other possible factors include biological variation in birthweights and lengths of gestation, and the ability to access maternity and postnatal care. The risk of stillbirth and infant mortality is higher in communities where marriages occur between couples with at least one shared ancestor (great grandparent or closer), such as some UK born Pakistani communities. One study shows that babies

#### Box 3. Congenital Anomalies

Congenital anomalies describe numerous development disorders (such as spina bifida and heart defects); the causes of most are unknown. The most effective preventative measures are those which are implemented before conception. These include managing diabetes, providing genetic counselling services for those at risk (those with a family history), and promoting the taking of folate supplements to prevent problems with the development of the spinal cord. However, 45% of pregnancies in the UK are unplanned,<sup>53</sup> so these interventions are not always possible. Improved prenatal screening and diagnosis of anomalies in early pregnancy can reduce infant deaths, since parents may opt to terminate a pregnancy.<sup>46</sup>

born to such couples are at increased risk of genetic diseases, increasing the risk of stillbirth by over 80%.<sup>52</sup>

### Maternal Age

Being an older mother (over 35) or younger mother (under 20) increases the risk of both stillbirth and infant mortality. In the UK, births to mothers over 35 increased from 8% to 20% between 1985-2013.<sup>13</sup> Older women are at the highest risk of stillbirth at the end of pregnancy (earlier in pregnancy the risk is similar to that for a women in her mid-20s). However, the Royal College of Obstetrics and Gynaecologists (RCOG) does not recommend inducing all older mothers early, as it is unclear how induction affects the risk of death for babies during labour or just after birth.<sup>54</sup> Babies born to women over 40 are 1.3 times more likely to die in the neonatal period than those born to younger women. The risk of neonatal death is higher for babies from multiple pregnancies, which are becoming more common, particularly in older women (Box 4). Older women are more likely to have pre-existing conditions such as obesity and diabetes, and complications such as gestational diabetes and pre-eclampsia.<sup>55</sup> Women under 20 are more likely to have babies of low birthweight, and the risk is higher the younger the mother is. This is thought to be linked to poor diet; it could also be because the baby has to compete for nutrients with the growth requirements of the mother.<sup>56</sup> Teenage mothers are also more likely to be from a lower socio-economic background and to smoke during pregnancy.<sup>57</sup> Teenage pregnancy has fallen from a high of 55 to 22.9 conceptions per 1,000 (1971-2014).<sup>58</sup> Some campaigns target pregnant teenagers to stop smoking, such as Tommy's Baby Be SmokeFree campaign.<sup>59</sup>

### Previous Stillbirth

Compared to women who have had a previous healthy pregnancy, women who have had a stillbirth are almost twice as likely to have another in a future pregnancy.<sup>60</sup> Researchers recommend that these women benefit from increased monitoring in subsequent pregnancies. Analysis by the charity Sands found that 1 in 10 maternity units do not offer extra monitoring or support in subsequent pregnancies for women who have had a stillbirth.<sup>61</sup>

### Infection

An estimated 10-25% of stillbirths in developed countries are caused by infection, through compromising a baby's major organs, damaging the placenta or by making the mother seriously ill. However, it can be difficult to tell if an infection was the cause of death, or if a baby with an

#### Box 4. Multiple Pregnancy

Babies from multiple pregnancies (e.g. twins or triplets) are 3.5 times more likely to die in pregnancy or in the first month of life than babies from single pregnancies, largely due to prematurity and low birth weight. Multiple pregnancies increased from 9.6 to 15.6 per 1000 births from 1980-2012. This is due to increased use of assisted reproductive technology and increased maternal age, both of which are more likely to result in multiple pregnancies.<sup>62</sup> NICE recommends that one embryo is transferred in IVF, to reduce multiple births.<sup>63,64</sup>

infection died of another cause<sup>65,66</sup> Infections are often bacterial (*E. coli*, Group B Streptococcus (GBS), *H. influenza* and chlamydia) and travel from the vagina into the uterus. Non-bacterial infections can also cause stillbirth, such as rubella, influenza, herpes simplex and *T. gondii*.<sup>67</sup> Infections cause 11% of post-neonatal infant deaths in England and Wales, although this may be an underestimate because such deaths cannot always be identified and recorded.<sup>12,68</sup> Premature babies with under-developed immune systems are the most susceptible to infections. One of the most common infections in newborns is GBS, which 14% of women in the UK carry harmlessly. However the bacteria can be passed to the baby during labour and can cause life-threatening illness.<sup>69</sup> Routine NHS screening for GBS is not available as there is insufficient evidence that the benefits outweigh the harms.<sup>70,71</sup> Immunisation is the most effective intervention to reduce infections. Women are offered a range of immunisations to protect them and their babies, but vaccines are not available for all infections.<sup>72-75</sup>

## Care in Pregnancy and Early Infancy

Improving care before, during and after pregnancy is seen as an important step in reducing stillbirths and infant mortality. Care of babies who make it to term but die before labour are an important target for care improvements, as babies identified at risk at this point can be safely delivered. Research from a 2015 enquiry for NHS England indicates which aspects of clinical practice could improve (Box 5).<sup>76,61</sup> Health care in the post-natal period and in the first year of life is provided by midwives, health visitors and GPs through regular child health and development reviews. These staff check and offer advice on feeding, weight gain and general health in a variety of settings. Parents are also offered a range of immunisations for their children during infancy.<sup>75,77</sup> Government advice is that women should aim to breastfeed exclusively for 6 months. This is linked to a lower risk of infant mortality as it reduces the likelihood of infection and SIDs. In the UK, 81% of mothers report trying breastfeeding, but only 34% are still breastfeeding at 6 months. Mothers who are young or from a lower socio-economic background are less likely to breastfeed than others.<sup>36</sup> Charities also advise parents, such as how to reduce the risk of SIDs.

## Reviewing Clinical Care and Research

Some professional bodies and charities, including the Royal College of Midwives, are concerned about the impact of staffing levels on health services.<sup>61</sup> The premature baby charity Bliss estimates 2,140 more nurses are needed to care for babies in England.<sup>78</sup> According to Sands an estimated 500 babies a year in the UK die or are left severely disabled because of an event during birth that was either not anticipated or not well managed.<sup>61</sup> After a baby dies due to incidents during labour, a review of care should be carried out locally but the results are not always shared between maternity units. A 2015 enquiry for NHS England found that for three quarters of stillbirths occurring at term, patients' notes contained no evidence of a local review having taken place. When reviews took place, few followed national guidance or involved parents' views.<sup>76</sup>

### Box 5. Improving Clinical Care

**Monitoring Growth** - Fetal growth restriction is when growth slows or stops. A baby with restricted growth is more likely to be stillborn or die shortly after birth. An estimated 60% of stillborn babies show signs of restricted growth. Fetal growth is monitored with ultrasound scans and tape measurement of the size of the uterus. However, in a third of cases where babies died at term but before labour, national guidance for screening and monitoring fetal growth was not followed. When reduced growth was detected, it was often not acted upon.<sup>76</sup>

**Acting on Reduced Fetal Movements** - From 20 weeks gestation fetal movements have a regular pattern, increasing in frequency until 32 weeks. Reduced or changed movements can indicate fetal distress. Over half of women who have a stillbirth at term report reduced fetal movements.<sup>79</sup> However, movements differ between women and between pregnancies, so defining reduced movements is difficult. A mother's own perceptions are the best measure available. If a woman feels her baby is moving less, it is more likely her baby will be stillborn.<sup>80</sup> It is unclear which investigations should be carried out when a woman perceives reduced movement. The RCOG's guidelines advise that women should be told that the frequency of fetal movements should not reduce. If they then perceive a reduction, tests on fetal heart rate and growth should be conducted.<sup>81</sup> However the implementation of this guidance has been poor. Local guidelines vary and are frequently of low quality.<sup>82</sup> A study is underway to examine the effectiveness of encouraging women to report concerns about fetal movements and the effectiveness of their subsequent monitoring.<sup>83</sup>

**Diagnosing Gestational Diabetes** - Any type of diabetes increases the risk of stillbirth, and increases risk factors for infant mortality (such as congenital anomalies). Gestational diabetes can develop in pregnancy and resolves after birth. However, it may not cause symptoms, so screening is used to identify cases. The main risk factors are obesity and ethnicity (South Asian, Black Caribbean and Middle Eastern are at higher risk). According to NICE guidelines women meeting these criteria should be screened,<sup>84</sup> with those diagnosed offered increased monitoring in pregnancy, and induction of birth at 38 weeks. Screening and monitoring could reduce stillbirths, but one study found that two thirds of women at risk were not tested.<sup>76</sup>

The RCOG has launched a five year Each Baby Counts programme that aims to halve the number of deaths and injuries due to problems in labour by 2020.<sup>85</sup> This will be achieved by collecting more comprehensive data on stillbirth and mortality and to identify which aspects of care to improve nationally. Post-mortems can often determine why a baby died which can inform decisions on care during future pregnancies, and improve understanding of the underlying causes.<sup>76</sup> However, the shortage of specialist pathologists and current low take up of post-mortems, are issues of concern. It is estimated that the number of specialist pathologists needs to increase by 20% just to meet current demand.<sup>86</sup> The Department of Health ambition is to halve the number of stillbirths and neonatal deaths in England by 2030.<sup>87</sup> In response, NHS England has released new guidelines in the 'Saving Babies' Lives' Care Bundle. This includes advice aimed at improving: smoking cessation rates in pregnancy; detection of fetal growth restriction; awareness of the importance of fetal movements and monitoring of the baby during labour.<sup>88</sup> There will also be an additional £4 million for equipment and training.<sup>87</sup> Similar policy initiatives exist in the devolved administrations.<sup>89,90</sup> Governments across the UK have no targets for overall infant mortality rates.

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