Why children die: death in infants, children and young people in the UK Part A

May 2014

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NATIONAL CHILDREN'S BUREAU
BRITISH ASSOCIATION FOR CHILD AND ADOLESCENT PUBLIC HEALTH

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Key points

- Infant, child and adolescent death rates in the UK have declined substantially and continue to fall.
- However, there are significant areas of concern:
    - The overall UK childhood mortality rate is higher than in some other European countries.
    - The key areas where the UK rates appear to be relatively high are infant deaths and deaths among children and young people who have chronic conditions.
    - Injuries are the most frequent cause of death in children after their first year of life, and although unintentional injuries are the most common, the failure to reduce intentional injury deaths among young people recently is also a pressing concern.
    - Several reports have shown that health services do not always deliver optimal care for children and young people, and lives may be lost as a result.
    - There are marked social inequalities in death rates.
- Many of the causes and determinants of childhood deaths are preventable.
- There are three levels through which we can work together to improve the health and lives of children and young people, and reduce their chances of death:
    - Government and the role of civil society.
    - Health systems and organisations.
    - Healthcare and public health services.

Introduction

Child and adolescent health in the UK has improved dramatically over the past 30 years. This improvement has undoubtedly been one of the success stories of modern healthcare. Yet, despite steady mortality declines, in 2012 in the UK over 3,000 babies died before their first birthday and over 2,000 children and young people died between the ages of one and 19[1].

A number of factors suggest that the UK is not providing optimal conditions for children to survive and thrive. Firstly, the UK performs poorly on several measures of child health and wellbeing, including mortality, compared with some other European countries[2,3,4,5]. Secondly, there are stark inequalities in survival chances between rich and poor children in the UK[6]. Finally, many children's deaths are potentially preventable. Although it is difficult to measure avoidability on a population basis, recent estimates suggest that 21% of child deaths involved 'modifiable factors' – in other words, something could possibly have been done to prevent the death[7].

Understanding why some children in the UK may have a greater chance of dying than their richer peers, or those in some other countries, is challenging. It requires going beyond the direct cause of death to examine the events leading to death and also the underlying factors that may have contributed to making death more likely. Preterm birth is an example of where this can be complex. Very preterm babies may die because the baby's lungs are not developed sufficiently for survival outside the womb, even with the most advanced neonatal intensive care. Some medical conditions can lead to preterm delivery, but may be more likely to occur if the mother was unusually young, smoked in pregnancy, or was materially disadvantaged. Thus the potential for prevention of childhood death may involve complex interactions between many factors including those that are intrinsic to the child, such as the child's genes; the social, economic, and physical environment into which the child is born and grows up; and the health services and systems that provide care for the child and family.

Outlining actions that could be taken to prevent childhood deaths in the future is the aim of this report. We will look at the causes of death and some of the underlying determinants such as poverty and social inequalities. Although the remit of this report concerns deaths that happen from birth through childhood and adolescence, it must be noted that stillbirths are a significant problem and many of the causes and underlying determinants are similar to those of deaths that happen later in childhood.

This report highlights the most recently available data on deaths, focusing specifically on areas where we could make a difference through what we do in policy and practice.

A snapshot of UK infant, child, and adolescent mortality

Over 5,000 children under the age of 19 years died in the UK, in 2012. As shown in Figure 1 and accommpanying Table 1, 60% of deaths occurred before the age of one year and 18% between the ages of 15 and 19 years. Mortality rates are lower in early childhood from one to four years, and are lowest for five to nine year olds and the early adolescents, 10 to 14 year olds.

Figure 1: Deaths by age group, as percentage of total, UK, 2012[1]

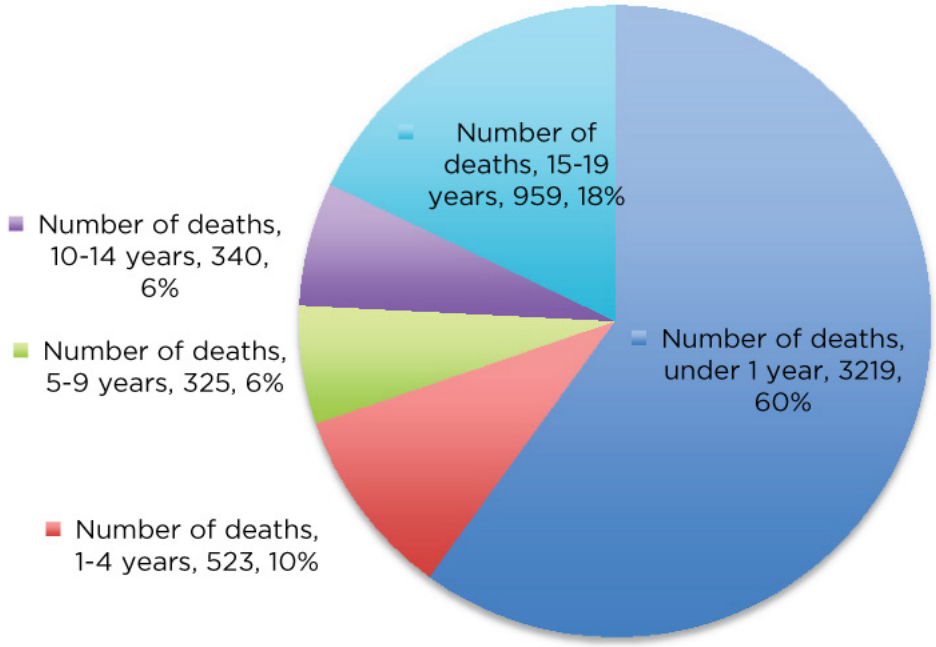


Table 1: Infant and childhood mortality rates by age and sex, UK, 2012

Age, years	Male	Female	Total	Numbers of deaths
Infant deaths per 1,000 live births[A]				
	4.4	3.5	4.0	3,219
Deaths per 100,000 population in age group[B,C]				
1-4	18	15	16	523
5-9	9	8	9	325
10-14	11	8	10	340
15-19	33	15	24	959

Source: Office for National Statistics

A Childhood mortality statistics, Table 2, 2012
B Death registrations by single year of age, Tables 1 and 2, and
C Mid-year population estimates, 2012

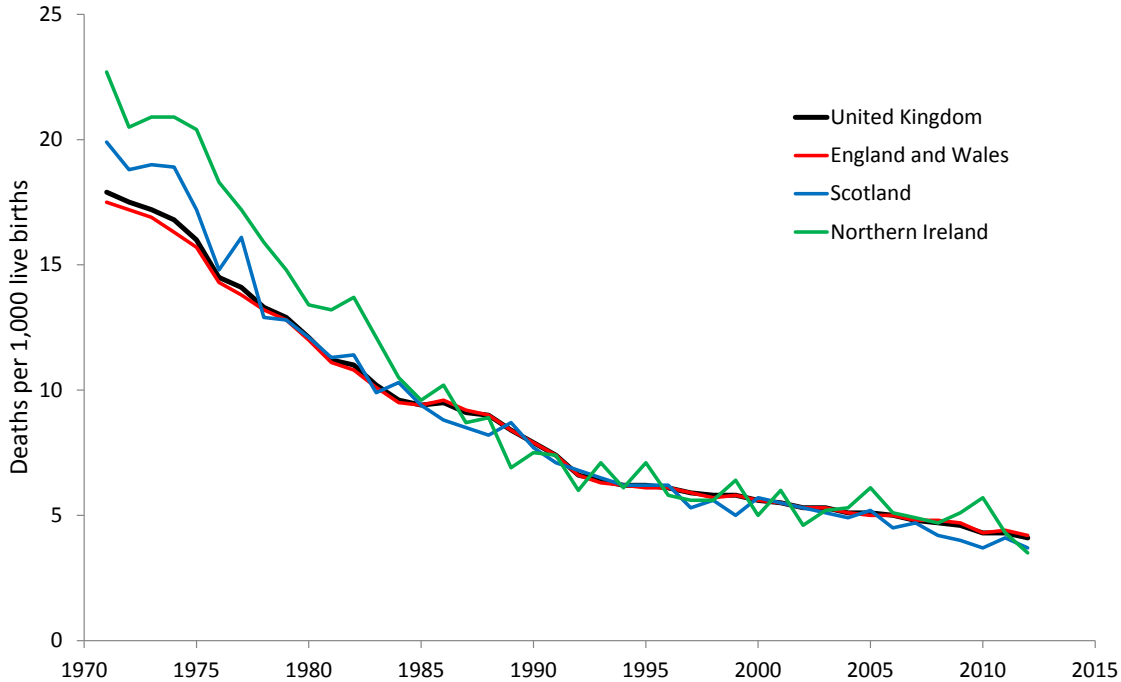
The highest death rates are in infancy and adolescence and the main causes of death vary by age group too, so to understand better and to think about how to prevent deaths from happening, it is important to look in more detail at narrower age groups. Furthermore, specific causes merit special consideration. For example, injuries, many of which are highly amenable to prevention, cause a substantial proportion of deaths. This tells us we could do better. What proportion of deaths may be amenable to healthcare is another important question and one which has caught

the imagination of the public, professionals, and policy makers. Unfortunately there is no simple answer. Finally, there are wider aspects of society and determinants of health and wellbeing, such as poverty and social inequalities, which have an important bearing on the likelihood that children will survive and flourish.

Deaths in the first year of life

Infant mortality (deaths of babies in their first year expressed as a rate per 1,000 live births) has long been considered as an indicator of the overall health status of a population. Infant deaths are also a reflection of the quality of midwifery, obstetric, and newborn care. Maternal health and the development of the fetus and baby are strongly influenced by the social, economic, and environmental circumstances that surround them. These factors can also affect their chances of death.

Figure 2: Infant mortality rates, UK, 1971-2012[1]



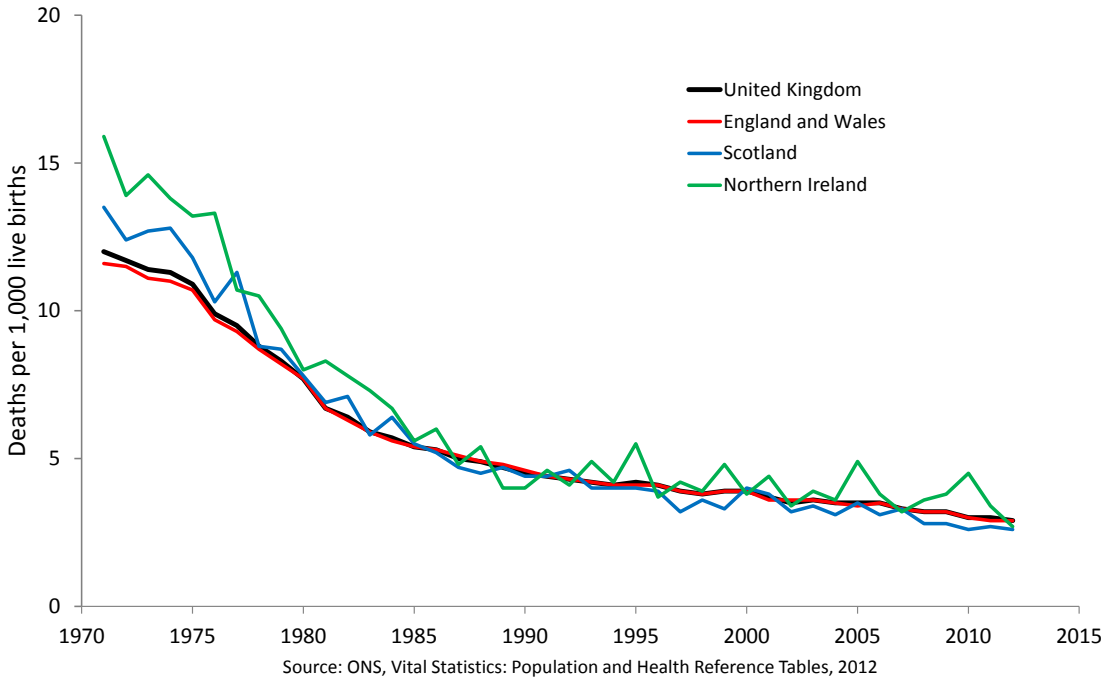
Source: ONS, Vital Statistics: Population and Health Reference Tables, 2012

Infant mortality rates for England and Wales and for the UK as a whole have been declining steadily for many years, with occasional exceptions. Because rates for Scotland and Northern Ireland are based on smaller numbers of births and deaths, they fluctuate from year to year, although rates for Scotland tend to be below those for England and Wales and those for Northern Ireland tend to be higher (Figure 2).

Infant mortality can be divided into neonatal mortality, deaths up to 27 days after live births, and post-neonatal mortality, deaths from 28 days but under one year. As in most high-income countries, the majority of infant deaths occur in the neonatal period and in the countries of the UK they account for around 70% of infant deaths, except in Northern Ireland where they account for nearly 80%. Just over three-quarters of neonatal deaths occur in the early neonatal period,

although the proportion is higher, over four-fifths, in Northern Ireland. Not surprisingly, neonatal mortality rates show the same downward trends as infant mortality, although the higher rates in Northern Ireland and the lower rates in Scotland are more marked (Figure 3).

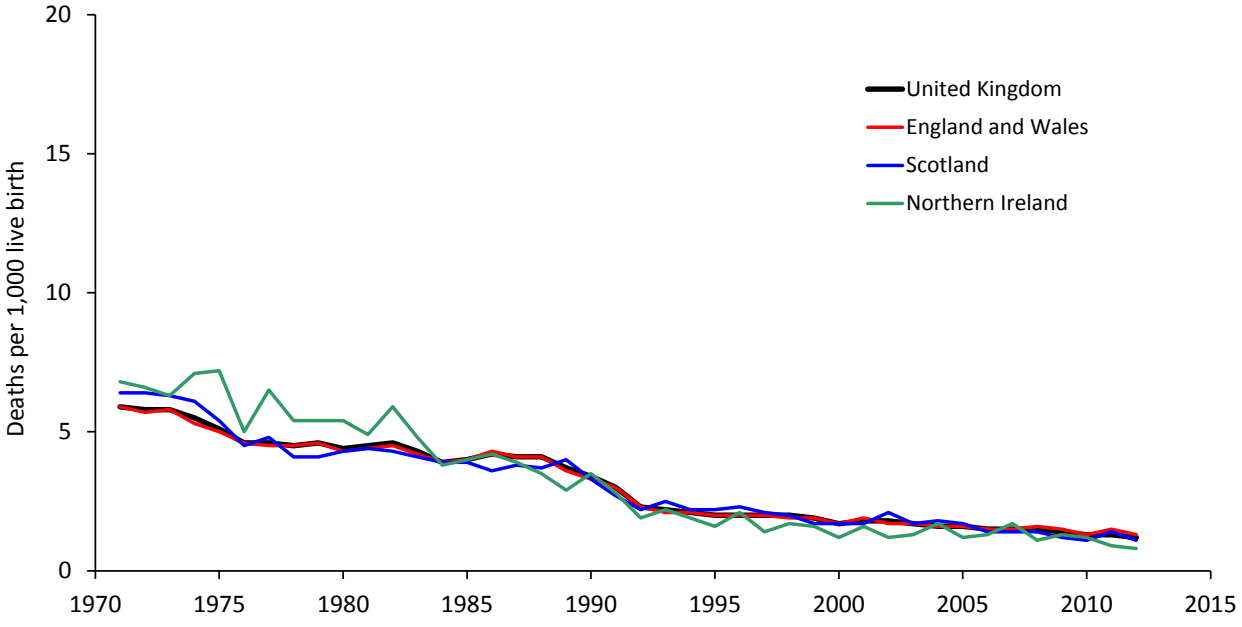
Figure 3: Neonatal mortality rates, United Kingdom and constituent countries, 1971-2012[1]



Source: ONS, Vital Statistics: Population and Health Reference Tables, 2012

Postneonatal deaths form a much smaller proportion of infant deaths, and trends in postneonatal mortality are much less marked, although there is a consistent downward trend as shown in Figure 4. There was a notable fall in the late 1980s and early 1990s when the rate of deaths from sudden infant death syndrome fell markedly.

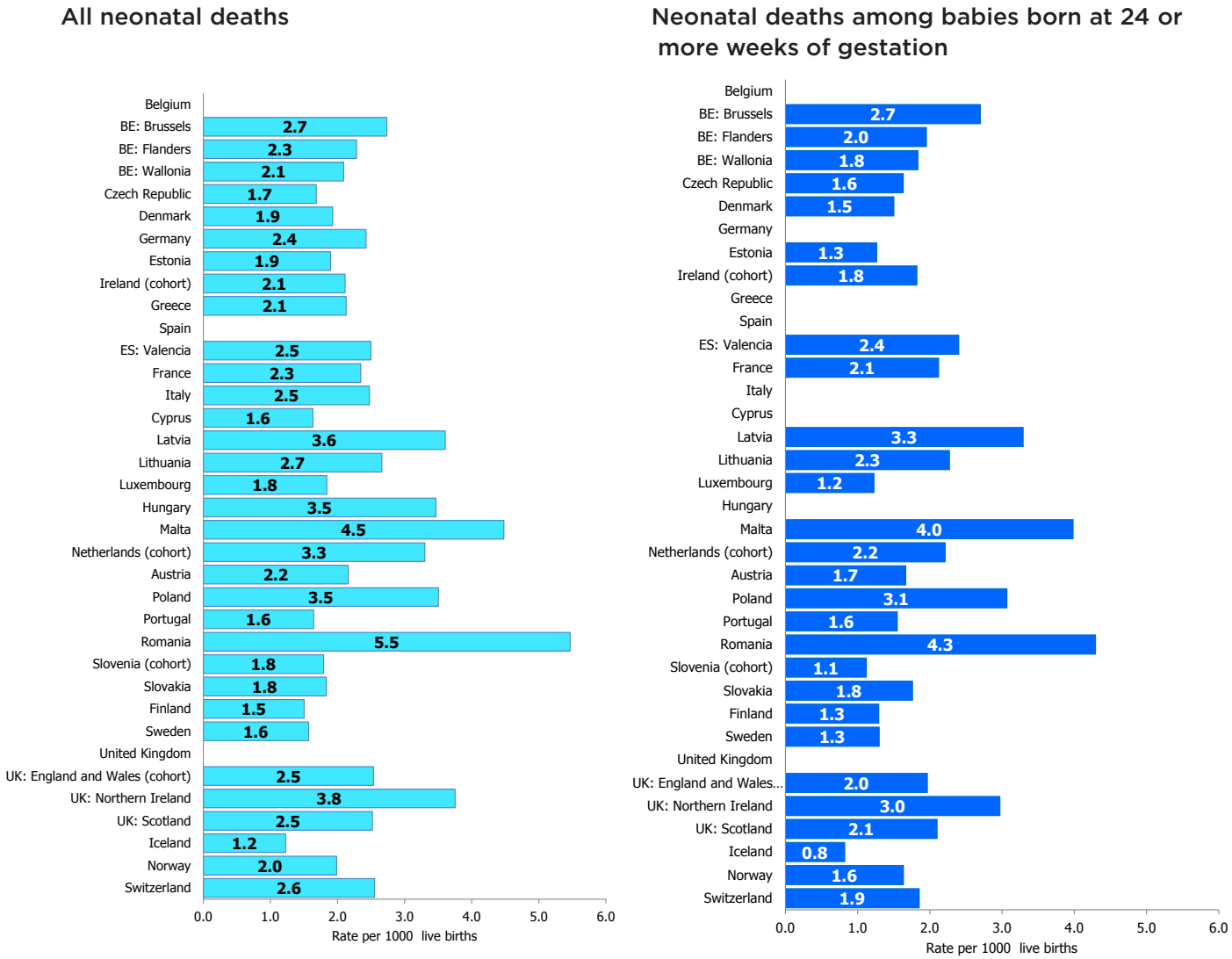
Figure 4: Postneonatal mortality rates, United Kingdom and constituent countries, 1971-2012[1]



Source: ONS, Vital Statistics: Population and Health Reference Tables, 2012

International comparisons of infant mortality, including neonatal mortality, are difficult and subject to caveats. The Euro-Peristat collaboration was formed to bring together clinicians and statisticians from each participating country to harmonise definitions and derive data from their countries in line with these definitions. In describing infant mortality, this report shows data from the second European Perinatal Health Report which brings together data for the year 2010 about the demographics and health of the childbearing populations, the care provided and the outcomes for mothers and babies[8].

Figure 5: Neonatal mortality in Europe, 2010[8]



Source: Euro-Peristat[8]

Figure 5 shows comparative neonatal mortality among all babies and those born at 24 weeks or more of gestation. This shows that the rates for babies born at 24 or more weeks ranged from 0.8 per 1,000 live births (in Iceland) to 4.3 per 1,000 live births (in Romania). There are no composite UK data, because constituent countries collect data in different ways, but the rate was 2.0 per 1,000 live births in England and Wales, 2.1 in Scotland, and 3.0 in Northern Ireland. The rates for many countries are based on relatively small numbers of deaths as in Scotland and Northern Ireland. The Nordic countries, Sweden, Finland and Iceland, are among those with the lowest neonatal mortality rates.

High proportions of neonatal and infant deaths are of babies who were born preterm, that is, before 37 completed weeks of gestation. These accounted for nearly two-thirds of infant deaths

of babies born in 2011 in England and Wales. Similarly, babies born weighing under 2,500 grams (defined as low birthweight) accounted for about three-quarters of neonatal deaths and two thirds of infant deaths.

Preterm births are those occurring before 37 completed weeks of gestation, and rates reported to Euro-Peristat ranged from around 5.7% to 10.5%. There is not a clear geographic distribution for preterm births, as there is for low birthweight. In the UK, preterm birth rates were 7.1% in England and Wales, 7.0% in Scotland, and 7.2% in Northern Ireland. These were higher than in the Nordic countries and lower than in Germany, Spain, and Belgium[8].

The percentage of babies born weighing less than 2,500 grams ranged from 3.4% to 9.8% in countries participating in Euro-Peristat. The countries with the lowest rates of babies born at low birthweight include Sweden, Norway, Denmark, Iceland, Finland, Ireland, Latvia, Lithuania, and Estonia. Rates for southern European countries tend to be among the higher rates, while the UK countries are in the middle range: 7.0% of babies born in England and Wales 6.5% in Scotland, and 5.7% in Northern Ireland had low birthweights[8].

Low birthweight, preterm birth, and neonatal and infant mortality are associated, so it is not surprising that the UK has higher rates of all these measures than the Nordic countries, but lower than many other European countries. However the associations between these risks and outcomes are not completely straightforward, since, for example, Northern Ireland has lower low birthweight percentages, but higher neonatal and infant mortality. That said, the rates fluctuate considerably year on year as the numbers are small.

Rates of low birthweight and preterm birth for a country's population can vary according to demographic factors such as maternal age distribution and multiple birth rate. In the UK, over 5% of mothers were aged under 20 years, and just under 20% were aged 35 years and over, which are the age ranges with the highest risk of infant mortality. In Sweden, only 1.6% of mothers were under 20 years of age but just over 22% were over 35 years[8]. Rates of multiple births in the UK countries were just over 15 per 1,000 women delivering, which is middle-range among European countries.

Babies born to women who smoke are at a raised risk of low birthweight. It is difficult to compare rates of smoking in pregnancy because countries collect data in different ways. It does appear that the UK has some of the highest rates with 26% of women smoking before or during pregnancy and 12% during pregnancy, compared, for example, with Sweden where 6.5% of women smoke at the beginning of pregnancy and 4.9% by the time the baby is due[8]. However, within the UK smoking in pregnancy is more common among women in more disadvantaged socio-economic groups, who also have a higher risk of low birthweight babies and other adverse outcomes.

Finally, two further specific problems concerning the early stages of life merit special consideration here; stillbirths and unexplained deaths in infancy. The UK appears to have the highest stillbirth rate of 12 high-income countries; the UK rate is 3.8 stillbirths per 1,000 births, contrasted with 2.2 per 1,000 in Norway[9]. Euro-Peristat has also reliably shown that the UK had among the higher stillbirth rates in Europe, because they compared rates of still births after 28 weeks gestation[8]. As is the case with infant deaths, variations in coding and death registration practices may account for some of the differences between countries, however these data show that further reductions in stillbirths should be possible. Exploring differences between countries helps point towards

possible actions that could be taken at practice or policy level. Important modifiable factors contributing to risk of stillbirth include smoking in pregnancy, and overweight or obesity and social inequalities[9]. Unexplained deaths in infancy are another important problem that require urgent attention. In 2010, there were 254 unexplained infant deaths in England and Wales[1]. 80% of unexplained deaths happen in the post-neonatal period, they are more likely among socially disadvantaged families, among those who smoke, and mothers who are very young[10].

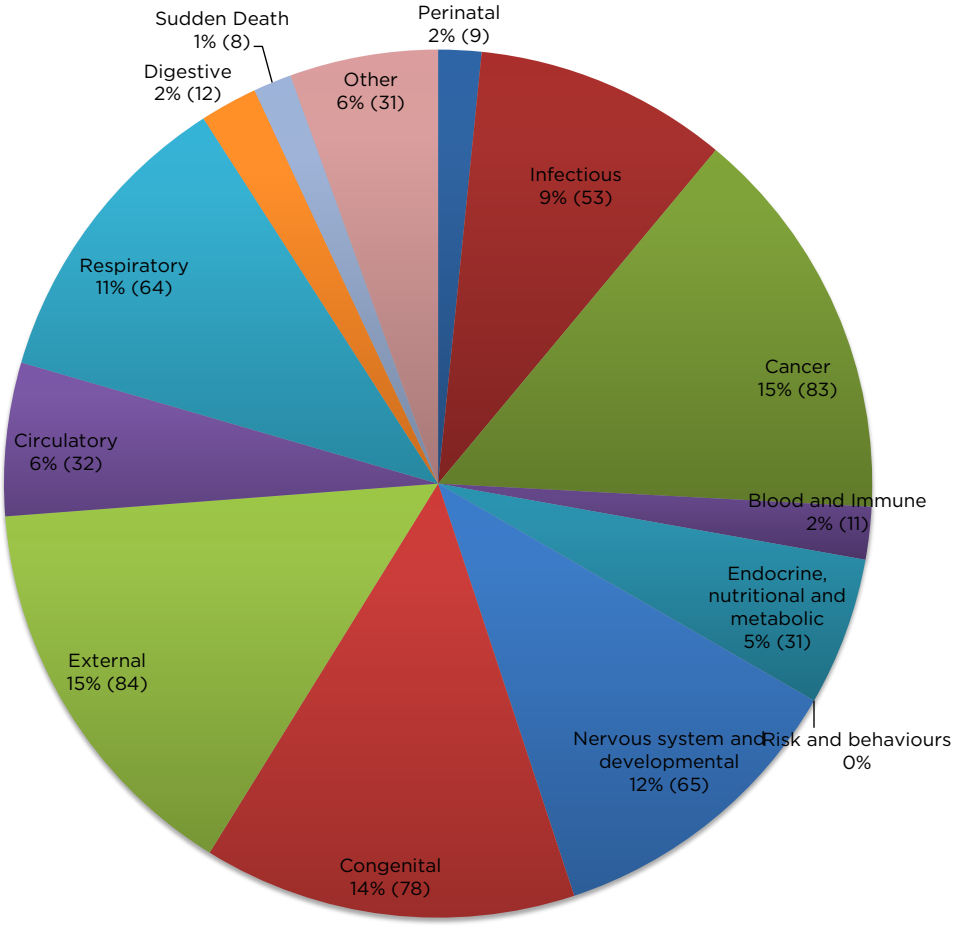
Infant mortality has a particular social relevance, as it is widely used as a marker of the overall health status of a population. As such, the UK has cause for concern. In 1970, the infant mortality rate in the UK was similar to the median rate for comparable countries (EU15+ countries, including European Union member countries before 2004, plus Australia, Canada, and Norway). However, trend data over three decades shows that UK infant mortality is now above the 75th centile among EU15+ countries[5].

The causes, associations, and risk factors for infant mortality outlined briefly in this section highlight that social disadvantage is important, this and many other problems contributing to deaths in early life, are amenable to interventions in practice and policy.

Deaths in childhood

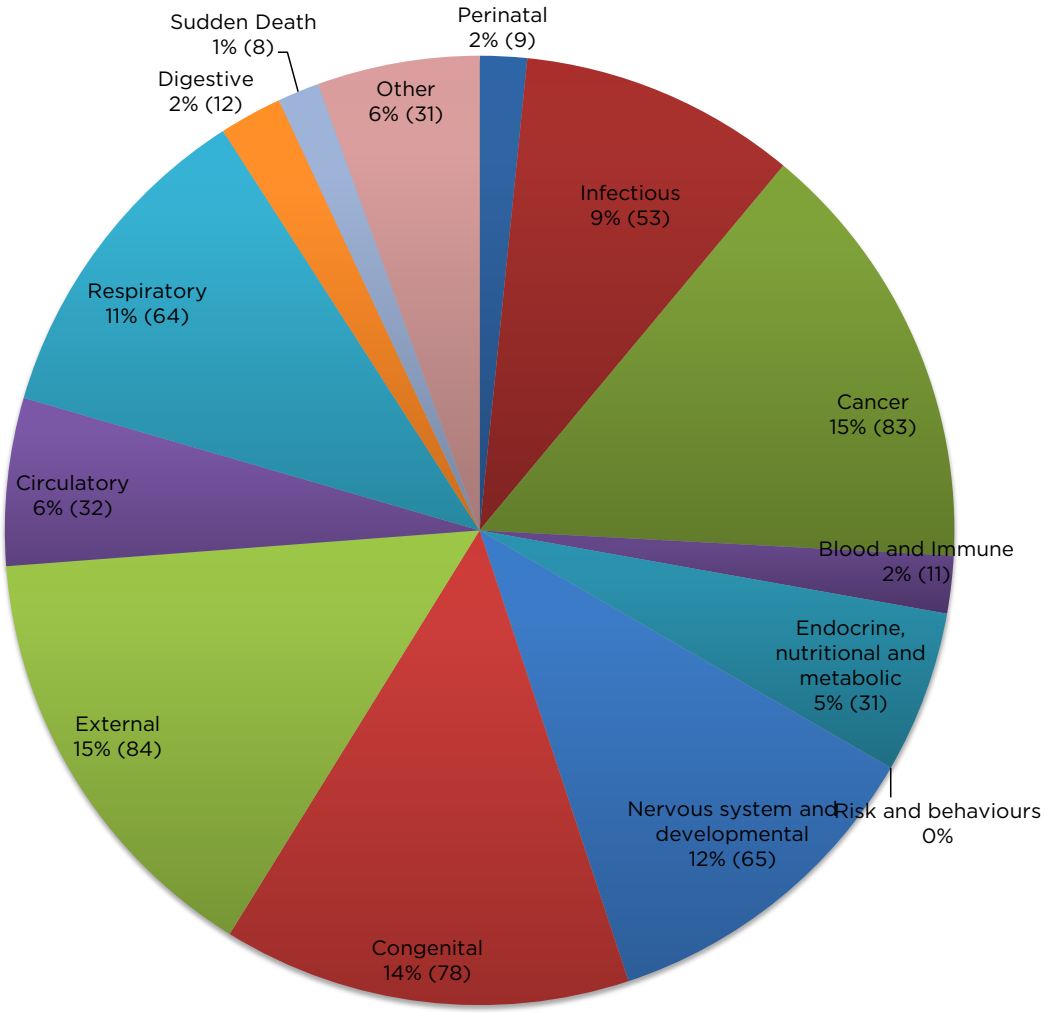
From one to four years old, the three most common causes of death are injuries and poisoning (external causes), cancer, and congenital causes (Figure 6). There is evidence that preterm birth impacts not only on infant mortality but has appreciable effects on mortality during later childhood[11].

Figure 6: Deaths by cause, percentage of total, and numbers, among 1-4 year olds in the UK, 2010[12]



In later childhood, from five to nine years old, the most common causes of death in the UK are injuries and poisoning, cancer, and congenital causes (Figure 7). The proportion of children who died with a chronic condition (or more than one) increased significantly in England in the decade to 2010, however intriguingly no such increase was found in Scotland or Wales[11].

Figure 7: Deaths by cause, percentage of total, and numbers, among 5-9 year olds in the UK, 2010[12]



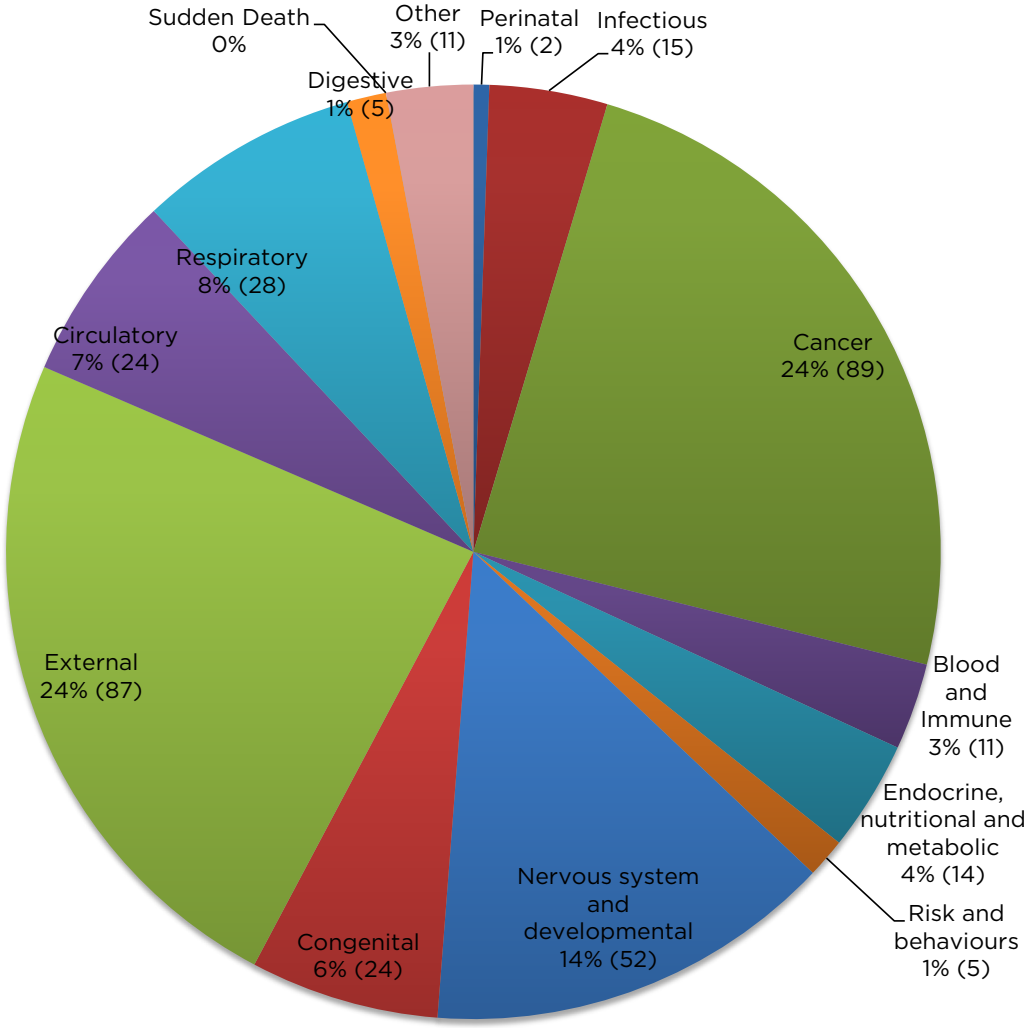
Survival rates from cancer in childhood vary, and there are many different types of cancer. However, there is some evidence that survival from cancer may be a little (but significantly) lower than in Northern European countries, and possibly that some tumours are at a later stage by the time children are diagnosed[13].

Deaths in adolescence

After infancy, late adolescence is the second riskiest time for death under the age of 19 years. Whilst we have made huge advances in reducing mortality among infants and young children in the past 40 years, death rates amongst adolescents have fallen little across the same period. As a result mortality amongst 15 to 19 year olds is still higher than any time in early childhood after the first 12 months.

From 10 to 19 years, the most common causes of death in the UK are injuries and poisoning and cancer (neoplasms). In early adolescence, from 10 to 14 years, these two categories contribute around half of all deaths, as shown in Figure 8. The proportion of young adolescents (age 10 to 14 years) in England who died with one or more chronic condition increased significantly between 2000 and 2010[11].

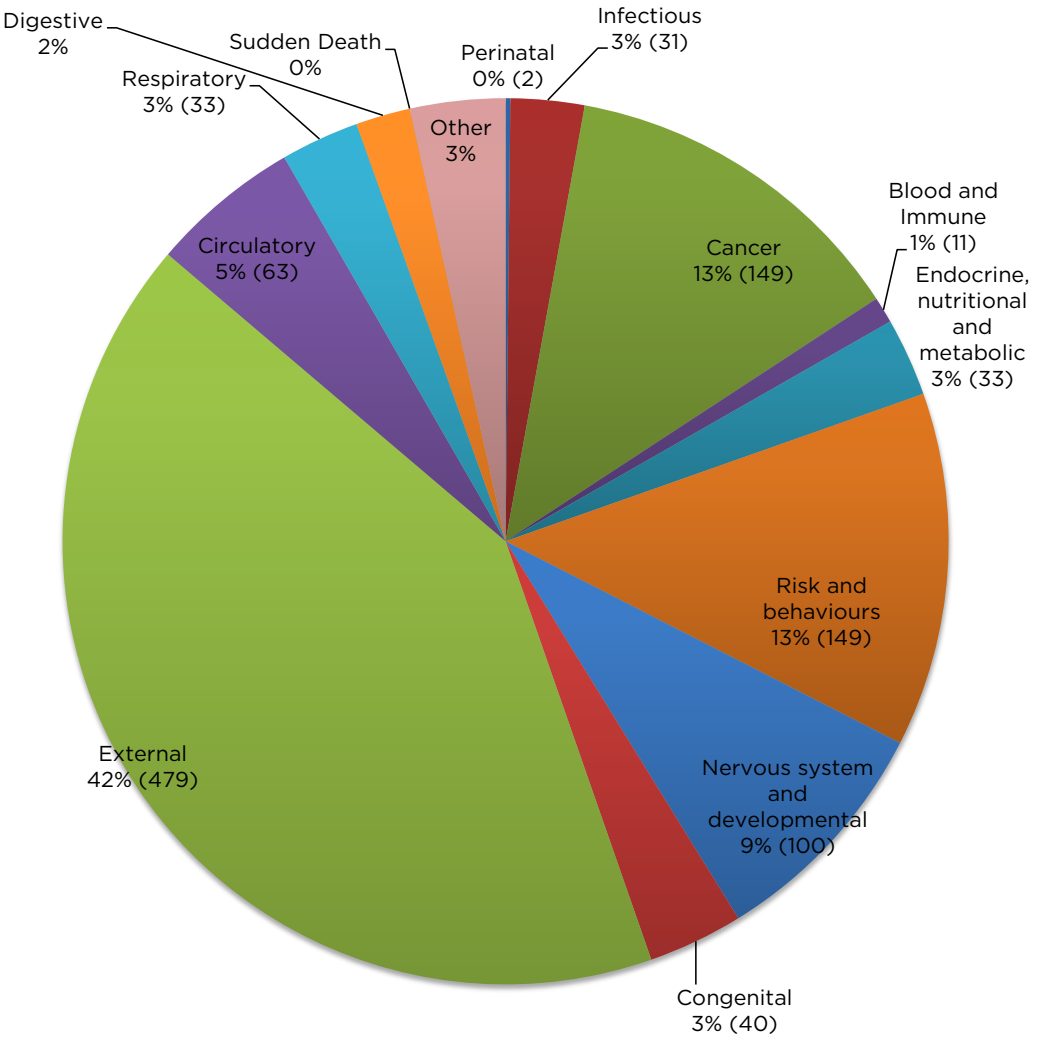
Figure 8: Deaths by cause, percentage of total, and numbers, among 10-14 year olds in the UK, 2010[12]



In later adolescence, from 15 to 19 years, the causes of mortality are largely split between injuries and poisoning (and risks and behaviours), and non-communicable diseases (NCDs); the most common cause within NCDs is cancer.

As shown in Figure 9, over half of deaths in this age group can be attributed to external causes, including injuries and poisoning, risks and behaviours, with major causes being transport injuries; intentional injuries, including suicide and violent deaths; and other non-intentional injuries, such as drowning or fires. Injuries are a common cause of death among adolescents who have chronic conditions including mental and behavioural disorders, accounting for approximately a third (33.2%) of deaths among 15 to 18 year olds in England who had a long-term condition, 39.7% in Scotland, and 43.8% in Wales[11].

Figure 9: Deaths by cause, percentage of total, and numbers, among 15-19 year olds in the UK, 2010[12]



Adolescence is a time of increasing freedom and personal autonomy, and exploratory behaviours, often involving risk, are part of normal development. However, injuries are non-random preventable events, amenable to public health and public policy initiatives. This is true for suicide and violent deaths as well as other injuries. Unfortunately there is evidence from a national case audit of children's deaths suggesting that many children who died from suicide had not had any contact with mental health services, and there were reportedly problems with services failing to follow up patients who had been referred but not turned up for appointments[14].

Deaths from injuries and poisoning

Injuries and poisoning are important causes of death in childhood and adolescence. Indeed, injury is the most frequent cause of death after the first year of life, responsible for 31% to 48% of deaths among children and young people[11]. The major causes differ by age group, and between boys and girls. Adolescent boys have the highest risk; they have three times the mortality rate from injuries compared with girls of similar ages[11]. Scotland, Wales, and Northern Ireland have notably higher rates of injury mortality among young people[11].

The most common causes of injury-related deaths are transport accidents, drowning, and intentional injuries, including self-harm and assault. Unintentional injury deaths are most often related to transport, responsible for 41% of injury deaths among 1 to 9 year olds, and 77% among

10 to 18 year olds[11]. Reductions in unintentional injuries account for most of the declines in injury related mortality rates over the past several years.

It is of great concern that there has been no reduction in rates of deaths from intentional injury among 10 to 18 year olds in three decades[11]. Indeed intentional injury deaths represent a substantial proportion of all injury deaths. In the four years to 2010, just over 34% of injury deaths among boys were intentional as were nearly 38% among girls[11]. Injury resulting in death among adolescents often occur when there is coexisting chronic conditions, for example injuries accounted for nearly 70% of deaths among 15 to 18 year olds with mental or behavioural problems[11].

Many deaths from injuries (both unintentional and intentional) and poisoning are preventable, for example through transport planning, social and public health policy. While the UK scores above average compared with the rest of Europe in the Child Safety Alliance grading system which assesses implementation of child safety policies (although not intentional injury prevention); injuries and poisoning are still preventable causes of death, with poor children more affected than rich ones, highlighting that more should be done[15].

Sweden and the Netherlands are the only two European nations which perform more strongly than the UK on the Child Safety Alliance score. Sweden is noteworthy for its road safety Vision Zero Initiative which aims to achieve zero road traffic deaths and serious injuries, chiefly through changes in system design[16]. Vision Zero is now secured in Swedish legislation. Other measures, such as reducing and enforcing speed limits for traffic, improving the skills of novice drivers, safe pedestrian crossings, and barriers around water such as garden ponds can save lives[17,18,19].

Sadly, despite the preventability of deaths from injuries and poisoning, these causes still account for between 31 to 48% of lives lost between one and 18 years old, and no real progress has been made in reducing deaths from intentional injury[11].

Healthcare amenable deaths

How important is healthcare to population child health? For an individual child, health services are clearly important, sometimes life saving. But many important things that contribute to child health, both at an individual and a population level, are part of the wider health system and society. Before the middle of the 20th century, healthcare probably contributed relatively little to improvements in health when compared with changes in living conditions brought about by increasing wealth and security that accompanied industrialisation and universal education[20,21]. However, since that time, paediatric medicine has developed into a sophisticated specialty, and our abilities to intervene successfully have improved dramatically. Furthermore, as overall health has improved, the marginal contribution made by healthcare to health will have increased.

Healthcare amenable mortality as a concept and as a measure, has contributed to the technical capacity for evaluating health services and for understanding how much healthcare contributes to population health through mortality reduction. Estimates of the scale of health gain attributable to healthcare range from 20% to 40%, but these are largely about the adult population[22]. This means of inquiry is of limited value to children's health because the number of deaths is small, making interpretation difficult or impossible. Still, healthcare amenable mortality is a helpful concept, and there are two possible ways it might be useful for child health. The first is through individual case audit, and the second is through combining causes into categories and/or

examining trends or several years' data combined as an average. Both methods are subject to considerable uncertainty, and should be used merely as indicators pointing the direction towards further inquiry.

The first method has been done to notable effect by the Confidential Enquiry into Maternal and Child Health in England, which conducted a meticulous audit into the deaths of a representative sample of children. They reported identifiable failures in a child's direct care in just over a quarter of deaths, and potentially avoidable factors in a further 43% of deaths[14]. An audit of asthma deaths is due to report soon. From an epidemiological perspective, this type of evidence does not demonstrate causality. However, from a clinical perspective it provides useful information, pointing out where to investigate further in our attempts to improve care. From a parental perspective, it is alarming and demands attention and indeed in the past decade, and especially since the Bristol Royal Infirmary Enquiry in 2001, there has been a welcome degree of scrutiny into the quality of care for children[23]. There is now a systematic multiagency process for gathering data after every childhood death, known as a Child Death Review (CDR), which attempts comprehensively to gather information on potentially avoidable factors in order to make recommendations on changes in practice.

The Department for Education (DfE) collects reports from CDRs, and publishes a yearly report on childhood mortality with an estimate of the percentage of deaths with identified modifiable factors. For example, in the year ending 31 March 2013 there were 3,857 reviews completed, and 21% of those deaths were judged as having modifiable factors[7]. Modifiable deaths are where there were factors which may have contributed to death, and which through nationally or locally achievable interventions may be modified to reduce the risk of future deaths. The most recent DfE report found that the highest proportion of deaths with modifiable factors were among children aged between one month and one year old, and between 15 and 17 years old; nearly 30% of deaths in these age groups were thought to have modifiable features[7].

Examining mortality by cause, and combining data from several years, may allow some comparison between countries as long as data collection is standardised to enable valid comparison. Focusing on deaths from illnesses that ought not to kill children in highly developed European health systems may reveal useful insights, though with the caveats outlined. For example, mortality rates from asthma, meningococcal disease, and pneumonia seem to be highly variable between countries[24]. It is possible that some or all of these differences may be explainable because data is captured in different ways between countries, or the process of death certification varies between countries. For example, in some countries death may be said to be from pneumonia but the underlying cause was a neurodevelopmental problem from which death was inevitable and pneumonia was the final event. Indeed a large proportion of deaths do occur in children with chronic and sometimes life-limiting conditions[11]. Although these data about healthcare amenable causes of death need further enquiry, there are some worrying consistencies in the findings with the UK seeming to have generally higher rates than many other European countries, suggesting at least that there may be scope for improvement in the UK.

Although much of the literature on assessing the contribution of healthcare to health focuses on mortality, data on deaths alone give an incomplete impression, especially for children. First and fortunately because the numbers are small, so variability can be large and interpretation must be made with caution. Second there are many other valuable aspects to healthcare for children beyond saving life, such as healing, relieving suffering, and improving the quality of life. These essential parts of healthcare are often more difficult to measure as morbidity data is scarce and often unreliable, and quality of care is difficult to quantify and compare reliably.

Social determinants of health

The social determinants approach involves improving the conditions that we experience through birth, life, education, and work that influence negatively on health and wider outcomes[6,25]. From before birth, a range of socio-economic circumstances can impact on the way in which we develop, and our future health, happiness and economic prosperity. Having a good start in life, maximising parental abilities through education and life-long learning, good work, adequate incomes and good quality environments, will all have an impact on outcomes for parents and their children in addition to the efforts of health promotion and access to healthcare.

Three important social determinants are poverty, inequality, and social policies that affect the ways we live, such as housing, parental leave allowance, and early years education. Absolute levels of poverty matter to child survival, but how fairly wealth is shared across the population is also important. How well our society protects children and young people through social policy also helps determine their chances of survival and affects how well they are able to fulfil their potential.

As has been shown elsewhere, there are substantial differences between the UK and some other European child mortality rates[2]. This is partly explained by the higher infant mortality rates in the UK, a high percentage of which is driven by the fact that nearly two thirds of the children who die before their first birthday were born preterm, and/or with low birthweight. UK rates of low birthweight and preterm births are higher than some other European countries including the Nordic countries, though lower than some Eastern European countries.

Rates of low birthweight are higher in less advantaged socio-economic groups[26], and are particularly linked to a number of negative health behaviours such as poor prenatal care, substance abuse, poor nutrition during pregnancy and smoking which are more common in these groups[27]. For example, prenatal smoking rates are higher in less advantaged socio-economic groups and smoking in pregnancy, for example, is associated with a 20 to 30% higher likelihood of stillbirth, a 40% higher rate of infant mortality and a 200% higher incidence of Sudden Infant Death Syndrome (SIDS)[28,29]. In addition there is a relation between teenage pregnancy and low birthweight, where there is competition for nutrients between the fetus and the growth needs of the mother[30]. Inadequate nutrition can also drive low birthweights, and we know that there are increasing numbers of families being referred in the UK to foodbanks which is an urgent and growing concern. We also know that breastfeeding is less common in less advantaged socio-economic groups and that it can protect against infection, and also save lives from SIDS[31].

Traditionally, social inequalities in infant mortality and low birthweight have been analysed according to the father's social class but this has now been changed. Babies born within marriage or a civil partnership and others who have been jointly registered by both parents are analysed according to the social class of the most advantaged parent, and babies registered by their mothers alone are analysed by their own social class. Infant mortality, subdivided into neonatal and postneonatal mortality is presented in this way in Figure 10. Wide differences in infant mortality and in low birthweight (shown in Figure 11) can be seen between babies born into managerial and professional families, those with parents who are self-employed or in semi-routine occupations and those in routine occupations. Although postneonatal mortality makes for only a small proportion of deaths in more advantaged households, it makes up a higher proportion of deaths in the least advantaged households.

Figure 10: Infant mortality rates by social class of most advantaged parent, babies born in England and Wales in 2011[32]

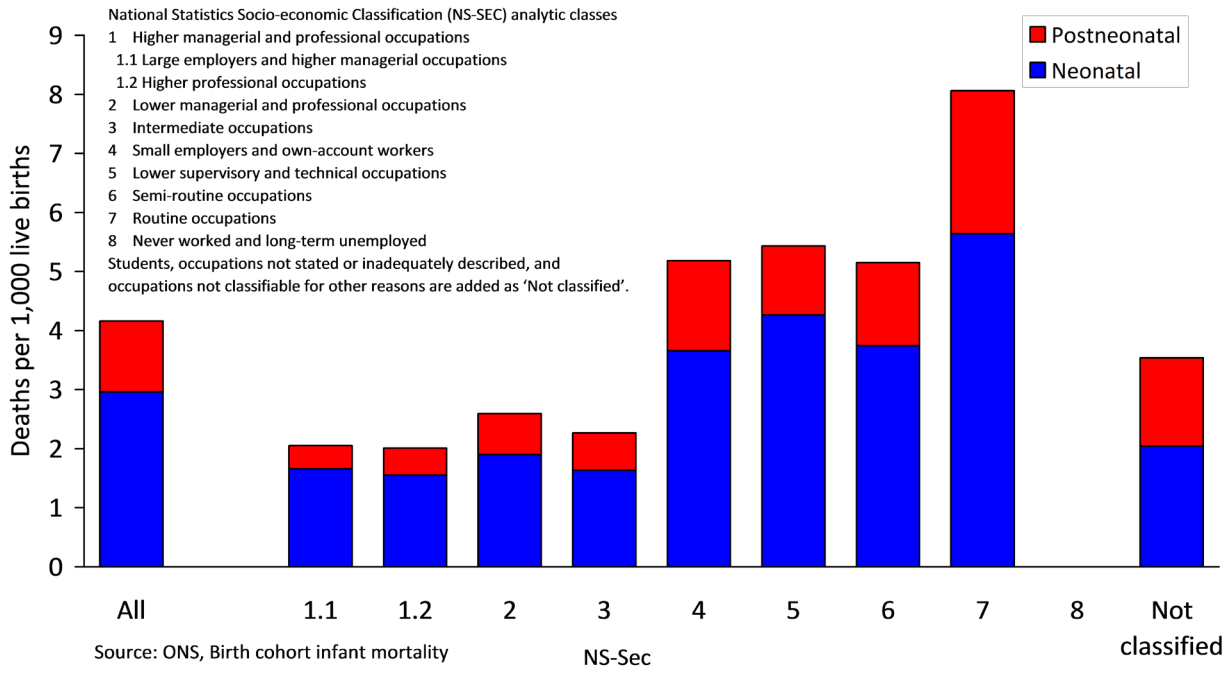
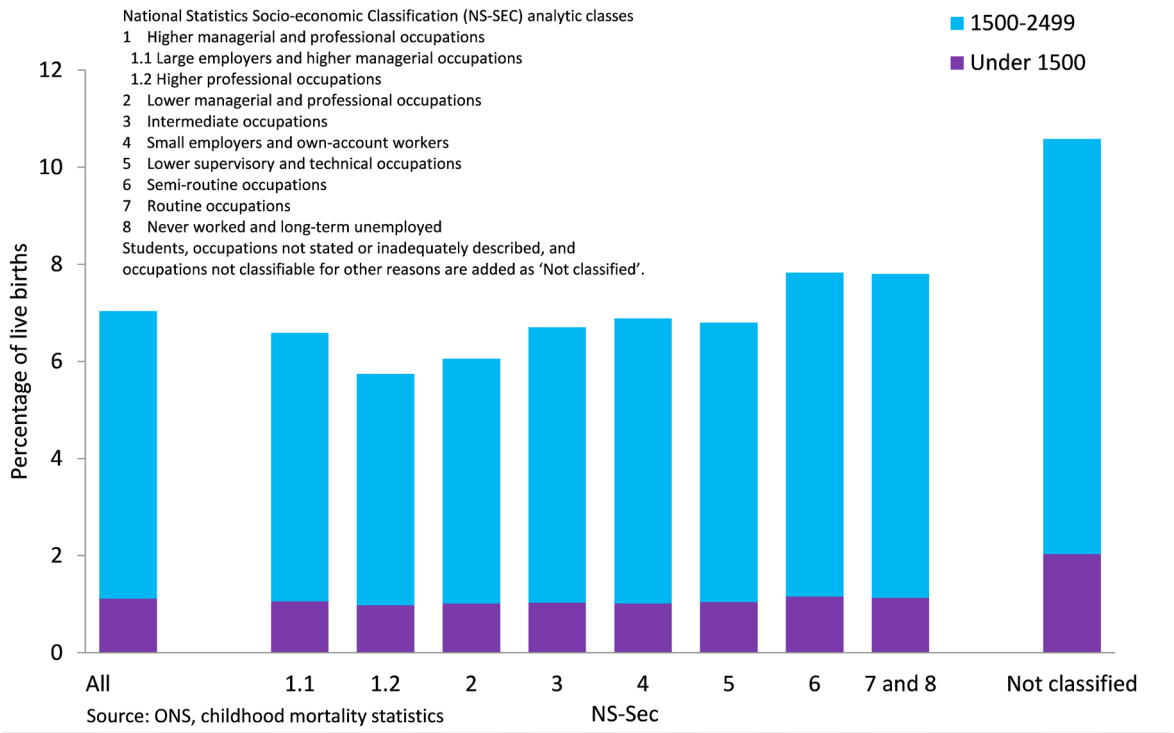


Figure 11: Low birthweight rates by social class of most advantaged parent, babies born in England and Wales in 2012[32]



These data (Figures 10 and 11) show that babies from poorer families are more likely to be born with low birthweight, and are more likely to die than children from richer families. This relation can be shown at country level too; the wealthier the country, the lower the child mortality rate[2]. The effect of country-level wealth on life chances is highly complex, but the important facts here are that economic policy matters to the lives of children.

The UK has among the highest rates of child poverty in wealthy countries[33]. It is crucial to note that the impact of poverty can be alleviated through supportive social policy, which means things to assist families to ensure they are not deprived of basic necessities in life such as secure housing and nutritious food. Countries make choices about social policy and these decisions are reflected in what happens to children and young people.

Table 2 below shows that Sweden has a lower percentage of the population who are at risk of poverty or social exclusion, but importantly that the UK disproportionately disadvantages children and young people because the risk is not equitably spread across the age groups[34].

Table 2: Percentage at risk of poverty or social exclusion, in 2011[35]

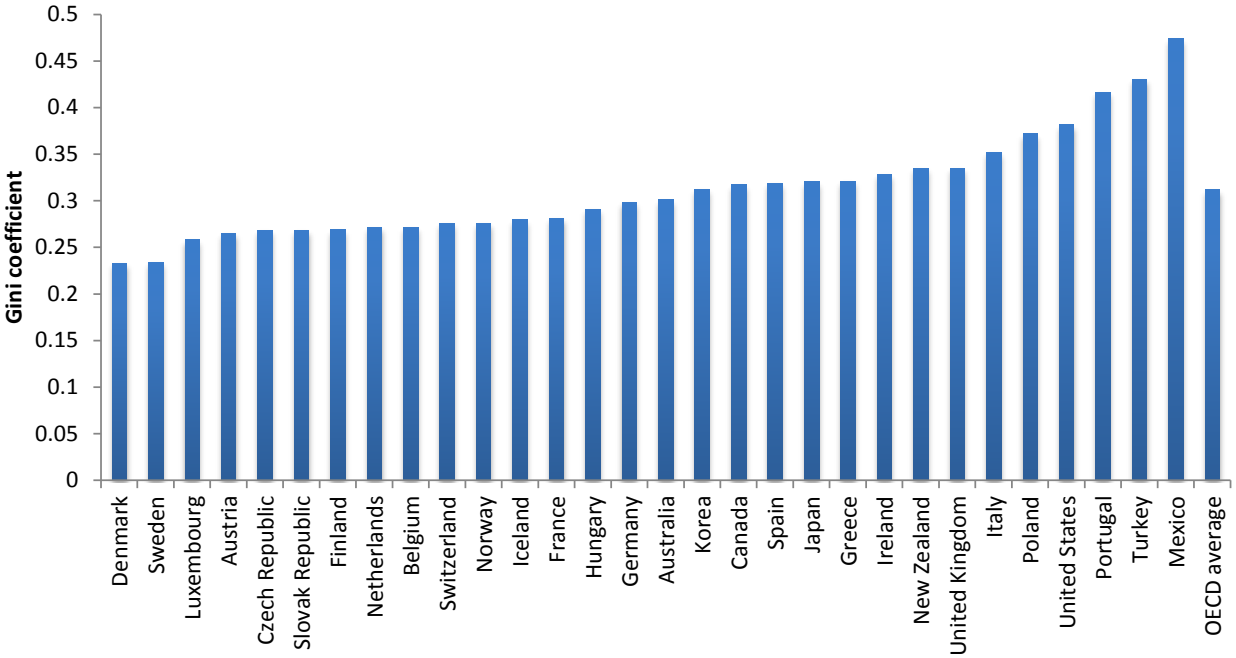
Country	Total (%)	Children age 0–17 years (%)	Adults age 18–64 years (%)	Age 65 and over (%)
Sweden	16.1	15.9	15.4	18.6
United Kingdom	22.7	26.9	21.4	22.7

Comparing how children fare in different countries shows that Britain's children unfortunately are amongst the more deprived in Western Europe[33]. This is reflected in mortality rates; there is a higher mortality rate among children under five years old who live in countries with a high proportion of deprived households[36]. As before, the lowest mortality rates are in the Nordic countries, with the lowest proportions of deprived households, and the highest mortality rates are in Eastern Europe, with the UK in the group of intermediate countries.

How fairly wealth is shared between people within a country is important for child survival too. Inequality matters to health. Children are more likely to die in countries where the rich are very much richer than the poor. This is true of adolescents as well[37].

The UK is above the OECD average for inequalities, as measured by the Gini coefficient and shown in Figure 12; that is we have a more unequal society than most.

Figure 12: Income inequality in the mid-2000s[38]



Social and economic policy matter to children's chances of survival. For example, the harsh effects of the unforgiving economic climate during the ongoing financial crisis gripping the UK could be softened through social policy. Countries that spend more on social protection have lower child mortality rates[2]. Social policy can save lives.

Key points

- Annually, around 6,000 children between 0 and 19 years die in the UK.
- Around two-thirds of those deaths happen in the first year of life.
- One in five deaths happen between the ages of 15 and 19 years.
- The most frequent causes of death in babies and young children are different from those in adolescents.
- Injuries are the most frequent cause of death after the first year of life, and many of these are highly preventable.
- The quality and safety of aspects of children's healthcare requires further scrutiny and improvement.
- Social and economic inequalities are matters of life and death for children.

Understanding why children die, and how to prevent deaths

Understanding why children die, and taking action to prevent deaths in childhood is our purpose. Since children's lives, their health, illnesses and chances of death are influenced by a wide variety of factors, where should we direct our attention? Avoidable mortality in the adult population has been defined as premature and unnecessary deaths but since all childhood deaths are premature by definition, are they all avoidable[39]? What is an unnecessary child death? What proportion of child deaths are – or could ever be – acceptable?

Taking the first question: where should we direct our attention? Setting aside biological factors that operate for all children regardless of which country they live in, there are three broad domains to consider: the role of government and civil society; health systems and organisations; healthcare and public health services.

And the second question, on avoidability, what we are really talking about is what goal should we set ourselves? How many deaths could be prevented? It is doubtful that this could ever be answered precisely, but we can begin to think about the notion of avoidability by comparing ourselves with other countries. The UK has the highest all-cause mortality rates among comparable European countries, but importantly this was not always the case[2]. The UK has failed to match mortality reductions made by other comparable countries over the past four decades[5]. Problems are particularly notable among infant deaths and deaths in childhood and adolescence from non-communicable diseases (NCDs) and conditions including neuropsychiatric causes[5]. The rise in prevalence of NCDs is part of the epidemiological transition affecting all age groups including the young. Tackling these problems has become an pressing issue in the UK as it has across the globe, and will require action at all levels of the health system and beyond. The finding that the UK has failed to match survival gains made by other countries in NCD mortality rates is of urgent concern.

In considering how to improve UK child health, we could start with the question; if Sweden and the Nordic countries can achieve a particular child mortality rate, why can't we?

These comparisons are difficult, given that countries have different populations that may be more or less liable to have certain diseases (for example, sickle cell disease deaths will be higher in populations with greater numbers from Caribbean or African ethnic groups). There are undoubtedly population differences between the UK and Sweden but rapid population change through immigration has meant that 6.8% of the Swedish population was non-national in 2012 in contrast to 7.6% in the UK[40]. Aside from these population caveats, comparison with another country with much better outcomes shows us what might be possible for us to achieve.

What is the scale of difference that would be achieved if in the UK we were able to match Sweden's childhood mortality rate? That question can be addressed by calculating excess deaths. This means adjusting the mortality rate (numbers of deaths per 100,000 population) to take account of the different population sizes in the countries being compared. If the UK had the same all-cause mortality rate for children under 14 years as Sweden we could have nearly 2,000 fewer deaths among children in that age group per year - five fewer children's deaths per day[2].

Comparing countries which have different approaches to setting priorities in government, different social values, systems and services, and different healthcare services can help by providing insights and potential lessons towards improvement. Using the natural laboratory that Western Europe offers can help give us direction in further investigation as we turn our attention to look

for explanations and solutions in the three broad categories outlined earlier; government and civil society; health systems and organisations; healthcare and public health services[2].

Government and civil society

The ways in which we organise our society, our cultural values, and the functions and choices of Government are things which affect children and their families at the level of the whole population. Although the impact of tax policy may be felt by individual children and families, the effects of economic conditions that help determine family wealth, shape social inequalities, and affect the neighbourhoods in which children grow up, may be seen by looking at what happens to the whole population of young people, and by measuring over many years.

Economic wellbeing of a country and the fiscal policies that shape the macroeconomic environment in which families live have a measurable impact on child survival. As discussed previously, the wealthier a country is, the greater the chances of children surviving their childhood. Tax policy affects distribution of wealth within a country, and more children survive in countries where wealth is shared more equitably than those that have wide gaps between the very rich and the very poor. There is a social gradient in many aspects of health and wellbeing too. Children from wealthier families tend to live longer and to have healthier lives. These inequities do not happen by chance, they are shaped in a large part by the choices governments make. Family policy and supportive social policy can help protect children from the harsh effects of poverty. More children survive in countries that support families better. Recently published research shows that standards of living are deteriorating for many families in the UK; 35% of households with children do not have an income that is high enough to ensure an acceptable standard of living[41].

The social determinants of health can help to explain why negative health behaviours are more common in low income groups. Having no job, no prospects, and little money in a developed economy can lead to low levels of self-esteem, poor mental health, depression, higher levels of stress, and difficult relationships, and can make having children young an appealing option[42]. We also know that maternal stress and being a young mother can lead to lower levels of breastfeeding initiation. Given that poor mental health is more prevalent in more disadvantaged socioeconomic groups, and that these groups are also more likely to have low levels of social support, tackling negative health behaviours such as smoking, or alcohol and drug consumption, requires more than just information. Policies to modify health behaviours need to address the social determinants of health, and interventions need to be proportionately targeted across the social gradient if they are to reduce health inequalities effectively[6].

Sweden has different cultural attitudes from the UK, and these translate into policy. For example, Sweden has lower levels of poverty but it also has a more equitable distribution of poverty and social exclusion between age groups, as shown previously. Furthermore, the Nordic cultural approach to the early years of life means that the quality of their early childhood education and childcare systems, together with long and equitable parental leave, speak of countries that understand childhood to be a special time deserving of protection.

Reducing childhood deaths and improving children's lives through actions at the level of civil society and state could be achieved by ensuring that all families have a sufficient income to buy essential goods and be free from stress about basic security of housing, heat, and food. These things could be achieved through more equitable distribution of resources through redistributive fiscal policy, and by social policy that protects the young and vulnerable.

Health systems and organisations

The ways that we deliver healthcare, the systems for funding health services, the emphasis we place on primary care; all these things affect the lives and health of children.

Child health systems and policy research is a relatively new field, and comparing general health systems only began in earnest about a decade ago, in 2000, when the World Health Organization published a report on health system performance. Research methods and acceptable standards of evidence are still being developed and agreed. This is an area for which it is difficult to test hypotheses, and using the gold standard research method of the biomedical science world, the randomised controlled trial, is extremely challenging and often impossible. Recommendations from this type of research are more likely to be constructs based on the best available evidence rather than the most desirable data[43].

Here we focus on everyday healthcare, because this is where most activity in the health service happens, and because everything else that happens in the health service, from the simplest to the most complex and sophisticated, relies on the performance of services at the first point of contact that families have with the system of care.

It is well established that countries with strong primary care systems deliver high-quality outcomes, and most international policy correctly focuses on strengthening primary care as the foundation for improving health systems[44]. Much less is known about exactly how best to organise everyday healthcare, for example, how primary and hospital care interact, in the best interests of children and young people. There is no overall measure of the quality of healthcare for children.

Country comparisons of health systems are fraught with difficulties, but this sort of health systems research can indicate areas that need further investigation and attention. The UK has distinct advantages in a highly equitable accessible system of universal primary care. This is a precious asset, and must be preserved. At the same time, there are striking differences between countries in the way that first contact and primary care services are organised and delivered, and there may be scope for learning and improvement. For example, all countries are struggling to adapt their health systems to meet the evolving health needs of children and young people. The epidemiological transition towards chronic illness and long-term conditions mandates a different approach to organising and delivering health services compared with the existing hospital-centric model which was designed more for acute and infectious illnesses requiring hospital admission. Countries with strong primary care systems which enable close cooperation between health professionals seem to be making progress in delivering high-quality care but there are other important differences too[2,4]. For example, investment in health workforce differs between countries; Sweden has more doctors per child than the UK, and GPs in Sweden are required to be trained specifically in paediatrics and work in teams with children's nurses and doctors[24].

The National Children's Bureau (NCB) has recently published a report on general practice for children and young people, making important points about the necessity to ensure that services meet current and evolving needs[45]. This topic is especially important since primary care plays a strong gate-keeping role in the UK, and delivers the majority of healthcare for children. So a well-functioning children's primary care service is the bedrock for the rest of the health service. The NCB report, and other recent reports acknowledge that there are some challenges in primary care for children[46,47]. It is crucial to ensure that the primary care workforce is appropriately skilled, as these reports make clear. However, a more flexible approach to delivering primary care, for

example, through a team of professionals, as is the case in many European countries with better outcomes in many areas of child health, may also offer a help towards achieving this goal[24,2]. Primary care is also crucially important to address the growing problem of chronic disease and long-term conditions, and a well-functioning acute care service should enable sufficient resource to direct towards the increasingly important area of chronic disease care in early life.

Healthcare and public health

As discussed previously, healthcare amenable deaths are an incomplete way of trying to address the question of possible differences in quality of care between countries, given the current differences in data reliability and comparability between countries and the important contribution that healthcare makes to health beyond preventing death, such as improving quality of life. However, the data that do exist point to possible areas of concern that should be further investigated.

Suboptimal care resulting in avoidable harm and poor health are other ways of examining healthcare. Disease-based audits of quality of care for two important diseases in childhood, diabetes and epilepsy, for example, reveal disturbing findings. Fewer than 6% of children with diabetes in England receive care consistent with published guidelines, and preventable diabetic emergencies and deaths are the consequence[48]. England's performance as measured by HbA1c, an indicator of diabetic control, is poor compared with Germany and Austria, as shown in the table below.

Table 3: Country comparison of quality of care for children with diabetes[49, 50, 51]

NICE HbA1c target, 2004	England and Wales, 2010/2011	Germany and Austria, 2011
HbA1c <7.5%	15.1% females 16.4% males	50–55%
HbA1c considered to be at risk levels	Over 30% (>80mmol/mol, 9.5%)	10% (>75mmol/mol, 9.0%)

A national audit of the quality of care for children with epilepsy, published in 2012, showed that 35% of children with epilepsy did not have an appropriate first assessment, and 40% did not see a paediatric neurologist when it was indicated, and that less than half of children had specialist nurse care as recommended[52].

A systematic assessment of variations in healthcare processes within the UK revealed substantial variations in some measures of care. For example, the emergency hospital admission rate for children with asthma ranges from 25.9 to 641.9 per 100,000 population; a 25-fold difference[53]. Further work is needed to assess how much of this variation is appropriate for differences in population need, and how much is unwarranted.

Public health services and policies are other important means of preventing deaths in the longer term, and improving health and quality of life. Tobacco control is a hugely important area for preventing disease and promoting health. Smoking habits often begin in adolescence, yet there are effective policies for tobacco control including banning smoking in public places, quit smoking supports, media campaigns, health warnings, bans on tobacco advertising, promotion and sponsorship, and taxes. The UK scores highly on implementation compared with many other

countries, but specifically for children and young people there are further actions that could be taken, noting that a ban on smoking in cars is soon to be implemented in England, with the rest of the UK likely to follow, and a review of standardised packaging of tobacco is currently underway[54]. Smoking cessation interventions in pregnancy can be effective, leading to higher quit rates (by 6%) and increases in birth weight (by 53g on average) compared with women who had usual care[55]. However since most women who smoke in pregnancy continue to do so, the most effective policies are preventative population-based and include tobacco price increases, and school-based health education programmes[56]. Alcohol consumption among young people in the UK is a considerable public health concern, with signs of alcohol-related liver disease affecting people at increasingly younger adult ages[57,58,59]. There is good evidence that minimum pricing of alcohol is effective at reducing consumption, and there are further harm reduction strategies that can be implemented to reduce harm from alcohol[60,61,62].

There is a growing movement for quality improvement in healthcare in the UK, and there could be much to learn from cross country comparisons. More reliable comparable data on mortality, morbidity, and quality of care, would go a long way towards enabling useful lessons to be learned from other countries.

Key points

- There are no simple explanations for why more children die (per capita) in the UK than in some other European countries.
- However, there are clear actions that could be taken to reduce the risk of children dying and to improve the health and quality of life of British children.
- There are effective interventions in economic and social policy, in health systems strengthening, and in healthcare and public health services.

Next steps

The UK could, in theory, achieve the same mortality rate as countries where children have a greater chance of surviving but how we might go about achieving this goal is less clear. There is no single cause for the disparities between countries and equally there are no simple solutions.

Health systems and policy research for children is at an early stage of development, and the problem of child mortality is highly complex. However, we can start to make reasoned general policy and practice recommendations by careful definition of criteria for action:

- Common causes of deaths or substantial contributors to the mortality burden.
- Diseases or conditions where significant deficiencies in care have been identified and for which there are identifiable and achievable solutions.
- Systems and organisation issues that seem to be important when comparing the UK with other European countries.
- Wider societal and policy issues that make a difference to the chances of children's survival.

Five things fulfil these criteria, from which specific recommendations for action could be based:

First, infant deaths. The highest mortality rates in childhood occur in the first year of life. In terms of scale, therefore, this is where the greatest scope for improvement lies. Preventing risk of preterm birth and low birthweight, and promoting maternal health are good ways forward.

Second, acute illness. It is important that measures are taken to improve recognition and management of serious illness across the health service – both primary and secondary care; community and hospital; general practice, paediatrics, and mental health.

Third, injuries and poisoning. These causes of death are highly preventable, with effective policies for most common causes of death from accidents and injuries. However, legislation, implementation, and enforcement are crucial. Crucially also, a concerted and sustained policy response to the problem of violence and self-harm among Britain's young people is needed urgently to address the lack of progress in reducing deaths and injuries from these causes.

Fourth, chronic disease. The numbers of children with chronic diseases are increasing, and there is evidence of comparatively poor outcomes for example, in asthma, epilepsy, and diabetes. Moreover the UK has failed to match the health gains for children and young people with chronic conditions made by other comparable countries, with particular concern regarding non-communicable disease mortality in young people. Urgent attention is needed to improve prevention and care for children and young people with long-term conditions, including mental ill health. Policy responses are needed from public health and healthcare, together with other domains including food and nutrition policy, tobacco and alcohol, transport, and environment.

Fifth, the role of civil society and government. Absolute resource availability and equity of distribution both have an impact on mortality and on life chances. Children's lives can be protected through supportive social policy and redistributive fiscal measures. The messages are stark and crucial. Poverty kills children. Equity saves lives. Social protection is life-saving medicine for the population.

It is a grave injustice that British children do not enjoy the highest standards of health, wellbeing, and of chances to fulfil their individual potential in life. That children in the UK may die unnecessarily should be a matter of national shame. As child health advocates, professionals, and policy makers, we have a duty to act urgently to improve the life chances of our children.

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