Child Health Reviews - UK

Clinical Outcome Review Programme

Overview of child deaths in the four UK countries

Report
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Foreword

I have been privileged to Chair the Royal College of Paediatrics and Child Health programme, Child Health Reviews - UK. The Programme has been innovative and bold, involving the work of an academic group in Module A, presented here, and contributions from paediatrician members of the Royal College of Paediatrics and Child Health throughout the four countries of the UK in Module B, presented in an accompanying report.

The aims of Module A were to examine the utility of existing datasets, the value of analyses based on linkages between death certificates and a child's whole history of hospitalisations and birth registration, to describe variation between UK countries and over time in children's mortality rates, and to build a picture of the underlying causes of death and accompanying co-morbidities.

The Module A team at University College London found that all-cause child mortality has declined in all age groups and UK countries since 1980. Injury is the most frequent underlying cause of death, accounting for around a third to just under a half of deaths in children aged one to 18 years. England appears to have had consistently lower death rates from injury than the other UK countries and this disparity has widened since 1980 for children aged 10 to 18 years. They estimate that 52 fewer deaths among children in this age group would be likely each year if all UK countries had the same mortality rate due to injury as England. Despite a decline in child mortality due to unintentional injuries, there has been no decline in deaths due to self-harm, assault or other undetermined intentional injuries in 10 to 18 year olds in any UK country. These findings require careful consideration by policy makers.

The University College London team identify the strengths and limitations of their approach, and suggest ways to improve access to data collections in the future. UK countries differ in data availability, the processes and time required, and the costs of accessing data. These differences limit cross-country UK comparisons that could inform policy and practice. The Royal College of Paediatrics and Child Health has pioneered the use of high quality extractions from patient management systems and electronic records in the National Neonatal Audit Programme, thus avoiding the burden of duplicate data collection by clinical and administrative teams, and reducing the costs and complexity of data associated with the use of data collections. Together with Child Health Reviews - UK, these programmes by the Royal College of Paediatrics and Child Health have advanced the use of electronic data to inform and advance children's healthcare, with the ultimate aim of improving their life-long health and wellbeing.

Neena Modi.

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List of abbreviations

CI	Confidence interval
HES	Hospital Episode Statistics
HSCIC	Health & Social Care Information Centre
ICD	International Classification of Diseases
ICD-9	International Classification of Diseases, version 9
ICD-10	International Classification of Diseases, version 10
ISD	Information Services Division, Scotland
LR	Likelihood ratio
NHS	National Health Service
NN	Neonatal
NISRA	Northern Ireland Statistics and Research Agency
NRS	National Records of Scotland
ONS	Office for National Statistics
PAC	Privacy Advisory Committee
PEDW	Patient Episode Database for Wales
PNN	Postneonatal
SMR	Scottish Morbidity Record
WHO	World Health Organisation

Age group definitions

Infant: zero to 364 days

Neonatal: zero to 27 days

Post-neonatal: 28 to 364 days

Child: one to 18 years (until the child's 19th birthday)

Executive summary

Key findings from this research

- The continuing importance of injuries as a cause of death in childhood and the lack of decrease in deaths due to intentional injury for children aged 10 to 18 years since 1980.
- The persisting effect of young maternal age as a risk factor for child death throughout early childhood, despite accounting for birth weight.
- The high proportion of deaths in children with chronic conditions; neurological conditions were the most prevalent.
- The small but consistent decrease in the proportion of children with a chronic condition who died during hospital admission.

1. Background

The four UK departments of health commissioned an epidemiological overview of deaths in children based on routinely collected vital statistics and administrative health care data. The two aims were;

- To inform policy about variation between UK countries and over time in mortality rates for children, their underlying causes of death and what other conditions they die with.
- To examine the usefulness of routinely collected data for evaluating child deaths.

This report sets out the findings of the overview, examining deaths in children aged one to 18 years in England, Scotland, Wales and Northern Ireland from 1980 to 2010.

2. Data sources

Implications

- Differences in access to data limit cross-country comparisons within the UK which could inform policy and practice. Datasets and access need to be harmonised. Death certification delays in England, Wales and Northern Ireland should be taken into account when reporting mortality rates. The process of death registration in these countries should be changed to minimise delay.

Key findings

- UK countries differed in the data available and in the procedures, costs and time required to access data on child deaths and associated hospital admissions.
- We found substantial delays in registration of deaths in England, Wales and Northern Ireland, particularly for older children who died of injuries.

3. Variation in rates of child death due to injury based on the underlying cause recorded on death certificates (1980-2010)

Implications

- Boys aged 10 to 18 years stand to gain most from preventive policies to reduce injury deaths in children aged one to 18 years.
- Preventive strategies need to focus on reducing deaths due to intentional injury in children aged 10 to 18 years.

Key findings

- Child mortality from all causes has declined in all age groups and UK countries between 1980 and 2010 by 50% to 70%.
- Injury is the most frequent underlying cause of death accounting for 31% of deaths in one to four year olds and nearly half (48%) of deaths in adolescents aged 15 to 18 years.
- England had consistently lower rates of injury deaths than the other UK countries. This disparity has widened since 1980 for children aged 10 to 18 years.
- We estimated that 52 fewer deaths would occur each year among children aged 10 to 18 years if all UK countries had the same mortality rate due to injury as England for children in this age group.
- There has been no decline in injury deaths due to intentional injuries (deaths due to self-harm, assault or undetermined intent) in 10 to 18 year olds in any UK country since 1980.

4. Multiple morbidity recorded on children's death certificates (2006-2010)

Implications

- Coded information on all causes of death mentioned on death certificates provides useful information on conditions in children who die, which should be used more widely.

Key findings

- Multiple morbidity was most frequently recorded on death certificates across the UK in children whose underlying cause of death was a neurological condition, congenital anomaly, respiratory problem, endocrine or metabolic condition, or mental health problem.
- Respiratory conditions were the most frequently recorded comorbidity but whether these problems were cause or consequence of terminal decline needs evaluation by case note review.

5. Variation in child mortality by birth weight and maternal age (1993-2010)

Implications

- Social disadvantage of mothers aged less than 30 years compared with those aged 30 to 34 years is linked to higher mortality rates through much of childhood despite accounting for birth weight.
- Universal policies are needed to address disparities in child mortality associated with maternal age.
- The greatest potential gains are through reducing disparities in post-neonatal mortality.

Key findings

- In England, Scotland and Wales, differences in mortality between children of mothers aged less than 30 years and those with similar birth weight born to mothers aged 30 to 34 years accounted for 11% of all deaths up to nine years old.
- Deaths in children born to mothers aged less than 20 years accounted for just one-third of the mortality difference for children of mothers under 30 years (vs 30 to 34 years) or 3.8% of all child deaths up to nine years old.
- Half of the mortality difference for children of mothers under 30 years (vs 30 to 34 years) occurred in the post-neonatal period.

6. Children who died with a chronic condition (2001-2010)

Implications

- Efforts to prevent deaths in children need to focus on improving the quality of care for children with chronic conditions.
- More information is needed on the proportion of children who die whose chronic conditions are terminal and who might benefit from improved end of life care.
- Linkage between death certificates and hospital records provide a cost-effective, comprehensive and scalable method for examining chronic conditions in children who die.
- Further linkage to primary care data would provide a more complete picture of chronic conditions in children.

Key findings

- Two-thirds of children who died in England, Scotland or Wales had a chronic condition.
- Between 30% to 40% of children who died were affected by a neurological/sensory condition, more than any other group of conditions.
- Information solely from death certificates underestimates the proportion of children who died with a chronic condition.

7. Place of death in children (2001-2010)

Implications

- The increase over time in the proportion of children who died outside hospital suggests that policy and practice can make a difference and reflects the need to ensure choice for children and families regarding place of death.
- Policies and practices within children's cancer services offer one model for increasing the proportion of expected deaths that occur outside hospital.
- Further research is needed to determine where within healthcare improvements are needed to prevent or delay death, or improve end of life care for children.

Key findings

- Around two thirds of children who died of causes other than to injury in England, Scotland or Wales died in hospital.
- Around half the children died during a hospital admission, one-third died out of hospital, and one-fifth died in hospital but not during an admission.
- There has been a small but consistent decrease in the proportion of children who died during an admission, and concurrent increases in the proportion of children who died out of hospital.
- The decrease in the proportion of deaths occurring during an admission was largest for children with cancer/blood conditions.

8. Future directions

- Epidemiological overviews and case note reviews are complementary and can be synergistic for understanding child deaths.
- Future epidemiological overviews should include:
  - antecedent health care events in the 30 days before death
  - the period of transition from paediatric to adult care for young people linkage to primary care data
  - linkage to intensive care data
  - linkage to sectors outside health

1. Purpose of the report

1.1 Background to the report

The four UK departments of health commissioned an epidemiological overview of deaths in children based on routinely collected vital statistics and administrative health care data. The overview has two main aims:

1) To inform policy about variation between UK countries and over time in:
    - which children die
    - what conditions they die with
    - their causes of death
2) To examine the usefulness of routinely collected data for evaluating child deaths.

1.2 Informing policy

Child deaths are an important indicator of the quality of support for children and families. Mortality rates are seen as important benchmarks for measuring the success of policies governing children's environments, child and family welfare, health inequalities and health care. When there is variation in mortality rates, between countries and over time, one explanation can be that deaths could be preventable given different policies. In this report, we compare child death rates between the four UK countries (England, Scotland, Wales and Northern Ireland). We examine how rates have changed over time, how they differ between boys and girls and between groups defined by markers such as maternal age. Our findings raise questions for policy makers about why disparities exist and persist.

The epidemiology of child deaths is changing as deaths due to infection and injury decline and as more of the children with serious problems in the neonatal period survive well into childhood and adulthood. Increasingly, children who die have complex, long-term conditions. However, the cause of death on the death certificate often reflects only their terminal decline not their long-term condition. We determined the prevalence of chronic conditions in children who died by analysing the child's trajectory of hospitalisations. By classifying chronic conditions, we also gained insight into which specialties within health care might be caring for these children. This information helps us to infer where efforts to reduce mortality or improve management of expected deaths might most effectively be targeted.

1.3 How useful are routine data about children who die?

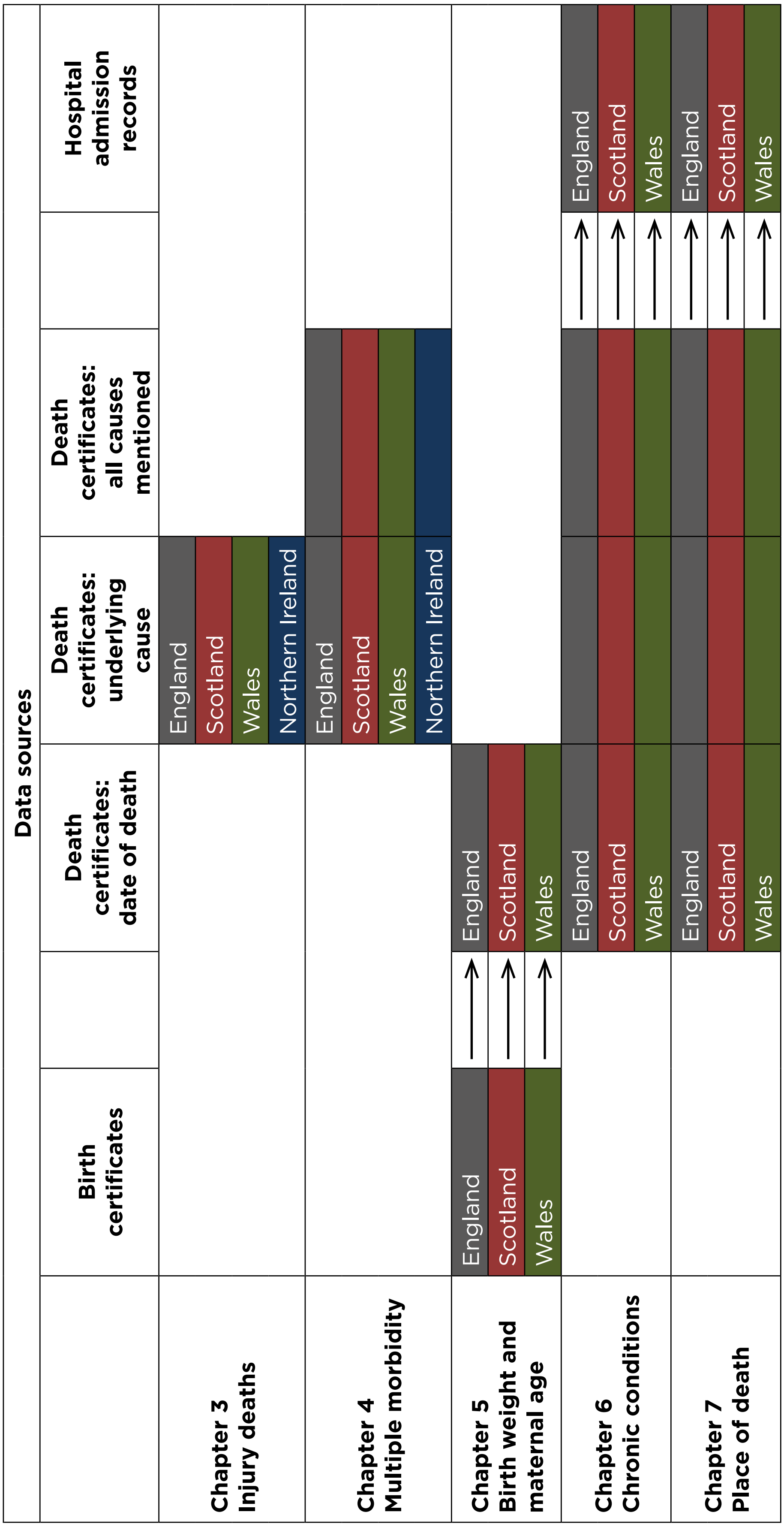
A previous confidential enquiry into child deaths in the UK relied on reports of child deaths from local networks of clinicians, coroners and police to report cases.[1] This report presents a different approach based on linkage of National Health Service (NHS) and vital statistics datasets.

In many countries, the accumulation of high quality, routinely collected, 'big data' mean that it is now possible to study the entire hospital trajectory of children who die by linking vital statistics (birth and death registration) with hospital administrative data. These linked administrative datasets are rich in terms of the amount of data they contain and comprehensive. Importantly, they use standard International Classification of Diseases (ICD) coding and are therefore comparable across countries. Such cross-country comparisons can be highly informative about the impacts of different policies in different countries and can be done relatively quickly and at low cost.

1.4 Overview of the report

This report illustrates some of the policy questions that can be addressed using administrative health data for children who died. Chapter 2 reports on the processes for obtaining the datasets and for taking account of delays in death registration in some UK countries. Thereafter, each chapter reports key questions addressed by different types of analyses and presents key findings and implications for policy. Taken together, the report illustrates the added value of information from the child's health care trajectory in addition to the underlying cause recorded on the death certificate. Each chapter illustrates this process step by step as additional information is incorporated into the analyses (Figure 1.1). We finish by discussing the place of routine data in future evaluations of child deaths.

Figure 1.1: Diagram showing administrative data used in analyses



	Data sources						
	Birth certificates		**Death certificates: date of death**	**Death certificates: underlying cause**	**Death certificates: all causes mentioned**		**Hospital admission records**
Chapter 3 Injury deaths				England			
				Scotland			
				Wales			
				Northern Ireland			
Chapter 4 Multiple morbidity				England	■		
				Scotland	■		
				Wales	■		
				Northern Ireland	■		
Chapter 5 Birth weight and maternal age	England	→	England				
	Scotland	→	Scotland				
	Wales	→	Wales				
Chapter 6 Chronic conditions			England	■	■	→	England
			Scotland	■	■	→	Scotland
			Wales	■	■	→	Wales
Chapter 7 Place of death			England	■	■	→	England
			Scotland	■	■	→	Scotland
			Wales	■	■	→	Wales

2. Data sources

Key findings

- UK countries differ in the data available and in the procedures, costs and time required to access data on child deaths and their hospital admissions.
- We found substantial delays in registration of deaths in England, Wales and Northern Ireland, particularly for older children who died of injuries.

Implications

- Differences in access to data limit cross country comparison within the UK which could inform policy and practice. Data and access need to be harmonised.
- Death certification delays in England, Wales and Northern Ireland should be taken into account when reporting mortality rates. The process of death registration in these countries should be changed to minimise delay.

2.1 Background and rationale

Our overview of child deaths throws a spotlight on differences in the data available between the four UK countries, the quality of the data, and the procedures for obtaining data. This information is relevant to government policies to increase the availability and use of administrative health data across the NHS as a resource to drive efficiencies in care, attract inward investment in research, and inform policy.[2;3]

Key question

- How do data sources and processes for obtaining data differ between countries?

2.2 Methods

The process of obtaining data for analysis started with submission of an application form stating the purpose that the data would be used for, specifying the variables required, and explaining how the data would be stored and kept secure. We had to justify requests for potentially disclosive fields such as date of death (see Table 2.1).

As our research was commissioned by the four UK departments of health, we were deemed to be conducting research ‘on behalf of the Secretary of State’ and did not need to obtain ‘approved researcher status’ for each member of the team to access data from the Office for National Statistics (ONS). In addition, department of health representatives on our advisory group and the funding intermediary, HQIP, were able to advocate for speedy release of data. A further advantage was our well-established relationships with the data providers, experience with most of the data sources, and a well-established secure environment to house the data.[4] Given these advantages, our experience of obtaining data is likely to reflect a best-case scenario.

Procedures for assessing applications varied. In Scotland, a Privacy Advisory Committee (PAC), which included lay and medical members, approved our application. Elsewhere, approval was by the data provider. We measured time intervals between our first contact with the data provider and receipt of data and retrospectively estimated time spent on data access and administering data cleaning algorithms (Appendix 6.2). All data providers required the data to be destroyed at the end of the study, although we could apply to extend this deadline.

Approximately one in five of all child deaths over five years of age in England and Wales are not registered until at least six months after death.[5] Because of these delays we limited our analyses to deaths that occurred before 1.1.2011. We captured late registered deaths by requesting updates for England, Wales and Northern Ireland until April 2013 to include deaths registered until the end of June 2012 (Appendix 3.3). Updates were not required for Scotland, since there were no appreciable delays. Deaths referred to the Procurator Fiscal in Scotland are registered without waiting for the outcome of a possible inquest.[6]

We illustrate the delay in death registration using data for 2006-2010 for England and Wales and, because of small numbers, for 1997-2010 for Northern Ireland. We plotted the proportion of deaths registered within one year of death for all post-neonatal deaths (Figure 2.1). We also plotted the proportion of deaths registered within one year and the time to registration for the group in which registration was most delayed – boys aged 15 to 18 years who died of injury (Figure 2.1 and Figure 2.2).

2.3 Results

2.3.1 Datasets

There were stark differences between the four UK countries in terms of datasets available for analysis (Table 2.1). At one extreme, Northern Ireland could provide only mortality data, but could not link this to hospital admissions. At the other extreme, Scotland linked seven datasets comprising birth and death registrations linked to maternity delivery records, neonatal and childhood hospital admissions, mental health admissions and cancer registrations. ONS provided birth linked to death registrations for England and Wales. Although linkage of these data with Hospital Episode Statistics (HES) might be possible in future studies, at the time of application, they were not routinely linked. We therefore restricted analyses to data contained in birth and death registrations in England, Wales and Scotland.

2.3.2 Obtaining the data

The time from first contact to receipt of data was longest for Scotland (14.5 months), due to the complexity of the data, and shortest for Northern Ireland (5 weeks). The Health and Social Care Information Centre (HSCIC) required a new application for each update of delayed death registrations in England and Wales. Overall, the process of obtaining the datasets (Table 2.1) required approximately 75 days of work for a senior data analyst over 12 months and considerable input and cooperation from staff at the data providers. The costs charged by data providers to extract the data ranged from nothing for mortality data from Northern Ireland to £7000 for linked data from Scotland. These costs did not include updates or denominator data.

Table 2.1: Datasets requested and time to receipt of data

	Organisation, dataset (no of records)	Sensitive fields*	Time to receipt of data			Costs
			from 1st contact	***from application***	***update application***	
England and Wales	Office for National Statistics Death registration data for England and Wales 1979-2012+ (250,025)		1.75 months	1 week	3 months	£5337
	Health and Social Care Information Centre Hospital Episode Statistics linked to mortality data for England 1998-2010 (557,344) Mortality data not linked to Hospital Episode Statistics for England 1998-2010 (17,289)	HES: 2001 Census output area,ordnance survey grid ref	4 months	2 months	4 months***	£4160
	NHS Wales Informatics Service (not advertised on provider website) Patient Episode Database for Wales linked to death registration data for Wales 1998-2010 (20,135)	admission/ discharge dates	7 months	N/A	2 months	No charge
	Office for National Statistics (not advertised on provider website) Birth registration data linked to death registration data for England and Wales (77,933)		8 months	6 months	N/A	£2551
Scotland	Information Services Division Death registration data linked to hospital inpatient, maternity, neonatal discharges, mental health and cancer registrations** (23,991)	month/year of birth, admission/ discharge dates	14.5 months	6.5 months	N/A	£7140
Northern Ireland	Northern Ireland Statistics and Research Agency Death registration data for Northern Ireland (11,147)		5 weeks	3 weeks	1 month	No charge
Denominators	Population estimates by 5 year age-group, sex and country for each calendar year					No charge
	Live births data by grouped maternal age and birthweight: England & Wales					£250
	Scotland					£1,739

* Death registration included DOD, DoR, age at death. Excluded date of birth and postcode.

\+ approval was sought to use the data that was held for a different purpose

**including SMR01 (general acute inpatient and day case discharges), SMR02 (maternity inpatient & day case discharges), SMR04 (psychiatric and mental hospitals and units: admissions, resident & discharges), SMR06 (cancer registrations), SMR11 (Scottish birth record, neonatal discharges), GRO birth and death registrations, SBNND (Scottish Birth and Neonatal Deaths).

***new application required for updates

Abbreviations: DoD = Date of Death, DoR = Date of Registration

2.3.3 Data preparation

The team spent the equivalent of six months of one full time analyst to clean the linked datasets from HSCIC for England, Scotland and NHS Wales Informatics Service. More time was spent cleaning the data for England compared with Scotland. The types of data errors encountered during cleaning are shown in Appendix 6.2.

There were long delays for registering deaths in England, Wales and Northern Ireland. In Scotland, the Procurator Fiscal can register the fact of death and consequently nearly 100% of deaths are registered within one year. Figure 2.1 shows the most extreme delays, which occurred for injury deaths in the boys aged 15 to 18 years. This is because culpability for many of these deaths is uncertain and coroner investigations are required to differentiate deaths due to violence or self-harm.

Figure 2.1: Percentage of deaths registered within one year of occurrence by country, age group and cause

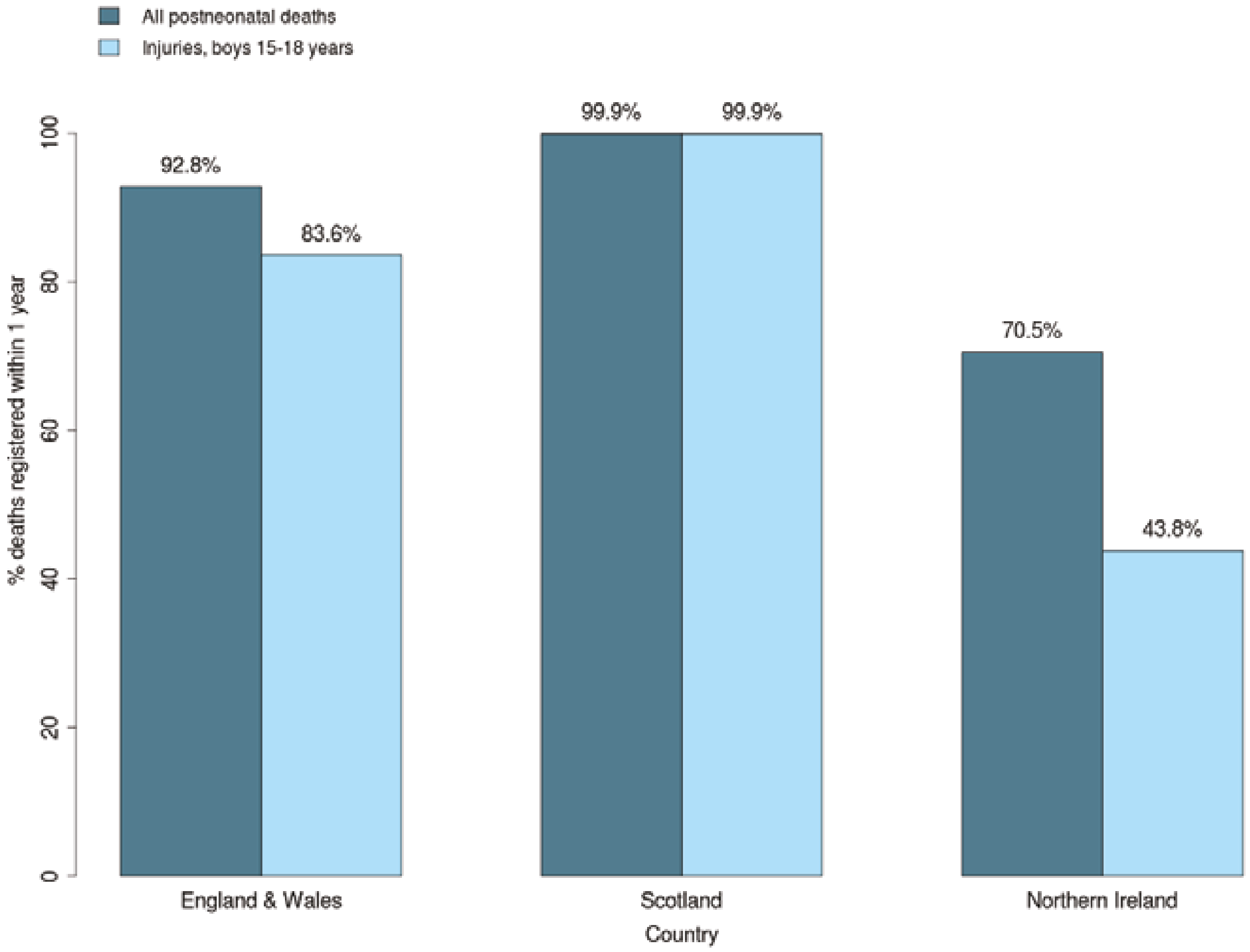
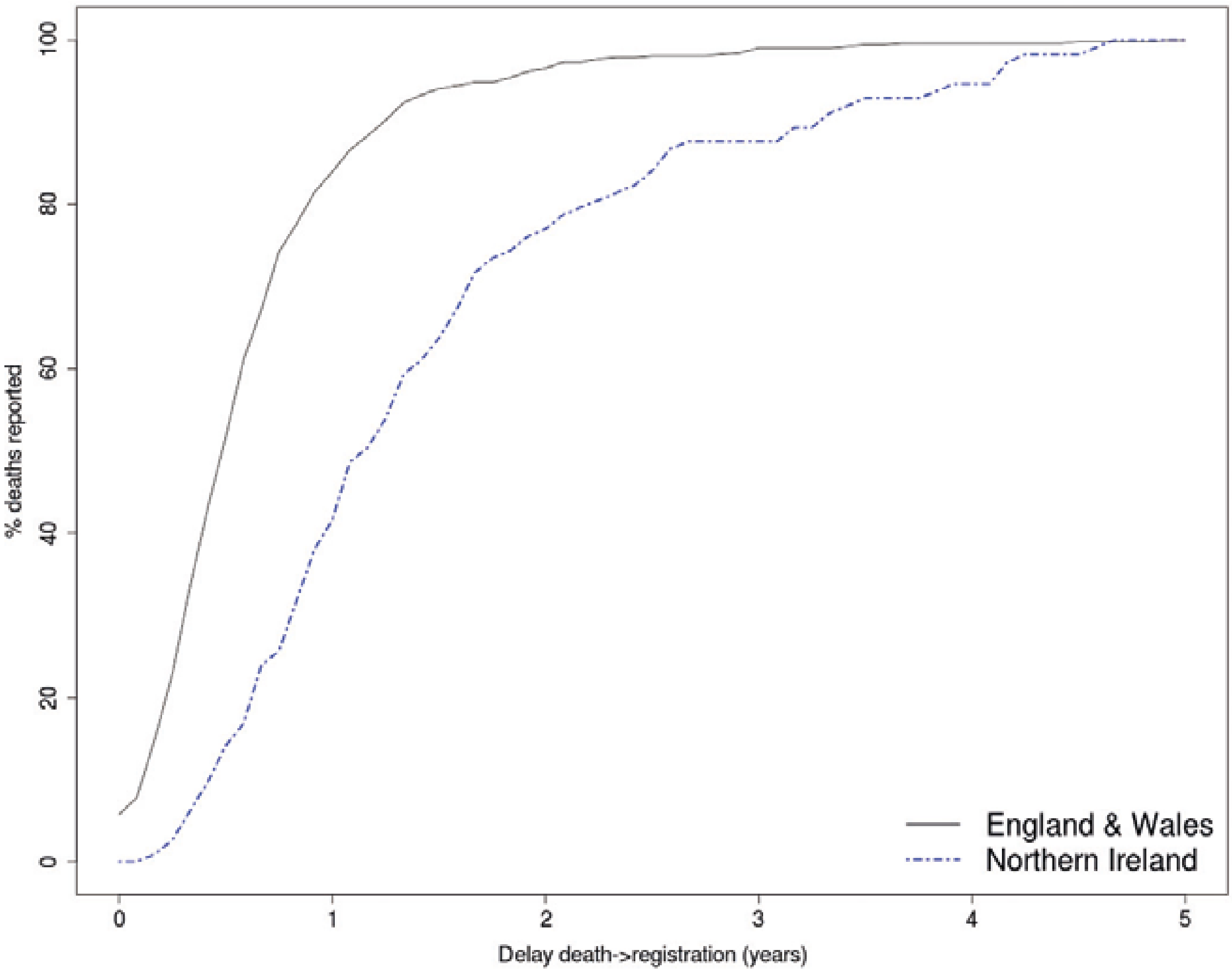


Figure 2.2 shows the proportions of injury deaths in children aged 15 to 18 years that were registered by 2 and 3 years after death were 96.1% and 98.7 % in England and Wales and 76.0% and 92.8% in Northern Ireland. Initially, we adjusted annual counts of death occurring in England, Wales and Northern Ireland in the last five years of the study period (2006-2010), according to methods reported elsewhere.[7] Updated data on deaths occurring in these three countries until the end of

2010 but registered up to June 2012 subsequently became available so that further adjustment made little difference and unadjusted results are presented here.

Figure 2.2: Percentage of deaths registered according to the time between death and registration



2.4 Discussion

2.4.1 Obtaining the data

Researchers and funding bodies need to be aware of the prolonged processes involved in obtaining and preparing the data and plan for adequate time, expertise and resources. Data providers could cut back on some of the administrative processes, such as requiring full applications for updates and, given resources to do so, could do more to assist with applications and ensure timely supply of data. Better information could also help researchers to help themselves. Two datasets (linked birth-death registration for England and Wales, and Patient Episode Database for Wales (PEDW) linked to death registrations) were not mentioned on the data provider websites (Table 2.1) and some key metadata tables were accessed only after talking to staff at the data provider. Many of these issues have been highlighted by the Administrative Data Taskforce.[2] A recent overview of nine Canadian agencies providing access to administrative health data highlights similar bottlenecks - varying arrangements for access and resources to support researchers.[8] The report suggests widening use of the affiliated researcher model to manage risk and speed access.

2.4.2 Data preparation

Data providers need to consider how to extend the period of access to maximise use of administrative health data and ensure transparency and rigour of analyses. Currently, the substantial investment of time and money to obtain, prepare and analyse routine data is dissipated when the original datasets are destroyed at the end of the project, as required by all data providers. Destruction of data prevents scrutiny of the data analyses should questions be raised about methods or fraud. Moreover, in our experience, identical copies of data extracts cannot be obtained at a later date as data providers do not keep copies of extracts and core data change continually due to updates. Prompt destruction of data is at odds with requirements by funders of primary research that data be kept for 15 years to allow scrutiny of the findings and to contribute to meta-analyses.

2.4.3 Analyses

For this study, we were able to conduct analyses of data combined from all four UK countries and held in one setting. For future studies, we would be required to access data for Scotland remotely, making cross-country comparisons more difficult.[9]

Biases due to delays in death registration for cases referred to coroners in England, Wales and Northern Ireland underestimate recent mortality rates and affect international comparisons, such as World Health Organisation (WHO) tabulations.[10;11] Changes are needed to the process of death certification to ensure that mortality data for England, Wales and Northern Ireland are up to date and comparable with other countries. It is important to review this in time for the implementation of the death certification reforms in April 2014.[12] In the meantime, registration delays should be taken into account using a statistical correction, which could be calculated for different age and sex groups and published by ONS.[5;7] These delays could be made clearer to data users if ONS, Northern Ireland Statistics and Research Agency (NISRA) and Information Services Division Scotland (ISD) published deaths by date of death, in addition to date of registration. In addition, international data repositories such as the WHO Mortality Database should clarify that data submitted is by date of registration and publish estimates of the delay between occurrence and registration by age group and ICD chapter. This information is required in order to interpret international comparisons of mortality rates.

This study highlighted the value of standardised datasets from all UK countries for carrying out cross-country comparisons of mortality. The Farr Institute,[13] a new initiative by the Government to create a UK health informatics institute with centres across England, Scotland and Wales, aims to promote harmonisation of routine health datasets for research across the UK.

3. Variation in rates of child death due to injury based on the underlying cause recorded on death certificates (1980-2010)

Key results

- Child mortality from all causes has declined in all age groups and UK countries between 1980 and 2010 by 50 to 70%.
- Injury is the most frequent underlying cause of death accounting for 31% of deaths in one to four year olds and nearly half (48%) of deaths in adolescents aged 15 to 18 years.
- England had consistently lower rates of injury deaths than the other UK countries. This disparity has widened since 1980 for children aged 10 to 18 years.
- We estimated that 52 fewer deaths would occur each year among children aged 10 to 18 years if all UK countries had the same mortality rate due to injury as England for children in this age group.
- There has been no decline in injury deaths due to intentional injuries (deaths due to self-harm, assault or undetermined intent) in 10 to 18 year olds in any UK country since 1980.

Implications

- Boys aged 10 to 18 years stand to gain most from preventive policies to reduce injury deaths in children aged one to 18 years.
- Preventive strategies need to focus on reducing deaths due to intentional injury in children aged 10 to 18 years.

3.1 Background and rationale

Injuries are increasingly important causes of death in children worldwide as other acute causes of death, such as infection and deaths due to chronic diseases decline, and as exposure to traffic and other hazards increase as more people live in dense, urban environments.[14] Injury mortality has declined in rich countries along with other causes of death, but the decline has been less marked for older children and adolescents compared with younger children.[15]

In our first set of analyses in this report we focus on deaths due to injury. Injury is the most frequent cause of death in children aged one to 18 years and injury mortality rates are strongly influenced by preventive policies.[14] From a policy perspective, variation in childhood injury mortality between countries with similar health care systems may be partly explained by the impact of policies such as health promotion programmes for injury reduction, health care management of serious injury, or public health interventions to reduce social, economic or neighbourhood determinants of injury.[16] The results should inform preventive policies by identifying groups most likely to benefit.

This chapter illustrates the type of analyses that are possible based solely on the underlying cause of death. Use of underlying cause for analyses of injury is valid because previous studies have shown that injury is reliably recorded as the underlying cause of death and is unlikely to miss children with fatal injury.[17] Moreover, as we show later in the report, there are very few children for whom injury contributed to death but was not recorded as the underlying cause of death (see chapter 4).

Key questions

- What is the most frequent underlying cause of death in children aged one to 18 years?
- How do trends in childhood mortality due to injury vary across the four UK countries?

3.2 Methods

We used anonymised death registration data for deaths occurring between January 1980 and December 2010 in UK children resident in the four UK countries (Appendix 3.1). Children were aged one to 18 years inclusive when they died. We present crude results for four age groups (one to four, five to nine, 10 to 14, 15 to 18 years), but use broader age groups for subgroup analyses to avoid small cell sizes. Population denominators by age group and gender were obtained from ONS, NISRA and NRS through ISD Scotland (Appendix 3.5).

We grouped the underlying cause of death into nine ICD chapter groups to reflect broad aetiological and system groups and to avoid small cell sizes (Appendix 3.4). We plotted mortality trends over time based on three year moving averages. We compared mortality rates for all causes of death and for injury in the four UK countries. However, analyses of trends in the nine ICD chapter groups are shown for the whole of the UK to avoid small numbers of deaths in some subgroups (ie. small cell sizes). We compared differences in injury mortality rates between countries in three five-year time periods from each decade of the study period, including the earliest and latest periods (1980-84, 1993-97 and 2006-10). Grouping years was necessary in order to ensure sufficient numbers of deaths to carry out inter-country comparisons of injury mortality trends. We calculated population attributable risks if rate differences between countries were significant at the 5% level. We used Poisson regression models that included interaction terms and adjustment for overdispersion to determine whether trends over time differed significantly between countries.[7]

We determined whether differences over time and between countries in injury mortality could be related to reductions in unintentional injury deaths (including transport accidents, other accidents and accidental poisoning), possibly related to policies to reduce accidents, or to differences in intentional injuries, that is injuries due to violence, self-harm or undetermined causes. A breakdown of codes used for the different types of injury can be found in Appendix 3.4.

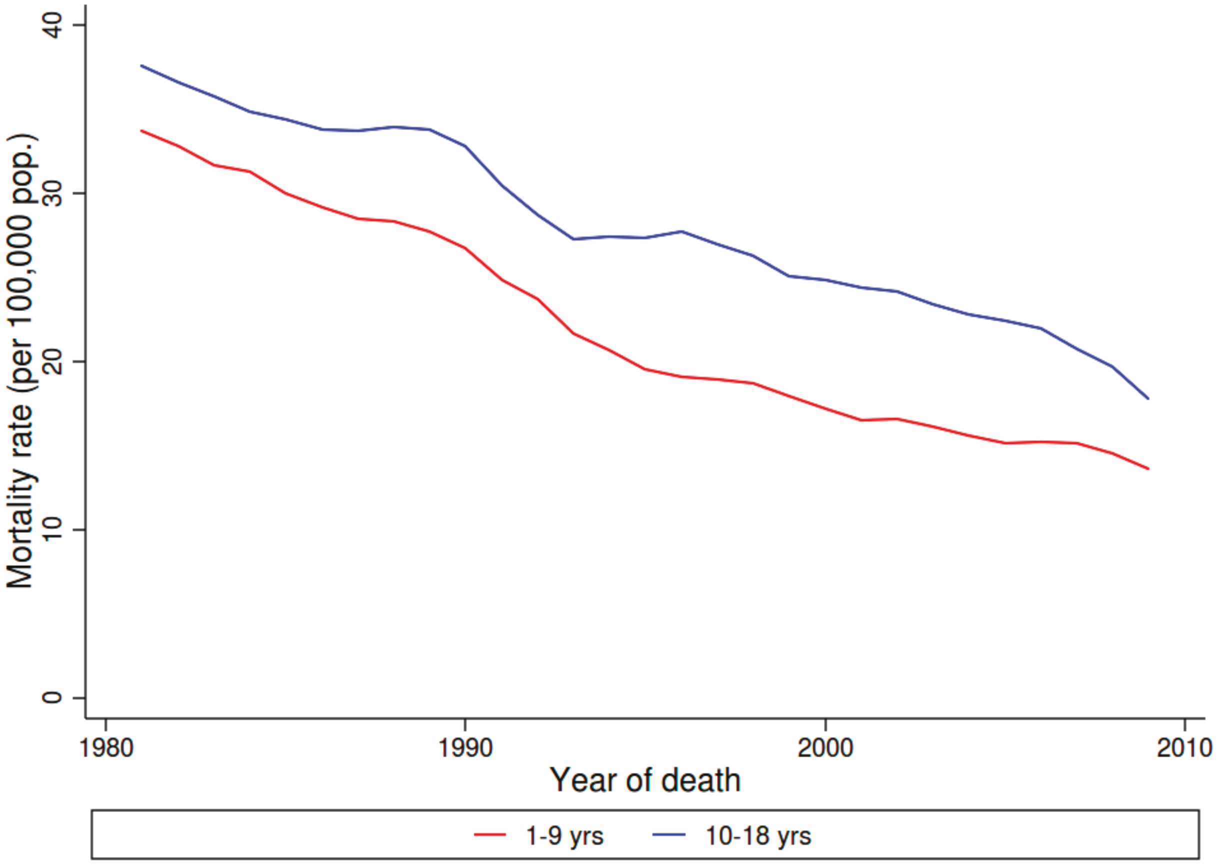
3.3 Results

3.3.1 Trends in all underlying causes of death

Overall mortality declined by 50% to 70% in all age groups and across all four UK countries between 1980 and 2010. In 2010, 1935 deaths occurred in children resident in the UK and aged one to 18 years. 57% of these deaths occurred in 10 to 18 year olds and 43% in one to nine year olds.

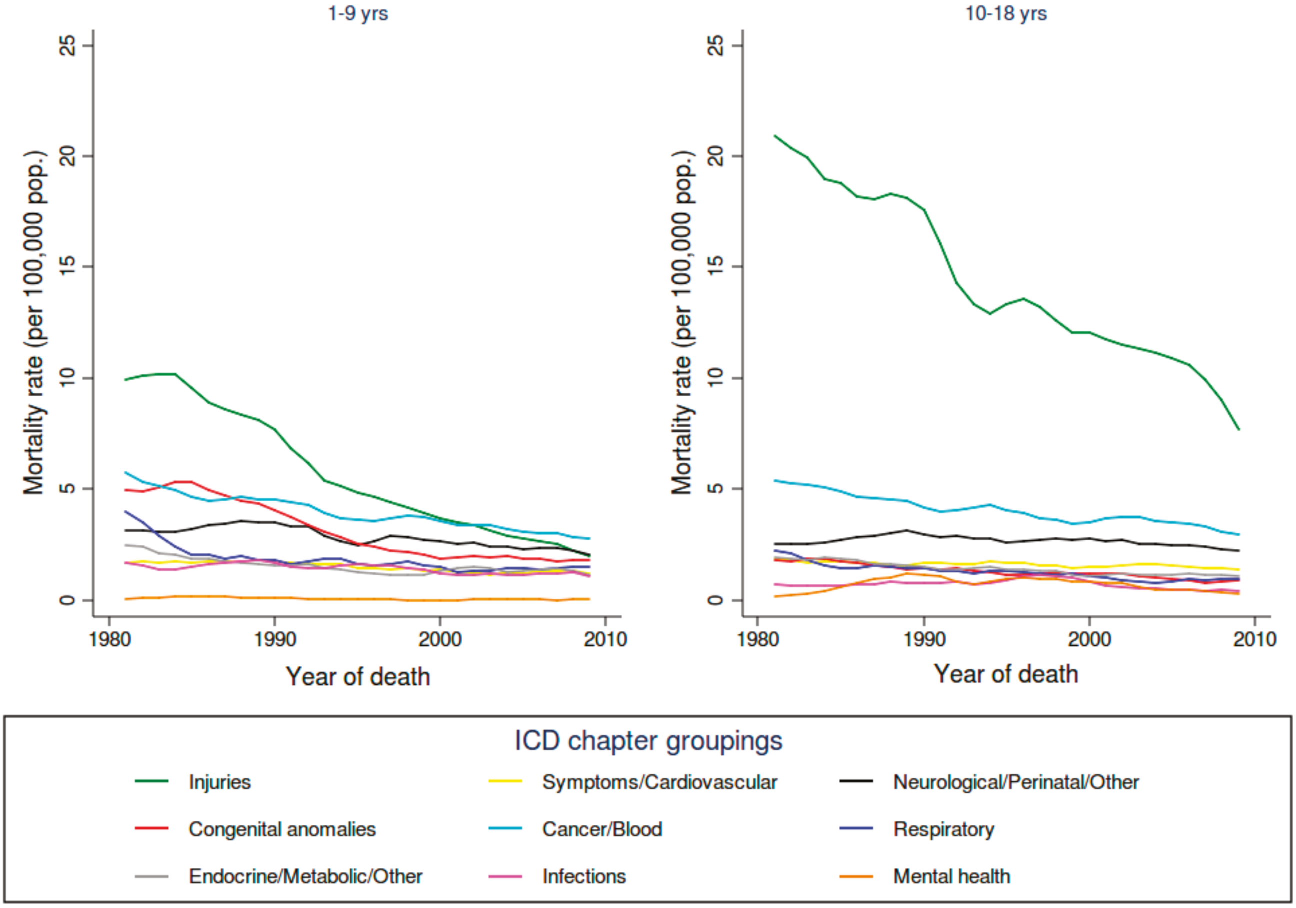
Figure 3.1 shows similar rates of decline in total mortality among younger and older children. In both age groups and for most years, injury was the most frequent cause of death, followed by cancer/blood conditions (Figure 3.2). However, in the most recent five years, cancer/blood accounted for most deaths in children aged one to nine years of age.

Figure 3.1: Smoothed child mortality rates by year and age group, UK 1980-2010



Three year moving averages have been applied

Figure 3.2: Smoothed child mortality rates by age group, year and underlying cause (grouped), UK 1980-2010



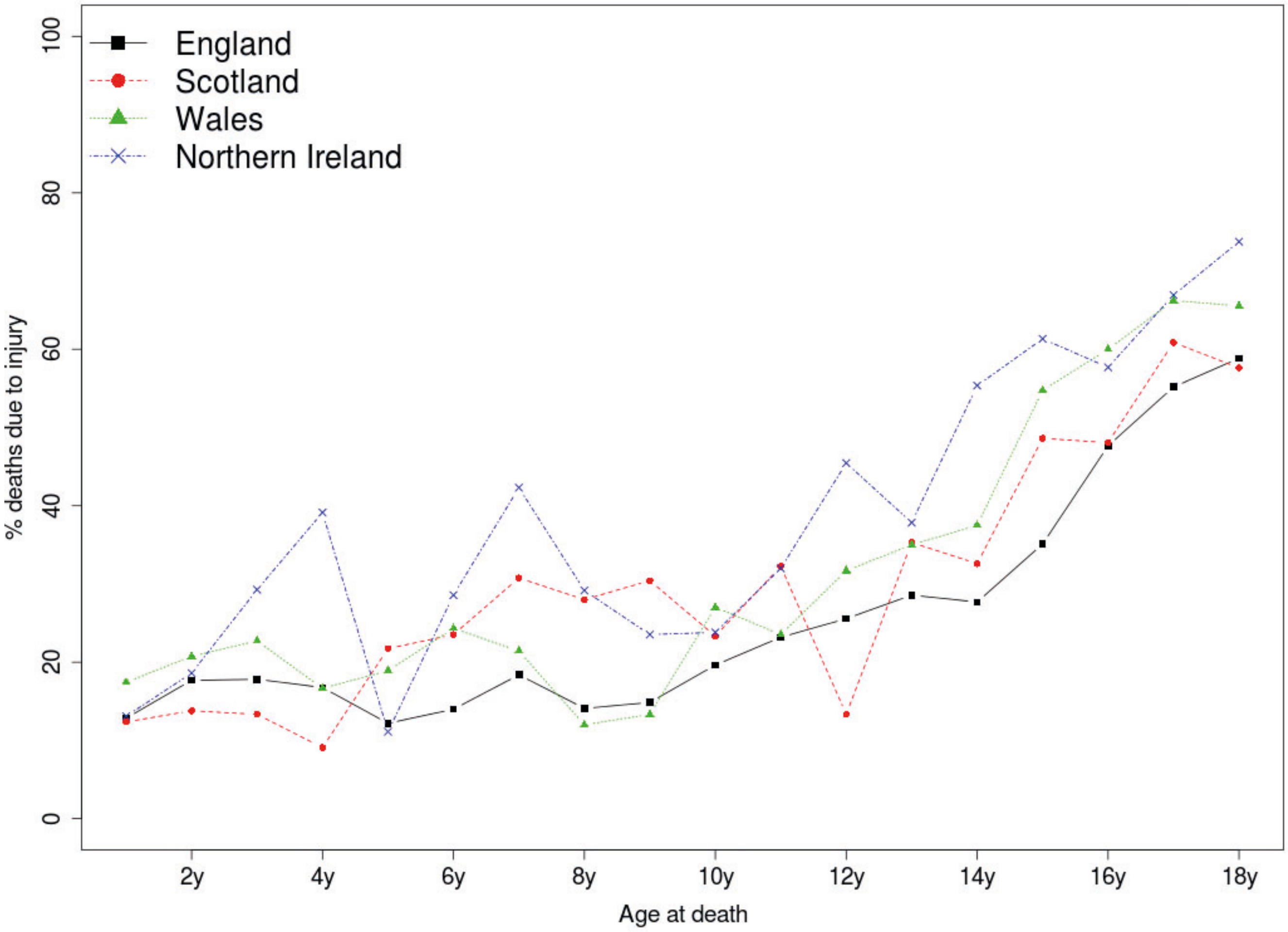
Three-year moving averages applied

Declines were similar for both sexes (data not shown), but were most marked for the one to four age group and least for five to nine and 10 to 14 years. UK mortality rates declined across all nine ICD chapter groups (Figure 3.2). The proportionate decline in each age group varied between 12% and 80%, depending on age group and underlying cause of death.

Injury accounted for 31% to 48% of all deaths between one and 18 years of age in the four UK countries during the most recent time period (2006 to 2010 for England and Scotland, and 2001-2010 for Wales and Northern Ireland). However, the proportion of injury deaths rose steeply with age, accounting for 58% to 74% of injury deaths in 18 year olds (Figure 3.3).

Death rates due to injury were highest for young people aged 10 to 18 years (Appendix 3.2). The highest rates of injury mortality were found among 15 to 18 year old boys. In this age group, injury mortality was approximately three times higher in boys than in girls. Injury mortality was lowest in five to nine year olds.

Figure 3.3: Proportion of child deaths due to injury by country and age at death, England, Scotland (2006-2010), Wales and Northern Ireland (2001-2010)[A]

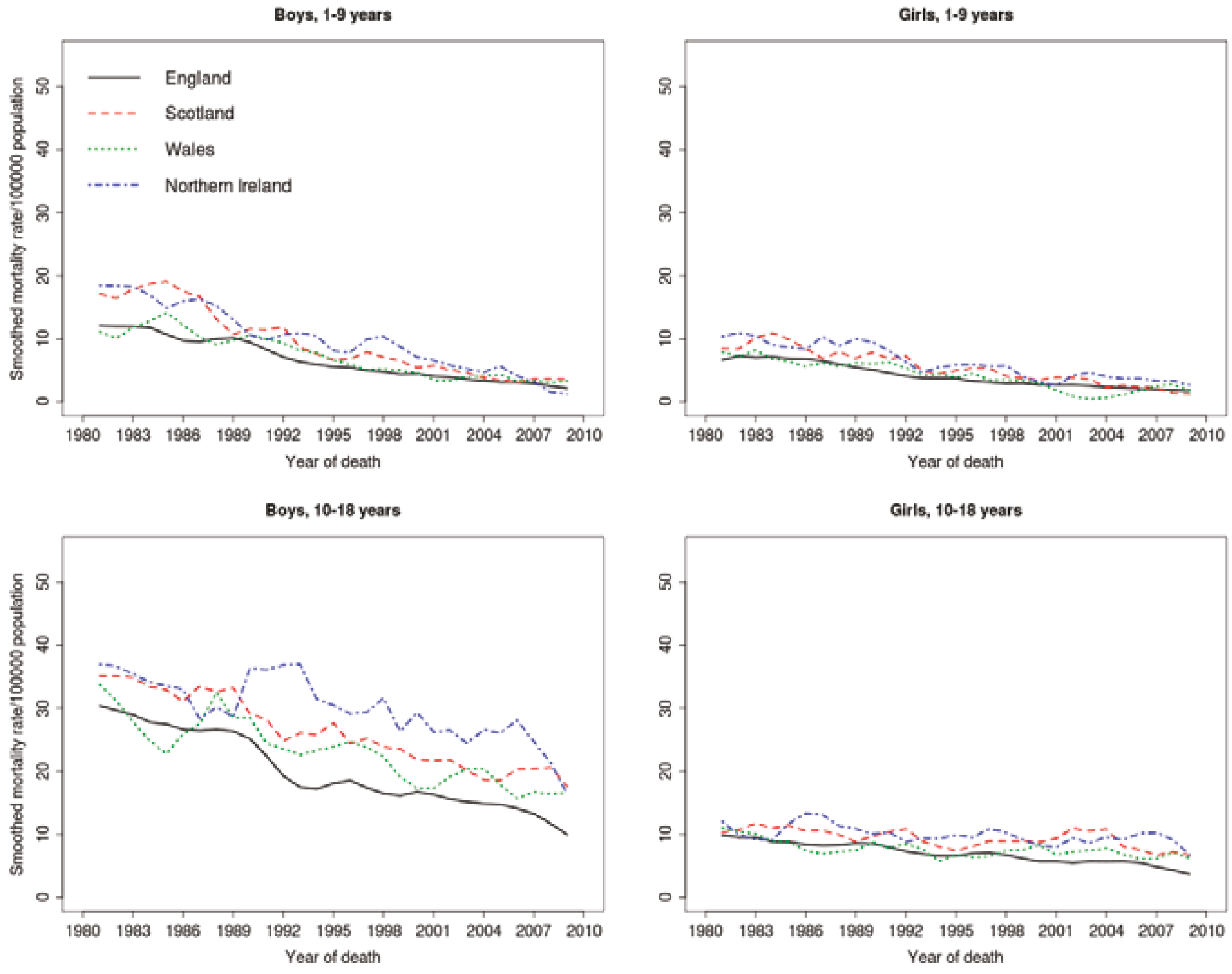


3.3.2 Trends in injury deaths

Rates of death due to injury declined in all four UK countries. England had the lowest mortality due to injury of all four UK countries for each age and sex group and in the majority of time periods between 1980 and 2010 (Appendix 3.2).

[A] Note that a longer time period had to be used for Northern Ireland and Wales to prevent large variations by single year of age due to the small number of deaths in children.

Figure 3.4: Smoothed injury mortality rates by age group, sex, country and year of death

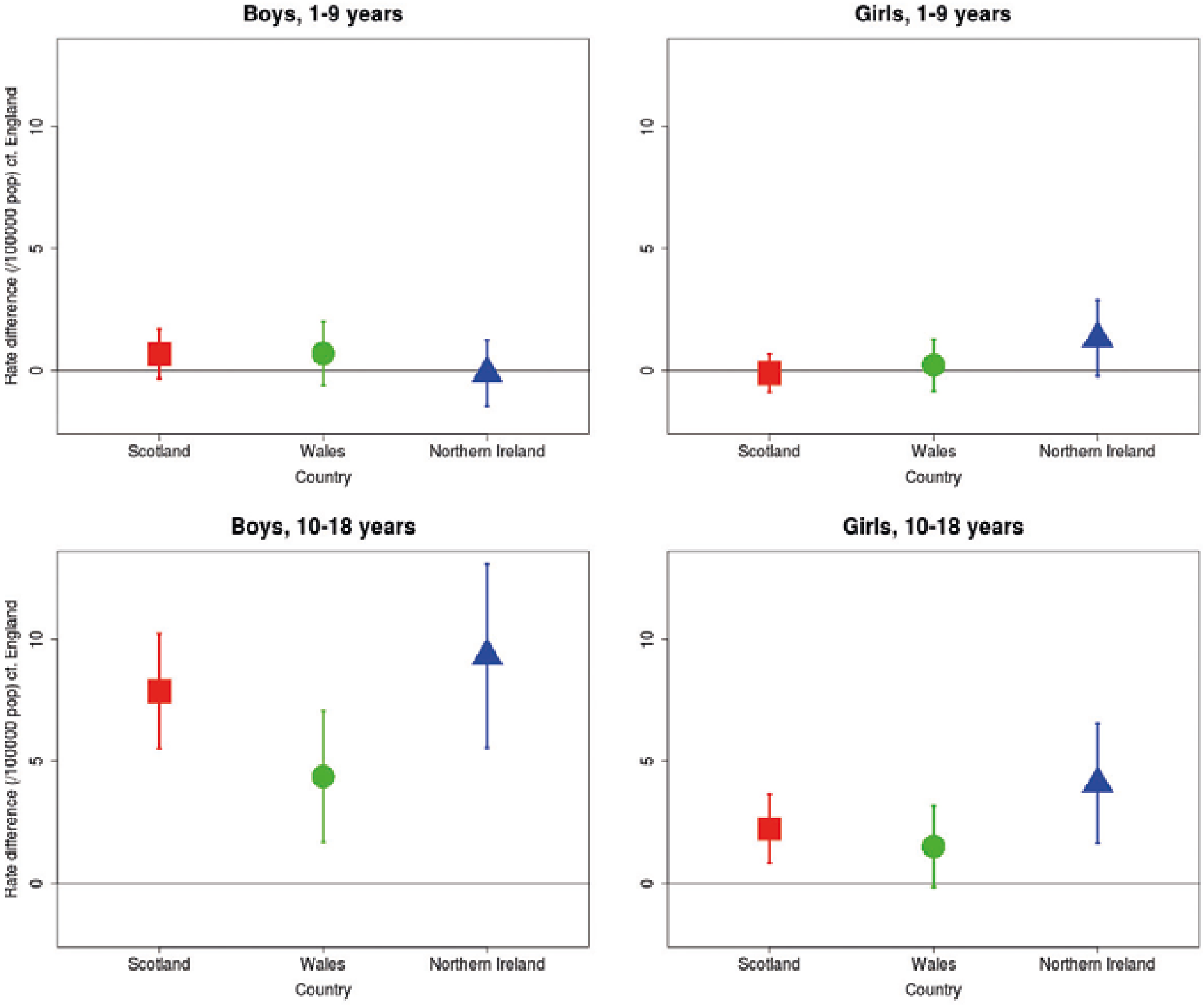


Three year moving averages applied

Rates of decline in injury mortality did not differ significantly between the four UK countries in children aged one to nine years (LR-test *p*=0.38 comparing models including sex, country, and time period with a model also including a time period:country interaction term). However, for older children aged 10 to 18 years the trend was towards increasing disparity, with Scotland, Wales and Northern Ireland experiencing increasingly higher mortality over time compared with England (the addition of a time period:country interaction term improved the fit of the Poisson model; *F*-test *p*=0.02), as shown in Figure 3.4.

In 2006-10, significant differences in rates were found for children aged 10 to 18 years (Figure 3.5).

Figure 3.5: Rate differences by age group and sex in injury mortality rates (2006-2010) comparing England with Scotland, Wales and Northern Ireland respectively.



A rate difference >0 indicates lower injury mortality rates in England

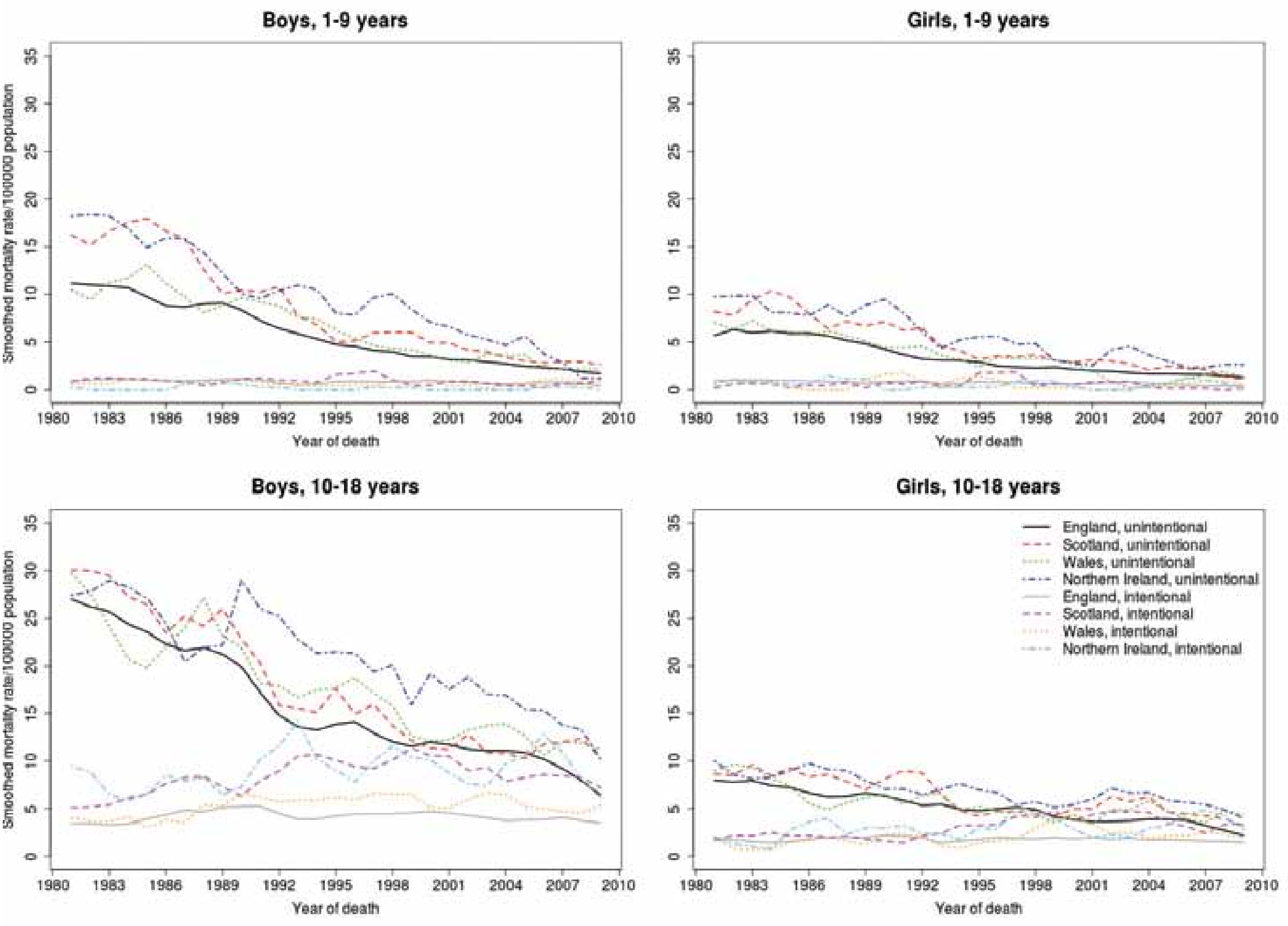
If all UK countries had had the same mortality rate as England for 10 to 18 year old boys, there would have been 113 fewer deaths in Scotland, 39 in Wales and 54 in Northern Ireland during the last five years (2006 to 2010) in this age group. For girls aged 10 to 18 years, there would have been 31 fewer deaths in Scotland and 23 fewer in Northern Ireland if they had experienced the same mortality rates as girls of the same age in England. Differences for girls in Wales were excluded from these calculations as there was no significant difference at the 5% level compared with England.

3.3.3 Type of injury accounting for the decline

Unintentional injuries accounted for over 77% of injury deaths in one to nine year olds (561/725 children – see Appendix 3.6) but for two-thirds of deaths among 10 to 18 year olds in 2006-10 (1976/3043 children). Transport accidents accounted for most of these unintentional injury deaths in both age groups (41% to 77%).

The decline in injury mortality in all four UK countries was accounted for by a decrease in unintentional injury deaths (Figure 3.6). The decline in traffic accidents and other accidents were similar within the two age groups (Appendix 3.6).

Figure 3.6: Smoothed injury mortality rates by sex, age group, country and type of injury, 1980-2010



Three year moving averages applied

There has been no decline since 1980 in intentional causes of injury in any country for boys or girls aged 10 to 18 years. Between 2006 and 2010, intentional injuries accounted for 34.1% (767/2,248) of injury deaths among boys aged 10 to 18 years and 37.7% (300/795) of injury deaths among girls in the same age group across the four UK countries.

3.4 Discussion

We found increased rates of death due to injury in Scotland, Wales, and Northern Ireland compared with England, particularly among older boys. This disparity is widening. Rates of death due to unintentional injury have declined more rapidly in England than in the other three countries. There has been no decline in intentional deaths in the 10 to 18 year group since 1980 in any of the four UK countries.

Similar declines in deaths due to injury have been observed in other European countries,[18] Australia,[19] and the United States,[20] although both the Unites States and Australia have historically had higher mortality from injury than the UK.[21] Increased use of safety measures such as traffic calming, bike helmets, smoke alarms and swimming classes have collectively been linked to the decline in injury deaths in children, although the effects of individual interventions have not been evaluated.[22] Less exposure to traffic as children use cars rather than walk has also been associated with a decline in road traffic accidents.[23]

National level data on poverty, unemployment or school achievement do not show a consistent pattern which could completely explain the observed differences in childhood injury mortality between the UK countries. Similarly, national level data on risky behaviour, including alcohol and drug use in adolescents, are not available for all four UK countries for similar time periods, making comparisons difficult. Appropriate individual level data on socio-economic status with matching population denominators would allow an assessment of how much of the inter-country differences can be explained by socio-economic circumstances.[24-27] Better understanding of the social, educational and health determinants of childhood injury deaths and their variation across the UK requires linkage of death certificates to administrative data from these sectors.[16;28;29] Such linkage is theoretically feasible in all four UK countries provided the legislative framework can be put in place and would inform targeting of preventive strategies.[2]

4. Multiple morbidity recorded on children's death certificates (2006-2010)

Key findings

- Multiple morbidity was most frequently recorded on death certificates across the UK (2006-10) in children whose underlying cause of death was a neurological condition, congenital anomaly, respiratory problem, endocrine or metabolic condition, or mental health problem.
- Respiratory conditions were the most frequently recorded comorbidity but whether these problems were cause or consequence of terminal decline needs evaluation by case note review.

Implications

- Coded information on all causes of death mentioned on death certificates provides useful information on conditions in children who die, which should be used more widely.

4.1 Background and rationale

Conditions mentioned on the death certificate other than the underlying cause of death can provide useful information about what children die with. Analyses of multiple conditions recorded on the death certificate can be used to estimate the proportion of children dying with comorbidity and which conditions occur together. We focused our analyses of multiple conditions on the contribution of respiratory problems as these are commonly recorded and may be preventable. However, non-intervention for respiratory problems may also be the way planned deaths are allowed to occur in children with terminal disease. Although our analyses cannot distinguish whether respiratory problems are a cause or consequence of imminent death, we can show how frequently they occur.

Key questions

- What is the prevalence of multiple morbidity in children who die and how does this vary according to the underlying cause of death?
- What is the frequency of acute respiratory problems in children who die?

4.2 Methods

The underlying cause of death is defined as the disease or injury "which initiated the train of events directly leading to death or the circumstances of the accident or violence that produced the fatal injury" [30] and is recorded on the lowest completed line in part 1 of the death certificate (see Appendix 4.1). Other conditions are recorded as part of the sequence of events directly leading to death in parts 1a or 1b of the death certificate or as contributory conditions in part 2: "Conditions contributing to the death but not directly related to the disease or condition causing it". Up to 14 other conditions can be recorded on the death certificate in addition to the underlying cause (Appendix 3.3).[31]

We identified acute respiratory conditions using ICD-10 codes from chapter 10 ("Diseases of the respiratory system"; codes given in Appendix 4.2). A respiratory condition may be recorded on the death certificate because it directly caused death or because it was part of the terminal sequence of events leading to death, for example a child with heart failure may die from respiratory failure (recorded in part 1a or 1b). An example of a respiratory condition recorded in part 2 would be a child who dies with severe cerebral palsy in whom recurrent inhalation of food contributed to worsening of her condition. We did not include respiratory arrest in our list of acute respiratory conditions (ICD10 code R09.2) as this describes a terminal event not an acute underlying condition.

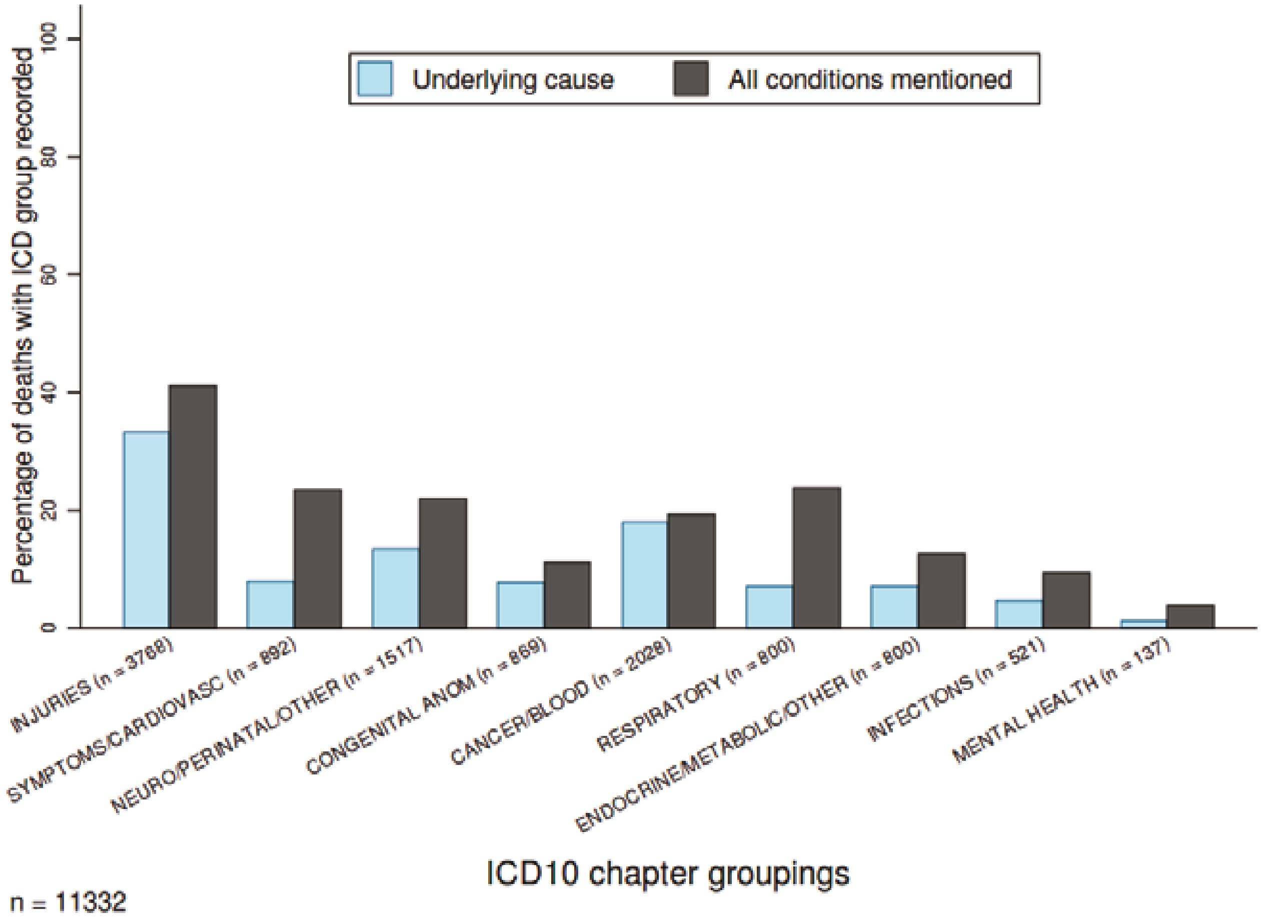
Our analyses combined data for the four UK countries for deaths occurring in 2006 to 2010 to children aged one to 18 years in order to avoid small cell sizes. We categorised all conditions into the nine ICD chapter groups described in chapter 3 (Appendix 3.4) and separately analysed underlying cause from other conditions mentioned elsewhere on the death certificate. We could not separate other conditions mentioned in part 1 from those mentioned in part 2 of the death certificate.

4.3 Results

Children whose underlying cause of death was within the chapter grouping comprising injury, symptoms or cardiovascular or cancer/blood conditions had the lowest rates of comorbidity measured by the fewest ICD chapter groups mentioned on the death certificate. In contrast, children with underlying causes in the group of conditions containing neurological conditions, congenital anomalies, respiratory problems, endocrine or metabolic conditions, or mental health problems, mostly had multiple morbidity as shown by the predominance of two or more chapter groups recorded.

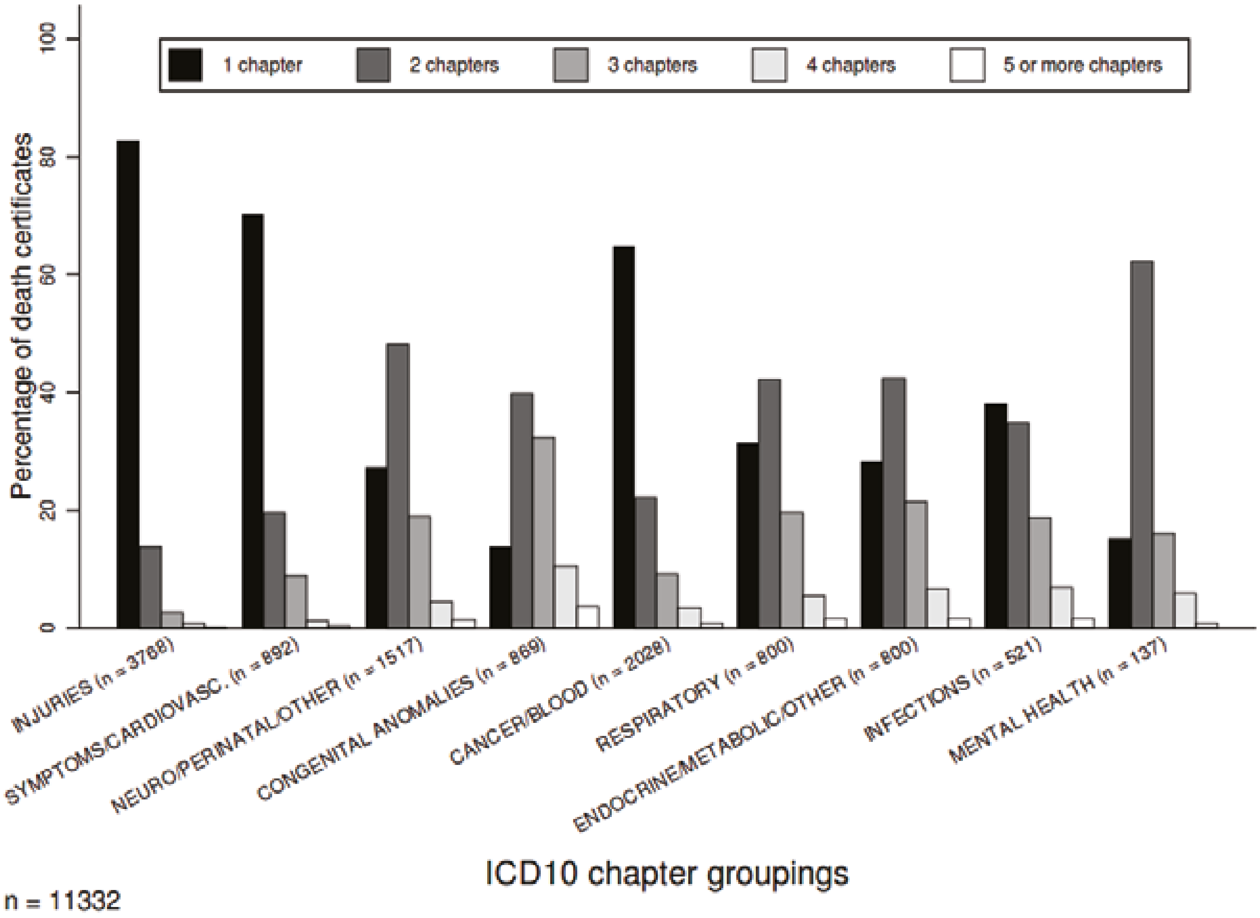
Among children who had cancer/blood conditions or injury mentioned anywhere on the death certificate, these conditions were recorded as the underlying cause of death in 92% and 81% of cases respectively (Figure 4.1). On the other hand, respiratory conditions were the second most frequently mentioned group of conditions but were recorded as the underlying condition in only 30% of deaths. Symptoms and cardiovascular conditions were similarly rarely mentioned as the underlying cause but frequently recorded elsewhere on the death certificate (Figure 4.2).

Figure 4.1: Distribution of child deaths according to underlying cause group and other grouped causes mentioned on death certificates, UK 2006-10



Note that the 'all conditions mentioned' bars add up to more than 100% since death certificates may list several contributing causes.

Figure 4.2: Distribution of child deaths by underlying cause group and number of different chapters mentioned on death certificates, UK, 2006-10



Respiratory conditions were recorded most frequently in children where the underlying cause of death was neurological conditions (49%), congenital anomalies (37%) or endocrine or metabolic conditions (36%). Respiratory conditions were rarely mentioned where injury was recorded as the underlying cause (3%) (Table 4.1). The contribution of respiratory conditions did not vary appreciably according to the age at death (Table 4.2). In all children where the underlying cause of death was within the group comprising neurological conditions, the five most frequently recorded respiratory conditions (accounting for 82% of respiratory mentions) were pneumonia or bronchopneumonia (J180, J189), respiratory failure (J969), other respiratory disorders (J988), and pneumonitis due to food and vomit (J690).

Table 4.1: Deaths grouped by underlying cause of death to show the proportion of other conditions mentioned on the death certificate, UK 2006-2010

Other conditions mentioned on death certificate (excl. ULC)	Underlying Cause Of Death (Ulc)									Total mentions* (%**)
	Injuries	Respira-Tory	Sympt/ Cardio	Neuro/ Perinatal	Cancer/ Blood	Endo/ Meta	Cong Anom	Infections	Mental Health	
	n = 3768	*n* = 800	*n* = 892	*n* = 1517	*n* = 2028	*n* = 800	*n* = 869	*n* = 521	*n* = 137	*n* = 11332
Injuries	-	51 (6.4)	73 (8.2)	138 (9.1)	183 (9.0)	95 (11.9)	238 (27.4)	29 (5.6)	85 (62.0)	892 (19.1)
Respiratory	110 (2.9)	-	71 (8.0)	746 (49.2)	224 (11.1)	287 (35.9)	320 (36.8)	122 (23.4)	23 (16.8)	1903 (70.4)
Symptoms/ Cardiovascular	254 (6.7)	232 (29.0)	-	356 (23.5)	233 (11.5)	198 (24.8)	350 (40.3)	109 (20.9)	27 (19.7)	1759 (66.4)
Neuro/Perinatal/ Other	153 (4.1)	212 (26.5)	67 (7.5)	-	98 (4.8)	145 (18.1)	185 (21.3)	103 (19.8)	12 (8.8)	975 (39.1)
Cancer/Blood	10 (0.3)	26 (3.3)	21 (2.4)	23 (1.5)	-	21 (2.6)	20 (2.3)	51 (9.8)	0 (0.0)	172 (7.8)
Endocrine/ Metabolic/Other	42 (1.1)	89 (11.1)	51 (5.7)	133 (8.8)	104 (5.1)	-	137 (15.8)	64 (12.3)	6 (4.4)	626 (43.9)
Congenital Anomalies	24 (0.6)	112 (14.0)	56 (6.3)	75 (4.9)	43 (2.1)	49 (6.1)	-	37 (7.1)	0 (0.0)	396 (31.3)
Infections	28 (0.7)	90 (11.3)	30 (3.4)	80 (5.3)	183 (9.0)	87 (10.9)	45 (5.2)	-	4 (2.9)	547 (51.2)
Mental Health	190 (5.0)	20 (2.5)	4 (0.5)	44 (2.9)	2 (0.1)	8 (1.0)	15 (1.7)	2 (0.4)	-	285 (67.5)

* Total number of death where condition group is mentioned but NOT as the underlying cause

** Proportion of all deaths (n=11332) where condition group is mentioned but NOT the underlying cause.
Note % sums >100% because of multiple conditions groups recorded for some deaths

Table 4.2. Deaths grouped by underlying cause of death to show the proportion with an acute respiratory condition mentioned on the death certificate, UK 2006-2010

Underlying Cause Of Death Based On Icd Chapter Group*	*n*	% with respiratory mention	% with respiratory mention by age group				% with acute respiratory mention	% with chronic respiratory mention
			1-4years	5-9years	10-14years	15-18years		
Neurological/Perinatal/Other	1517	49.2	51.9	48.6	55.2	43.3	48.8	0.7
Congenital Anomalies	869	36.8	39.3	32.5	32.3	38.5	36.5	0.9
Endocrine/Metabolic/Other	800	35.9	36.3	36.6	39.5	31.7	35.6	0.4
Infections	521	23.4	21.2	30.0	25.9	23.3	23.2	1.0
Cancer/Blood	2028	11.1	13.3	8.0	9.7	12.7	10.9	0.4
Symptoms/Cardiovascular	892	8.0	9.7	9.3	13.2	3.6	7.3	0.8
Injuries	3768	2.9	4.4	6.7	4.0	2.0	2.7	0.3

4.4 Discussion

Our findings are consistent with clinicians' experience that respiratory problems are a frequent complication in children with severe neurological conditions or complex chronic conditions such as congenital anomalies and endocrine/metabolic or other digestive conditions. These respiratory problems include infections, aspiration pneumonia and respiratory events during the child's terminal phase (respiratory failure) but exclude respiratory arrest, which is a terminal event. Using death certificates alone, it is not clear whether these respiratory conditions are a cause or consequence of terminal decline.

Comparative analyses of cohorts of children with these conditions using health care records to track their trajectory of care are needed to determine whether poor quality management of respiratory problems were associated with death or serious morbidity. In parallel, case note reviews or other qualitative analyses of clinical records or parent perspectives might generate insights into the role of respiratory conditions in planned deaths of children with severe life limiting conditions. The recent report from the Child Health Reviews programme, 'Coordinating Epilepsy Care: a UK-wide review of heathcare in cases of mortality and prolonged seizures in children and young people with epilepsies' echoes our findings. Respiratory infection or failure was considered by clinicians conducting case-note review to be the most frequent cause of death for 33 children who died with epilepsy.

5. Variation in child mortality by birth weight and maternal age (1993-2010)

Key findings

- In England, Scotland and Wales, the difference in mortality between children of mothers aged less than 30 years and those with similar birth weight born to mothers aged 30 to 34 years account for 11% of all deaths up to nine years old.
- Deaths in children born to mothers aged less than 20 years account for just one-third of the mortality difference for children of mothers under 30 years (vs 30 to 34 years) or 3.8% of all child deaths up to nine years old.
- Half of the mortality difference for children of mothers under 30 years (vs 30 to 34 years) occurred in the post-neonatal period.

Implications

- Social disadvantage among mothers aged less than 30 years compared with mothers aged 30 to 34 years is linked to higher mortality rates through much of childhood despite accounting for birth weight.
- Universal policies are needed to address disparities in child mortality associated with maternal age.
- The greatest potential gains are through reducing disparities in post-neonatal mortality.

5.1 Background and rationale

Low birth weight and young maternal age are major risk factors for infant mortality.[32-34] Young maternal age is a marker of social disadvantage which has important health effects throughout childhood and well into adult life despite accounting for birth weight.[35] However, enduring effects of young maternal age on deaths in later childhood are hard to detect because of the low number of deaths after the first year of life. Evidence using data for the whole country are needed.[36]

The results are important for policy makers who need to know whether increased rates of child deaths linked to young maternal age are explained by biological disadvantages at birth, such as low birth weight, or whether the social disadvantage of young motherhood continues to contribute to the risk of child death after taking into account the child's condition at birth.[36] A persisting link between social disadvantage and increased risks of child death would raise the need for preventive policies after birth that effectively diminish the hazards for children living in disadvantaged circumstances.[37] Policy makers also need to know which groups of children are at highest risk and what proportion of child deaths might be affected by preventive strategies that target only high risk groups.[38]

The analyses in this chapter are limited to birth weight and maternal age because these are markers of biological and social disadvantage that are routinely recorded on death certificates. We use birth cohorts to determine the association between young maternal age and the risk of child death after taking birth weight into account.

Key questions

- How does the decline over time in child mortality vary according to birth weight and maternal age?
- How does the increase in mortality with low birth weight and young maternal age change as children grow older?
- Do disparities in child mortality according to maternal age remain after taking into account birth weight?

5.2 Methods

5.2.1 Birth cohort linked to death records

We used a birth cohort based on birth registration data linked to death certificate data to determine the effects of birth weight and maternal age on infant and child mortality. Multiple births were excluded from the analysis.[39] We also excluded births weighing less than 500g due to the large number of improbable weights in this group, which are likely to be due to recording errors.

Descriptions of data sources and data cleaning algorithms are given in Appendix 5.1. In brief, in England and Wales, singleton birth registrations from 1st January 1993 to 31st December 2010 were linked to deaths registered up to end of September 2012. In Scotland, we derived a birth cohort ending in deaths from the linked dataset provided by Information Services Division (ISD) Scotland.

5.2.2 Denominator data

Denominator populations were provided for singleton births as aggregate data grouped by maternal age, birth weight (500g groupings) and calendar year by ONS and NRS through ISD Scotland (Appendix 5.1). As social class is coded for only 10% of live births in England and Wales, we did not examine this factor. As for the numerator, we excluded births weighing less than 500g from the denominator as described in Appendix 5.2.

We grouped birth weight into three categories (very low birth weight 500 to 1499g, low birth weight 1500 to 2499g, and ‘normal’ birth weight, 2500g+) and maternal age into five categories (<20, 20 to 24, 25 to 29, 30 to 34, and 35+ years). Age at death was grouped as neonatal (zero to 27 days), post-neonatal (28 to 364 days), one to four years, five to nine years, 10 to 14 years and for Scotland, 15 to 18 years.

5.2.3 Statistical analyses

To avoid small numbers in some subgroups, data for England and Wales and Scotland were analysed by grouped calendar period for births occurring in 1993-2001, 2002-2010, and for Scotland, 1981-1992. Deaths in children aged 10 to 14 years or more were examined only for children born in 1993-1996 in England and Wales (and in 1981-1996 in Scotland), since this allowed complete follow-up time for all children born in this period.

To determine disparities associated with low birth weight and maternal age for each child age group at death and calendar period, we calculated risk ratios and 95% confidence intervals (CIs). We used birth weight above 2500g and maternal age between 30 and 34 years as the baseline comparison groups representing the least disadvantaged populations. Multivariable models were used to determine the relative effect of maternal age on mortality whilst adjusting for the effect of birth weight. These models used combined data for England, Wales and Scotland in the model to avoid small group sizes (details of methods for data cleaning and analyses in Appendix 5.2).

5.3 Results

We analysed 68520 births linked to death registrations in England and Wales between 1993 and 2010 and 14588 births linked to death registrations in Scotland between 1981 and 2010. Taking results for a single year of births in 1993, 5003 out of 671263 children in England and Wales (rate 745/100,000 live births) and 484 out of 61201 children in Scotland (791 /100,000 live births) had died by age 14 years (i.e. 0.7% to 0.8% died before their 15th birthday).

In the latest birth cohort (2002-2010), 0.8% to 0.9% of babies were born with very low birth weight and 5.6% to 5.9% with low birth weight (<2500g). 6.8% to 7.6% of mothers were less than 20 years when their baby was born and 7.9% of these weighed less than 2500g. In contrast, 28.3% to 28.4% of births were to mothers aged 30 to 34 years and 5.2% of their babies weighed less than 2500g at birth (Table 5.1).

Table 5.1: Number of live births by birth weight, maternal age and country, 2002-2010

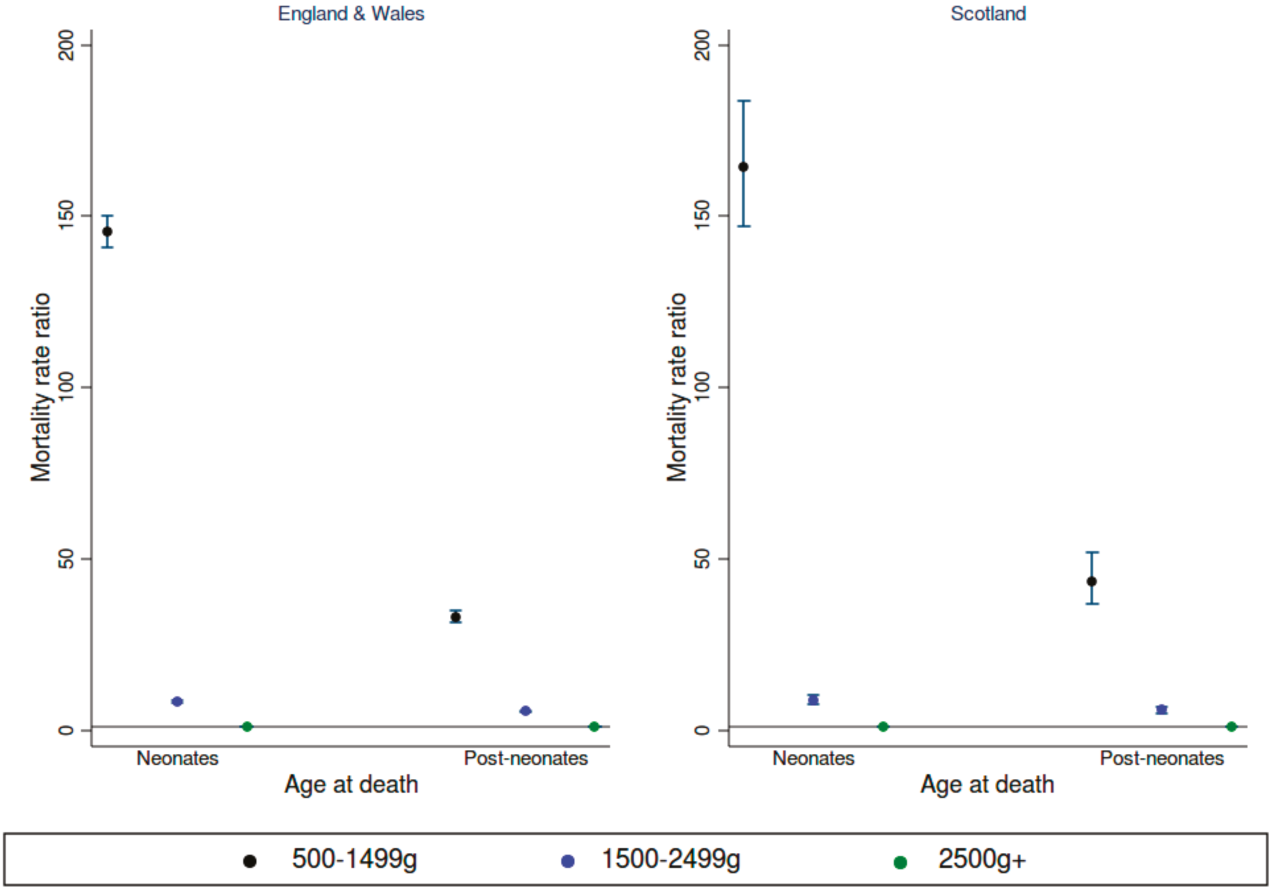
Birth weight	England & Wales *n* (%)	Scotland *n* (%)
500-1499g	52826 (0.9%)	3824 (0.8%)
1500-2499g	286245 (5.0%)	22929 (4.8%)
2500g+	5408752 (93.5%)	451827 (94.3%)
Not stated	32309 (0.6%)	322 (0.1%)
Total	5782413 (100%)	479067 (100%)
Maternal age	**England & Wales *n* (%)**	**Scotland *n* (%)**
<20 yrs	390044 (6.8%)	36281 (7.6%)
20-24 years	1111036 (19.2%)	90433 (18.9%)
25-29 years	1523503 (26.3%)	123503 (25.8%)
30-34 years	1639380 (28.4%)	135859 (28.3%)
35 years+	1118437 (19.3%)	92985 (19.4%)
Not stated	13 (0.0%)	6 (0.0%)
Total	5782413 (100%)	479067 (100%)

5.3.1 Birth weight

As expected, there was a steep decline in the relative risk of death associated with low birth weight as children grow older. This is shown by the diminishing relative risks for low birth weight compared with birth weight of 2500g+ as children grow older (Figure 5.1, Figure 5.2 and Appendix 5.3). Nevertheless, there was a persisting, significant disadvantage of low birth weight in late childhood. For example, children born in England and Wales with low birth weight had a two to three-fold increased risk of death at 10 to 14 years of age which was statistically significant at the 5% level.

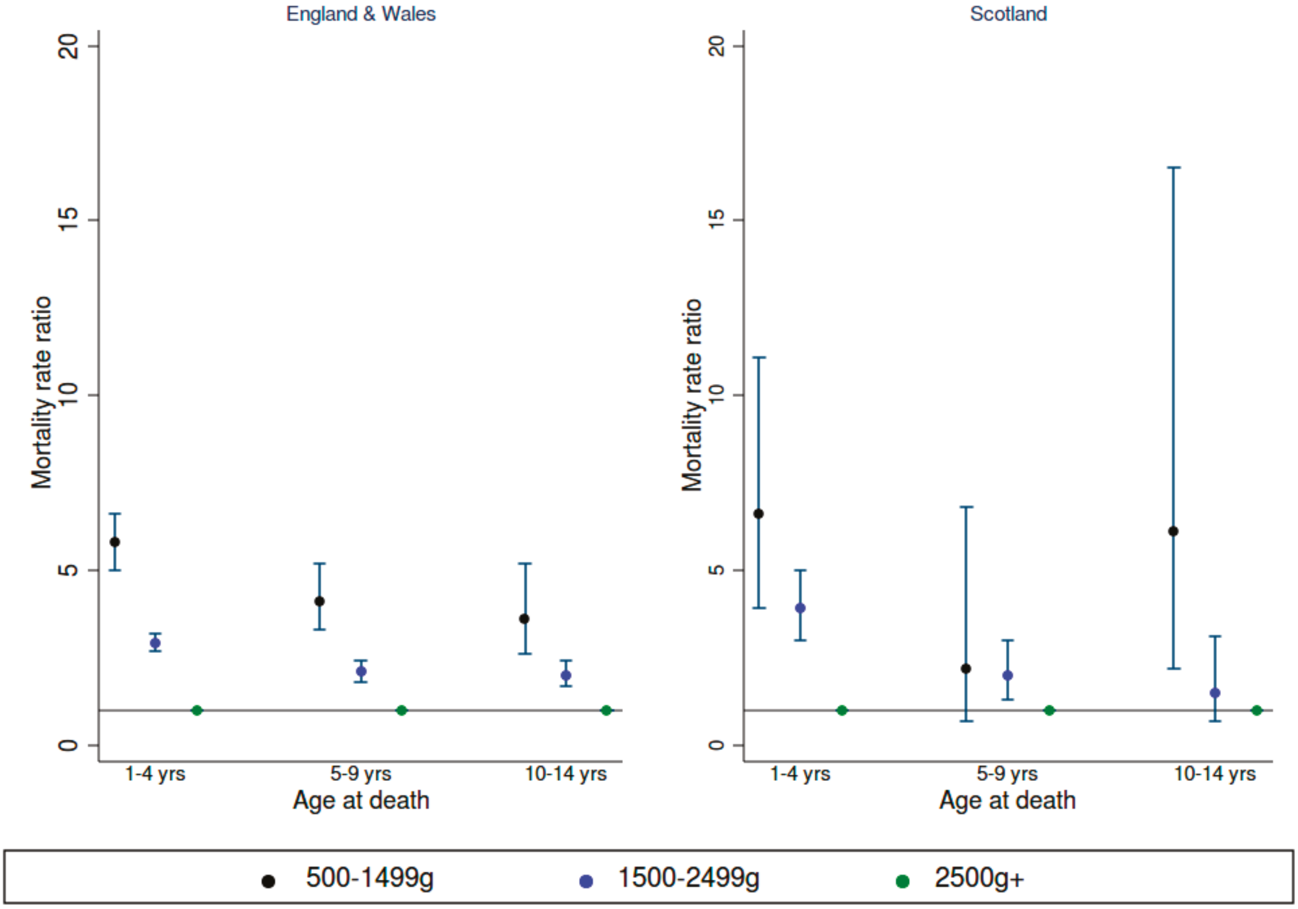
Mortality reductions were seen over time from the early period (1993-2001) to the later period (2002-2010) across all birth weight groups (Appendix 5.3). The relative association between birth weight and mortality did not change over time for neonates but increased for post-neonates and children aged one to four years. We found similar patterns in Scotland, although the 95% confidence intervals are wider due to fewer deaths (Figure 5.1, Figure 5.2 and Appendix 5.3).

Figure 5.1: Mortality rate ratios by birth weight, country and age group at death (neonates/post-neonates), 1993-2010



Time period indicates year of birth

Figure 5.2: Mortality rate ratios by birth weight, country and age group at death , 1993-2001 and 1993-1996 (children aged 10 to 14 years)



Time period indicates year of birth

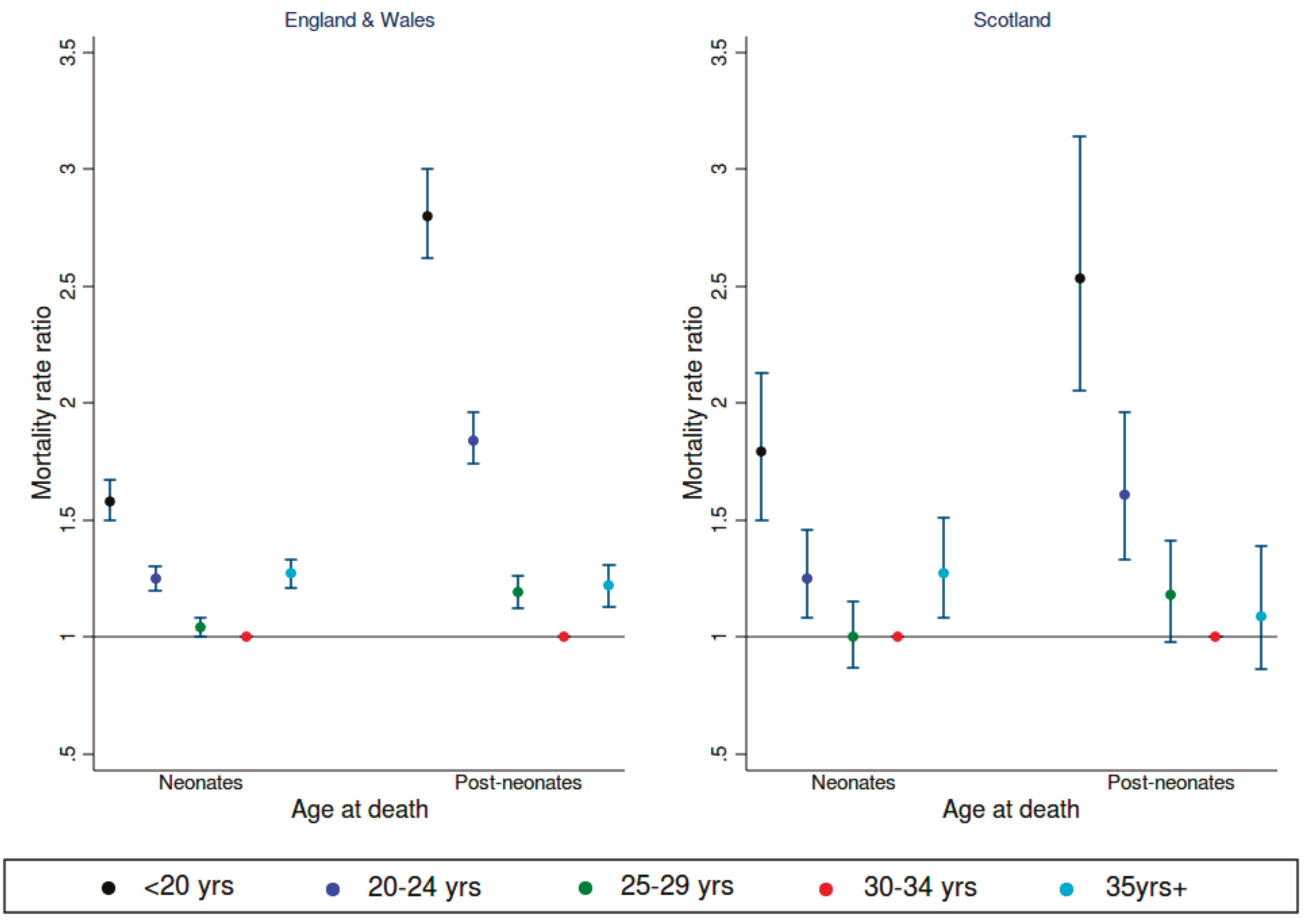
5.3.2 Maternal age

Children born to mothers aged less than 20 years had higher mortality in infancy and throughout childhood than children born to mothers aged 30 to 34 years. The increased risk of death for children born to mothers under 20 years old remained significant at the 5% level in England and Wales throughout childhood, including for children dying at 10 to 14 years of age (Figure 5.3, Figure 5.4 and Appendix 5.4). Similar patterns, but with smaller relative risks were seen for children of mothers aged between 20 and 29 years.

Among infants, relative risks for young maternal age compared to mothers aged 30 to 34 years (used as the baseline) were larger for post-neonatal deaths than for neonatal deaths. This finding may reflect compensatory care for high risk children of disadvantaged mothers by hospital services during the neonatal period, followed by a widening gap during the post-neonatal period when care is more likely to be provided in the home (Figure 5.3). Children of mothers aged 35 years and over had increased mortality during early childhood. This may partly relate to increased mortality risks due to congenital malformations and other complications associated with increased parity and maternal age.

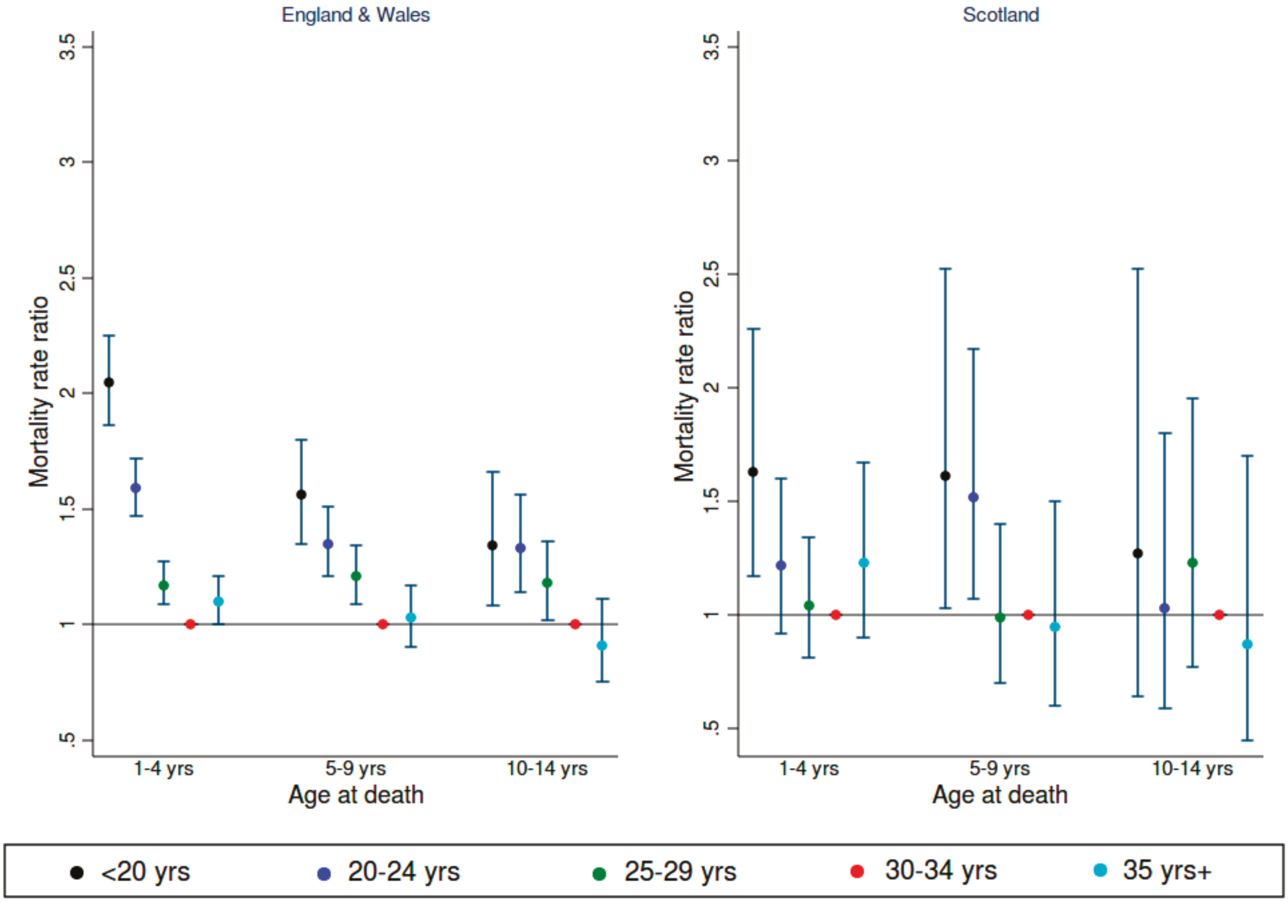
Mortality rates decreased over time from the early (1993 to 2001) to the later period (2002 to 2010) across all maternal age groups (Appendix 5.4). The relative association between young maternal age and mortality, measured by the rate ratio, did not change appreciably over time (Appendix 5.4). Although children born to the youngest mothers had the highest risk of death, many more deaths occurred among children born to young mothers aged 20 to 25 and 25 to 29 years than to mothers aged less than 20 years (Appendix 5.4). Similar patterns in the association between maternal age and child mortality were found for Scotland, albeit with wider 95% confidence intervals.

Figure 5.3: Mortality rate ratios by maternal age, country and age group at death (neonates/ post-neonates), 1993-2010



Time period indicates year of birth

Figure 5.4: Mortality rate ratios by maternal age, country and age group at death, 1993-2001 and 1993-1996 (children aged 10 to 14 years)



Time period indicates year of birth

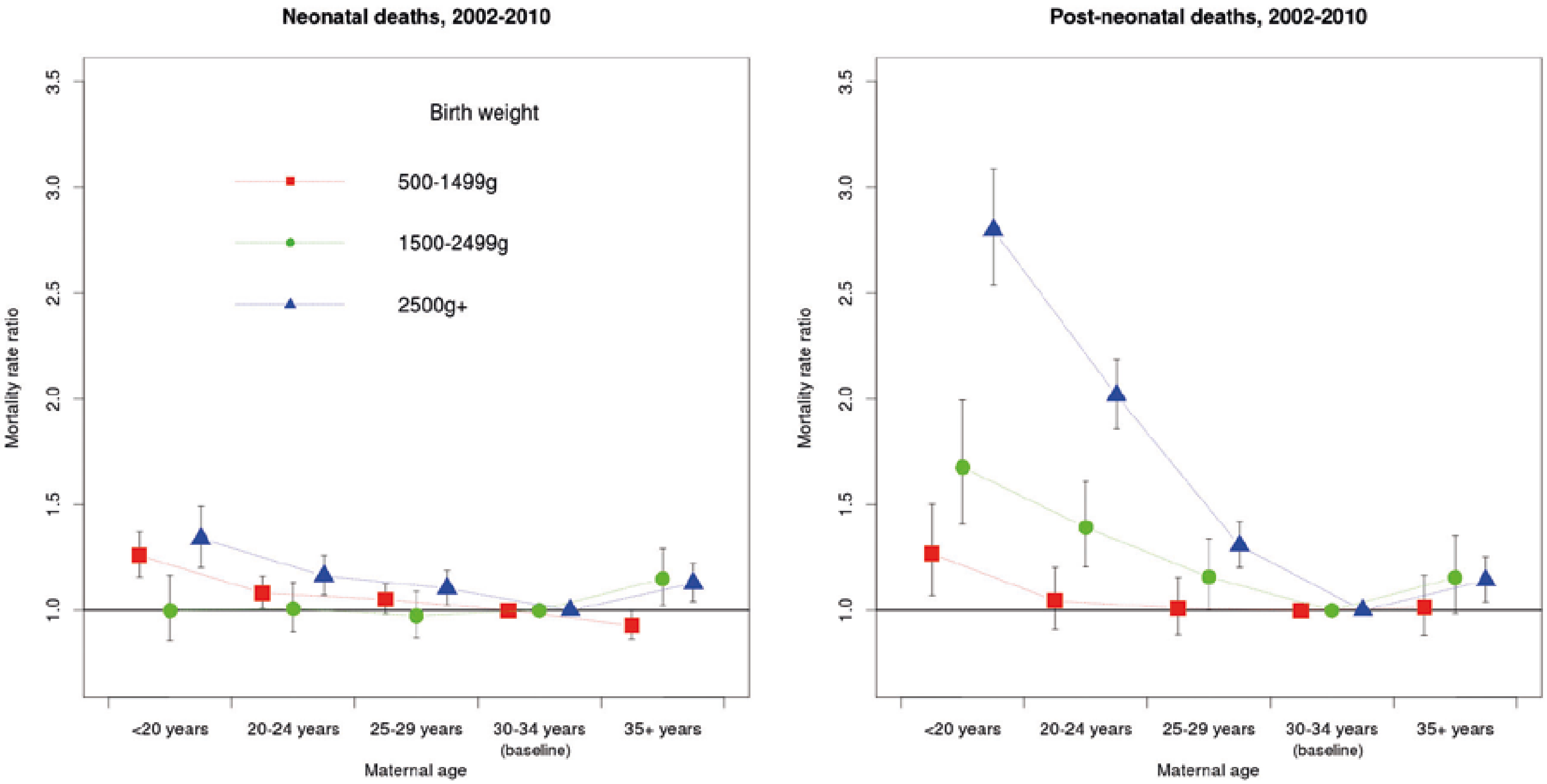
5.3.3 Disparities in child mortality associated with maternal age after accounting for low birth weight

Maternal age was significantly associated with mortality among all children aged less than 10 years at death after adjusting for birth weight (Figure 5.5 and Figure 5.6), but not for children aged 10 years or over (LR-test $p=0.13$). Among neonates and post-neonates, the association between maternal age and mortality differed significantly according to birth weight category (LR-test $p<0.001$); the association between maternal age and mortality was stronger among children in the heaviest birth weight group (Figure 5.5). In infants, an inverse J-shaped relationship between maternal age and mortality was apparent – children born to women aged less than 30 and over 35 years were at increased risk of death compared to children born to women aged 30 to 34 years.

Disparities due to maternal age adjusted for birth weight were lowest in the neonatal period, when outcomes for high risk babies are strongly related to risk factors present at birth (eg: gestation, congenital anomalies, birth asphyxia) and the quality of health care. The largest effects of maternal age were seen among post-neonates with normal birth weight with smaller effects of maternal age for babies weighing 500 to 1500g. These patterns may reflect effects of parental care for babies weighing over 2500g and more intensive engagement with healthcare services for babies with low birth weight. Among post-neonates, 22.5% of deaths in the UK are due to unexplained causes, which are strongly associated with maternal alcohol use, smoking and deprivation.[40]

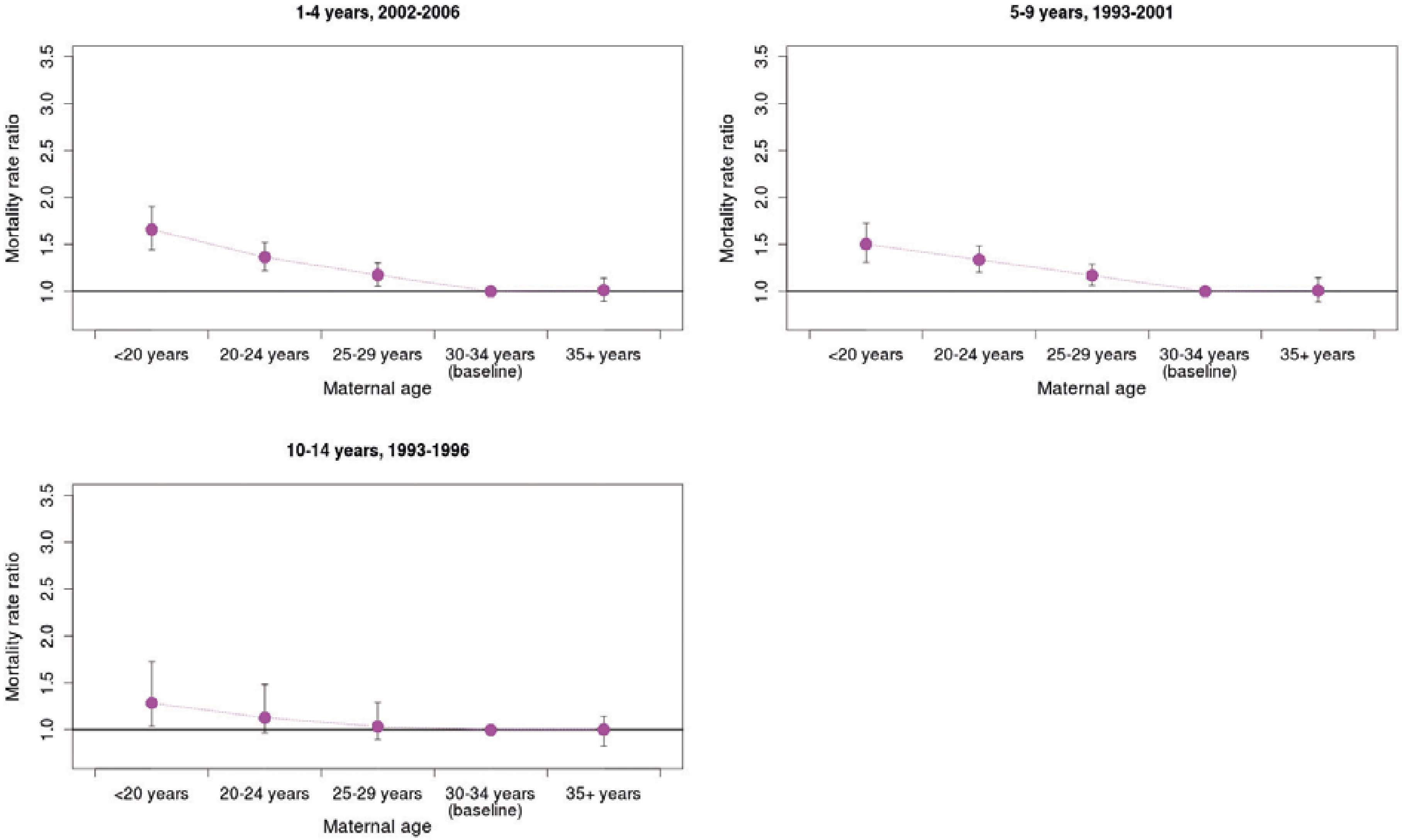
In children aged one to nine years at death, only maternal age at birth under 30 years was associated with higher mortality compared to a maternal age of 30 to 34 years. The association between maternal age and mortality did not vary significantly according to birth weight; therefore mortality rate ratios are not shown separately according to birth weight for children aged one year or more (Figure 5.6).

Figure 5.5: Mortality rate ratios by maternal age at birth (compared to 30 to 34 year old mothers) by age group at death (neonates/post-neonates), England, Scotland and Wales, 2002-2010



Time period indicates year of birth. Data is shown combined for the three countries.

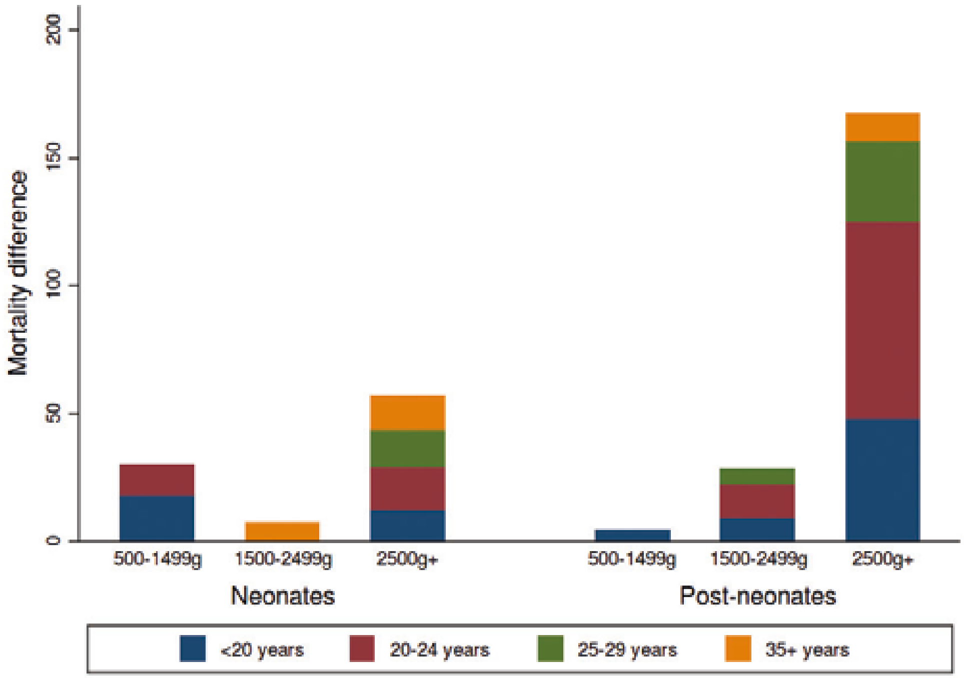
Figure 5.6: Mortality rate ratios by maternal age at birth (compared to 30 to 34 year old mothers) by age group at death, England, Scotland and Wales, 2002-2006 (one to four year olds), 1993-2001 (five to nine year olds) or 1993-1996 (10 to 14 year olds)



Time period indicates year of birth. Data is shown combined for the three countries.

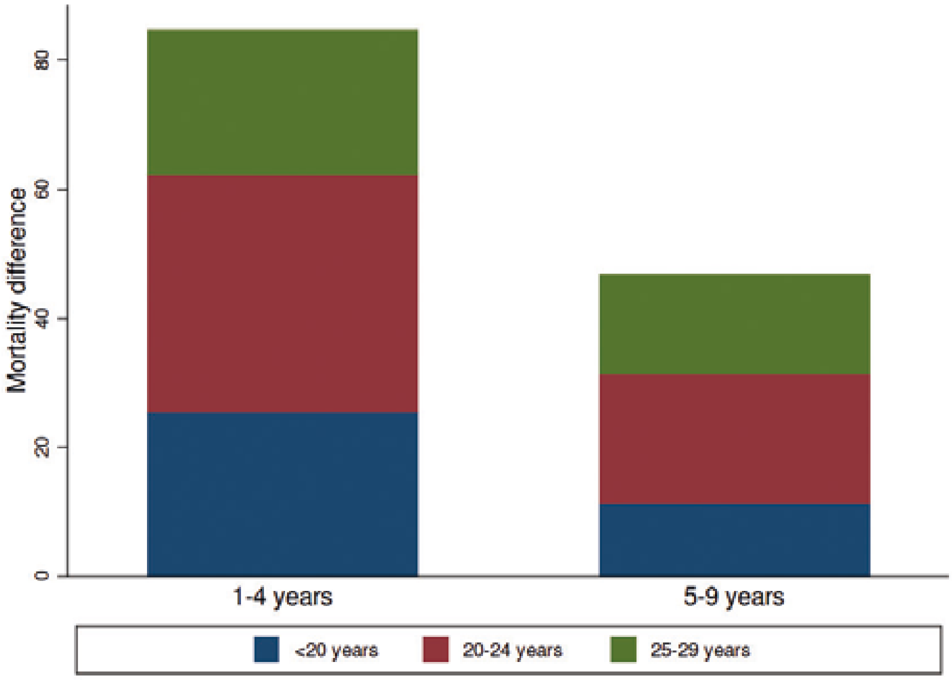
We calculated the average difference in the number of deaths in one year in England, Scotland and Wales for children born to mothers aged less than 30 years compared with children of mothers aged 30 to 34, with a birthweight adjusted mortality rate ratio compared to 30 to 34 year olds where the 95% CI did not include 1 (Figure 5.7, Figure 5.8, Appendix 5.5 and Appendix 5.6). We did not calculate rate differences for children of mothers aged 35 years or more as mortality rates for this maternal age group differed only for some neonatal and some post-neonatal birth weight groups. Differences were not calculated for children who died aged 10 to 14 years as maternal age was not significantly associated with mortality after adjusting for birth weight.

Figure 5.7: Average yearly mortality difference by maternal age group (compared to 30 to 34 year olds), by age at death (neonates and post-neonates), England, Scotland and Wales, 2002-2010



Data is shown combined for the three countries. Estimated mortality differences are adjusted for birth weight.

Figure 5.8: Average yearly mortality difference by maternal age group (compared to 30 to 34 year olds), by age at death, England, Scotland and Wales, 2002-2006 (one to four year olds), 1993-2001 (five to nine year olds)



Data is shown combined for the three countries. Estimated mortality differences are adjusted for birth weight.

There were on average 695718 births per year in 2002-2010 of which 363867 (52%) births were to mothers aged less than 30 years and 134602 (19%) were to mothers aged 35 years and over. If all children born to mothers aged less than 30 years had the same mortality rate as children born to mothers aged 30 to 34 years, there would have been 397 fewer deaths in children aged up to 9 years each year. These calculations are based on groups where rates differed significantly from those for children of mothers aged 30 to 34 years. This difference in death rates between children of mothers aged less than 30 years and those aged 30 to 34 years comprises 11% of the total number of deaths per year (397/3472).

Two-thirds (266/397) of the mortality difference for children of mothers under 30 years (vs 30 to 34 years) was in infants (19%, 76 in neonates, and 48%, 190 in post-neonates), one fifth was in children aged one to four (84/397, 21%), and 12% (47/397) was in children aged five to nine years old (Appendix 5.5). Only one-third (33%; 132/397) of the mortality difference was in children born to mothers aged less than 20 years at delivery, accounting for 3.8% of all deaths.

5.4 Discussion

Children born to mothers less than 30 years old had an increased risk of death compared with children of mothers aged 30 to 34 years. This association persisted for children up to nine years of age and is independent of the association with low birth weight. Differences in mortality between children of young mothers (<30 years) and mothers aged 30 to 34 years accounted for an average of 397 deaths in the UK each year, or 11% of all child deaths aged 0 to nine years. Only one third of this mortality difference occurred in children of mothers aged less than 20 years. Despite declines in mortality rates across all child age and birth weight groups since the 1990s, the increased risk associated with maternal age has not changed appreciably.

Decreasing rates of pregnancy in young mothers is a policy priority in many developed countries. By their 18th birthday, 7.3% of girls in England have had a pregnancy;[41] 56% of these continue to a live birth.[42] Poorer socio-economic status is strongly linked with under-18 conception rates, which are four times higher in the most deprived wards in England and Wales compared to the most affluent.[43] Women with higher educational qualifications tend to delay their first birth,[44] leading to a selection effect of low-risk women and their subsequent children into older maternal age groups. The differences in mortality for children of young mothers compared with mothers aged 30 to 34 years are therefore likely to be strongly related to socio-economic status. In effect, young maternal age at birth is a marker of social disadvantage.

We found that children born to mothers aged less than 30 years had a higher risk of dying than children with a similar birth weight who were born to mothers aged 30 to 34 years. The reasons for why these differences in mortality by maternal age are observed are complex. We could not tease out which of the many environmental, social and biological factors explain this association as risk factors such as mother's socio-economic status, level of education, ethnic group, health status and gestational age at birth and parity were not recorded on all birth certificates. Coded data on socio-economic status, as recorded by father's occupation on the birth certificate, is available for births in Scotland and for 10% of live births in England and Wales and parity has been recorded only for married women.

Our findings have implications for policies to reduce child deaths and improve child wellbeing. Policies to reduce teenage pregnancies are beyond the scope of this report. Services targeted at mothers under 20 years, such as the Family Nurse Partnership, would miss a large proportion of the mortality difference associated with mothers aged less than 30 years – a group that accounts for 52% of all births. However, targeting half of all births would be inefficient and parents at all ages and in all socio-economic groups need support at times to reduce risks of child death or other serious outcomes. These findings argue for improvements in universal support and services for all children and their parents.

Future research should use large, population-based, healthcare datasets to examine the interrelationships between socioeconomic status, maternal age and child deaths, taking into account measures of biological disadvantage at birth such as birth weight, gestational age, parity, Apgar score, and neonatal intensive care admission. These analyses are achievable in Scotland, where births, deaths and neonatal care are already linked to hospital administrative data. In England and Wales, such analyses would be possible given linkage of birth registration and NHS Numbers for Babies (NN4B) to hospital administrative data. Such linkage would ensure complete data capture of all births (including those outside hospital), accurate data on birth weight and gestational age, and would allow examination of the cause of death.

6. Children who died with a chronic condition (2001-2010)

Key findings

- Two-thirds of children who died in England, Scotland or Wales had a chronic condition.
- Between 30% to 40% of children who died were affected by a neurological/sensory condition, more than any other group of conditions.
- Information solely from death certificates underestimates the proportion of children who died with a chronic condition.

Implications

- Efforts to prevent deaths in children aged one to 18 years need to focus on improving the quality of care for children with chronic conditions.
- More information is needed on the proportion of children who die whose chronic conditions are terminal and who might benefit from improved end of life care.
- Linkage between death certificates and hospital records provide a cost-effective and thorough method for examining chronic conditions in children who die.
- Further linkage to primary care data would provide a more complete picture of chronic conditions in children.

6.1 Background

Mortality from infections and injuries in previously healthy children has decreased in the UK since the 1980s (see chapter 3). An increasing proportion of deaths now occur in children with complex health problems[45] who already have regular contact with health services. We hypothesised that improvements in quality of health care for these children could lead to reduced mortality.[1;46] In this chapter, we report on the burden of chronic conditions in children who die.

Identifying children who die with chronic conditions is not straightforward. As described in chapters 3 and 4, death certificates capture the underlying cause of death and other relevant conditions, but there is evidence that these records often miss important underlying chronic conditions.[47]

Linkage between death certificates and hospital records offers a more systematic and reliable way of capturing information about conditions affecting children who were admitted before death. We expect that with more information from the hospital trajectory, more chronic conditions will be identified. We tested this hypothesis using linked data from death certificates and hospital records from England, Scotland and Wales. Because injury is the most frequent cause of death in children over one year of age (see chapter 3), we examined the proportion of deaths due to injury in children with a chronic condition and the proportion of injury deaths involving children with a chronic condition.

Key questions

- What proportion of children who died had a chronic condition?
- How did the proportion of children who died with a chronic condition vary according to the amount of information included from the child's hospital trajectory?
- What proportion of children who died with a chronic condition died of an injury?
- Of children who died of injury, what proportion had a chronic condition?

6.2 Methods

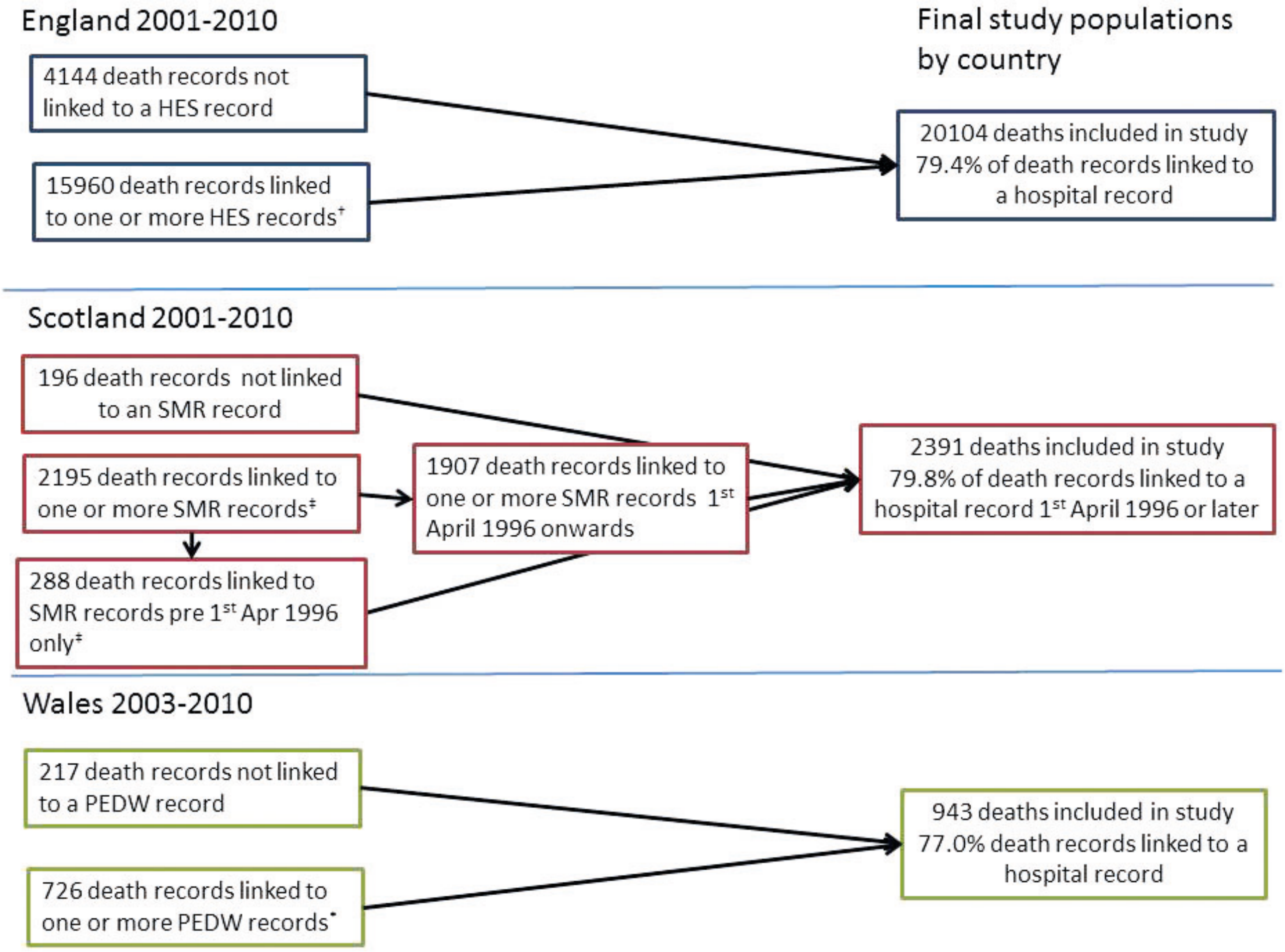
6.2.1 Study population

We used death certificates from children aged one to 18 years who were residents of England, Scotland or Wales at the time of death. Death certificates from the three countries were linked to HES for England, the Scottish Morbidity Record (SMR) and the PEDW for Wales. Methods used to link death certificates to HES have been described elsewhere and data sources are described in chapter 2.[48] Scottish death certificates were linked to SMR using names, dates of birth and post codes using a probabilistic algorithm which has been described elsewhere[49] and Welsh death certificates were linked to PEDW using the NHS number. A summary of the characteristics of the linked data sources used in this study can be found in Appendix 6.1. Linked records were cleaned and hospital admissions linked according to the algorithm described in Appendix 6.2.

We included any child deaths that occurred on or after the 1st January 2001 since this was when England and Wales introduced coding of causes of death on death certificates using ICD-10 (Scotland introduced ICD-10 coding for death certificates in 2000). In Wales, multiple cause coding on death certificates was only provided for deaths registered 2003 onwards. Therefore, the study period for Wales was 2003-2010. Deaths certification data were linked to hospital admissions records that contained information on diagnoses identified during admission that were coded using ICD-10 from 1st April 1997 in England, 1st April 1996 in Scotland and 1st January 1998 in Wales. Consequently, children with linked data from hospital admission records had different amounts of longitudinal data depending on their age and their year of death. For example, a child who died in England aged 18 in 2001 would have up to five years of hospital data available, whereas a child who died aged 13 in 2010 would have 13 years of longitudinal hospital data available.

The proportion of death certificates successfully linked to a hospital record with ICD-10 coding is shown in Figure 6.1. We assumed that failure to link indicated no hospital admissions in the NHS during the preceding years for which hospital data were available. A very small, but unquantified proportion of these cases are children who did have a prior admission but whose records failed to be linked.

Figure 6.1. Number of deaths in children aged one to 18 years and percentage of children's death certificates linked to a previous hospital admission by country



†Linked HES records are available for admissions ending 1st April 1997 onwards

‡Linked SMR records are available for admissions ending 1st January 1981 onwards; universal diagnosis coding in ICD-10 began for admissions ending on 1st April 1996 onwards

*Linked PEDW records are available for admissions ending 1st January 1998 onwards

6.2.2 Identifying children with chronic conditions

To identify children with chronic conditions we developed a list of ICD-10 codes indicating chronic conditions in children. This work, which involved a multi-step iterative process, was undertaken in collaboration with a panel of clinicians. A more detailed outline is provided in Appendix 6.3. Our code list builds on published, validated code lists for chronic conditions in children.[45;50-55] In brief, we defined a chronic condition as any health problem requiring follow-up by health services in more than 50% of cases, where follow-up could be repeated hospital admission, specialist follow-up through outpatient department visits, medication, or use of support services such as physiotherapy. This definition is more sensitive than previously published definitions of chronic conditions in children.[45;56;57]

The final list of ICD-10 codes indicating chronic conditions can be found in Appendix 6.3. We categorised chronic conditions into eight groups to ensure sufficient numbers of children to make statistically sound comparisons. Conditions were grouped according to the likely clinical pathways or specialist input required to manage the conditions. The conditions listed below in brackets show some of the most frequently occurring codes on hospital records from children who died in each group:

1. **mental health/behavioural conditions** (learning disability, mental retardation, self-harm)
2. **cancer/blood conditions** (acute lymphoblastic leukaemia, endocrine system tumours, brain tumours)
3. **chronic infections** (congenital cytomegalovirus, congenital toxoplasmosis, HIV)
4. **respiratory conditions** (unspecified asthma, cystic fibrosis, sleep apnoea)
5. **metabolic, endocrine, renal, digestive, genito-urinary conditions** (noninfective gastroenteritis/colitis, dependence on renal dialysis, chronic kidney disease)
6. **musculoskeletal/skin conditions** (scoliosis, congenital anomalies of skull, congenital malformation syndromes associated with short stature)
7. **neurological/sensory conditions** (epilepsy, cerebral palsy, presence of cerebrovascular fluid shunt)
8. **cardiac conditions** (cardiac septal defects, patent ductus arteriosus, infection/inflammation of cardiac and vascular devices, implants and grafts)

Some clinical codes in hospital admission data (such as dependence on a wheelchair, provision of respite care and attention to gastrostomy) indicate a chronic condition but were not specific enough to classify the condition into one of the eight groups. We included these non-specific codes only when calculating the proportion of children with one or more chronic conditions.

6.2.3 Injury deaths

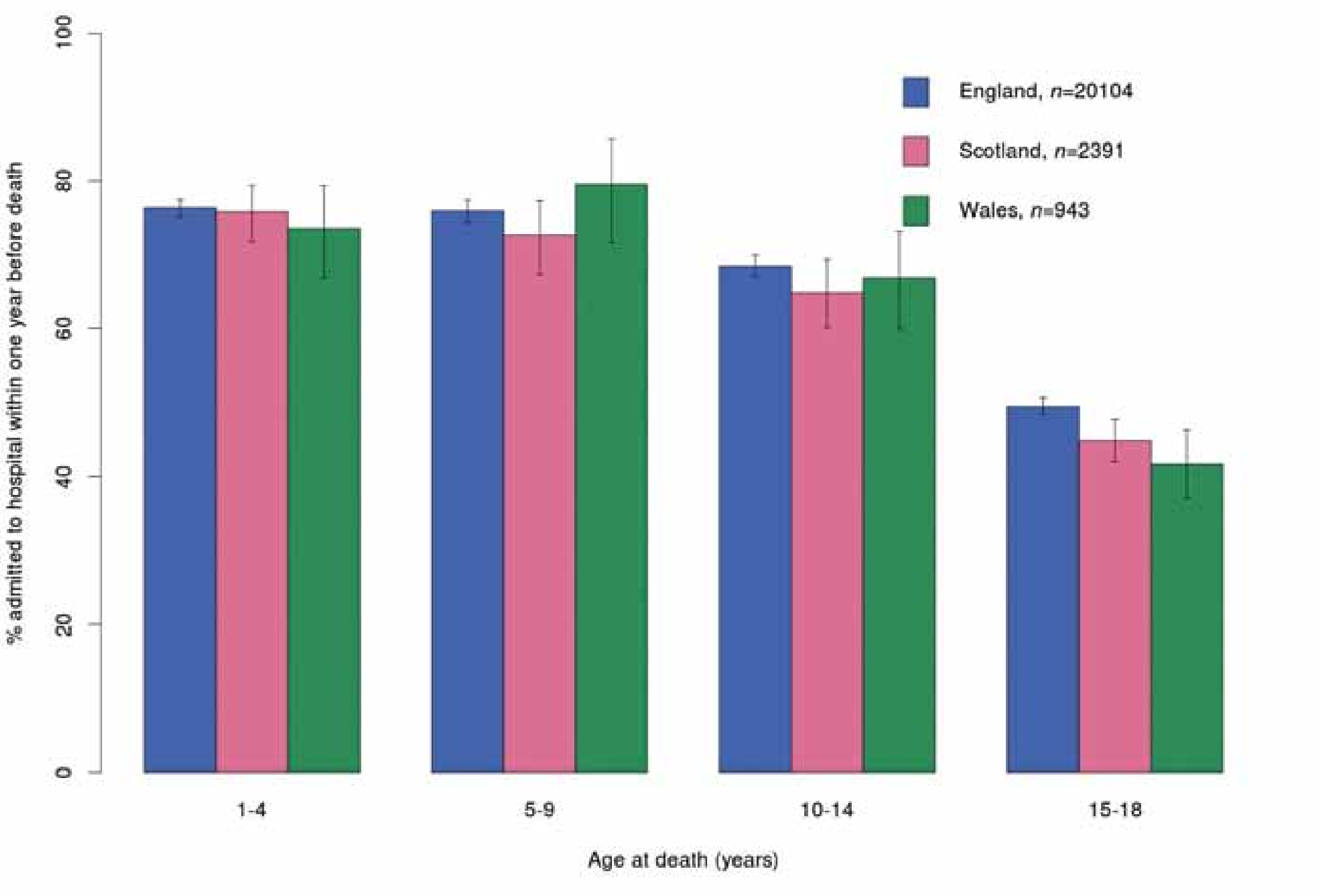
Injury deaths were identified through the underlying cause of death on the death certificate as specified in Appendix 3.4. This is the same definition as in chapter 3.

6.3 Results

6.3.1 Previous hospital admission in children who died

Overall, 64.0% (of 20104), 58.1% (of 2391) and 58.2% (of 943) of children who died in England, Scotland and Wales respectively had a hospital admission in the year before death. This proportion varied by age group: around 75% of children who died aged up to 14 years have had a hospital admission within one year before death, compared with only 45 to 50% of children aged 15 years and over (Figure 6.2).

Figure 6.2: Proportion of children who died who had a hospital admission in the year before death, by age group and country

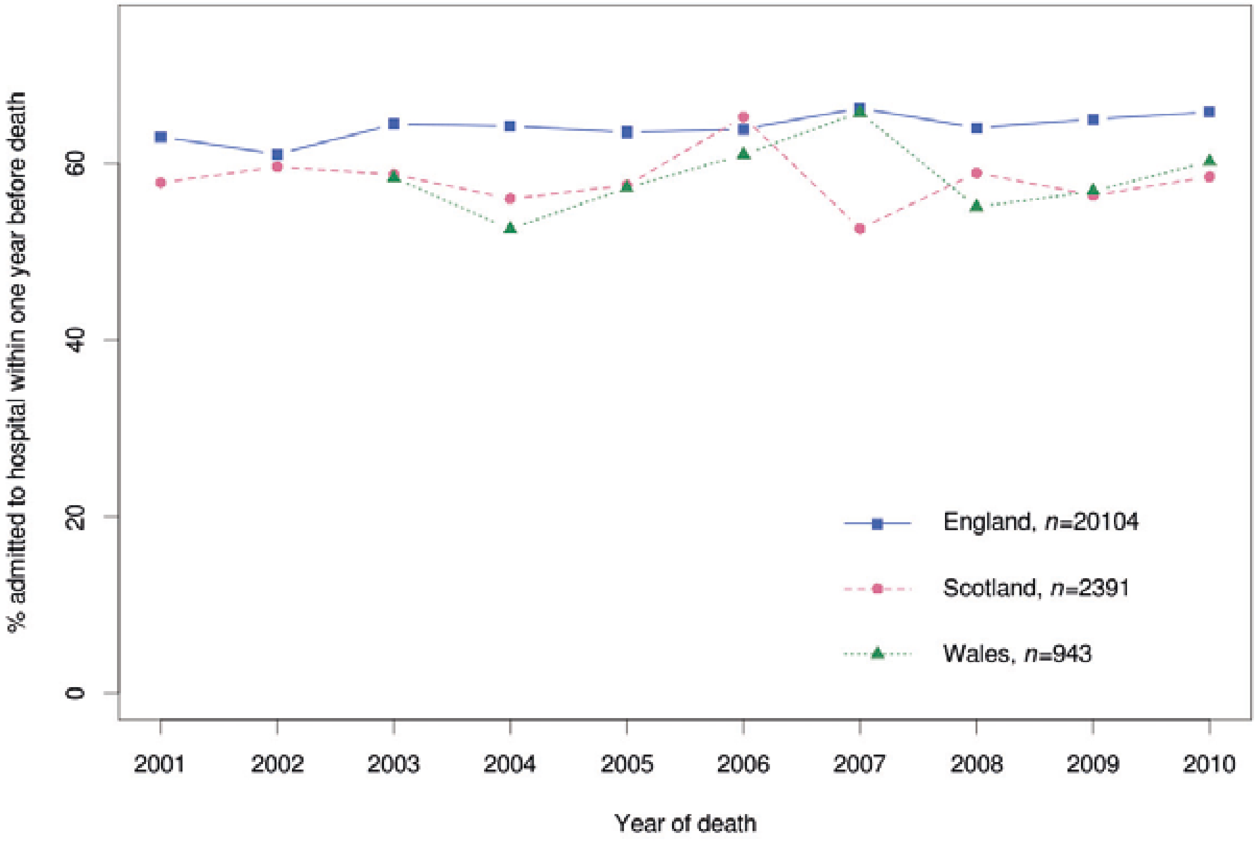


Data for England and Scotland covers deaths occurring 2001-2010, data for Wales covers deaths occurring 2003-2010

Among children aged nine years or less, the proportion of children who had been admitted in the year before death was similar among boys and girls. Among children aged 10 years and older, girls were more likely than boys to have been admitted to hospital in the year prior to death; this pattern was similar across the three countries. In England, for example, 44% of boys aged 10 to 18 years (2398/5455 boys) had been admitted to hospital in the year before death, compared to 61% of girls of the same age (1578/2580 girls). Boys and older children are more likely to die of accidents, rather than from medical conditions compared to girls and young children (see chapter 3).

The proportion of children who died having had a hospital admission in the year before death remained relatively stable across the study period in the three countries (Figure 6.3).

Figure 6.3: Proportion of children who died who had a hospital admission in the year before death, by calendar year of death and country



Data for England and Scotland covers deaths occurring 2001-2010, data for Wales covers deaths occurring 2003-2010

6.3.2 The value of adding more data from children's linked hospital trajectory

The proportion of children who died with one or more chronic conditions increased from 59% to 66% based on data just from death certificates, to 71% to 74% after including data from the child's whole hospital trajectory back to the first available hospital record (Table 6.1).

Table 6.1: Proportion of children with one or more chronic conditions according to amount of data included from the child's hospital trajectory, % (95% CIs)

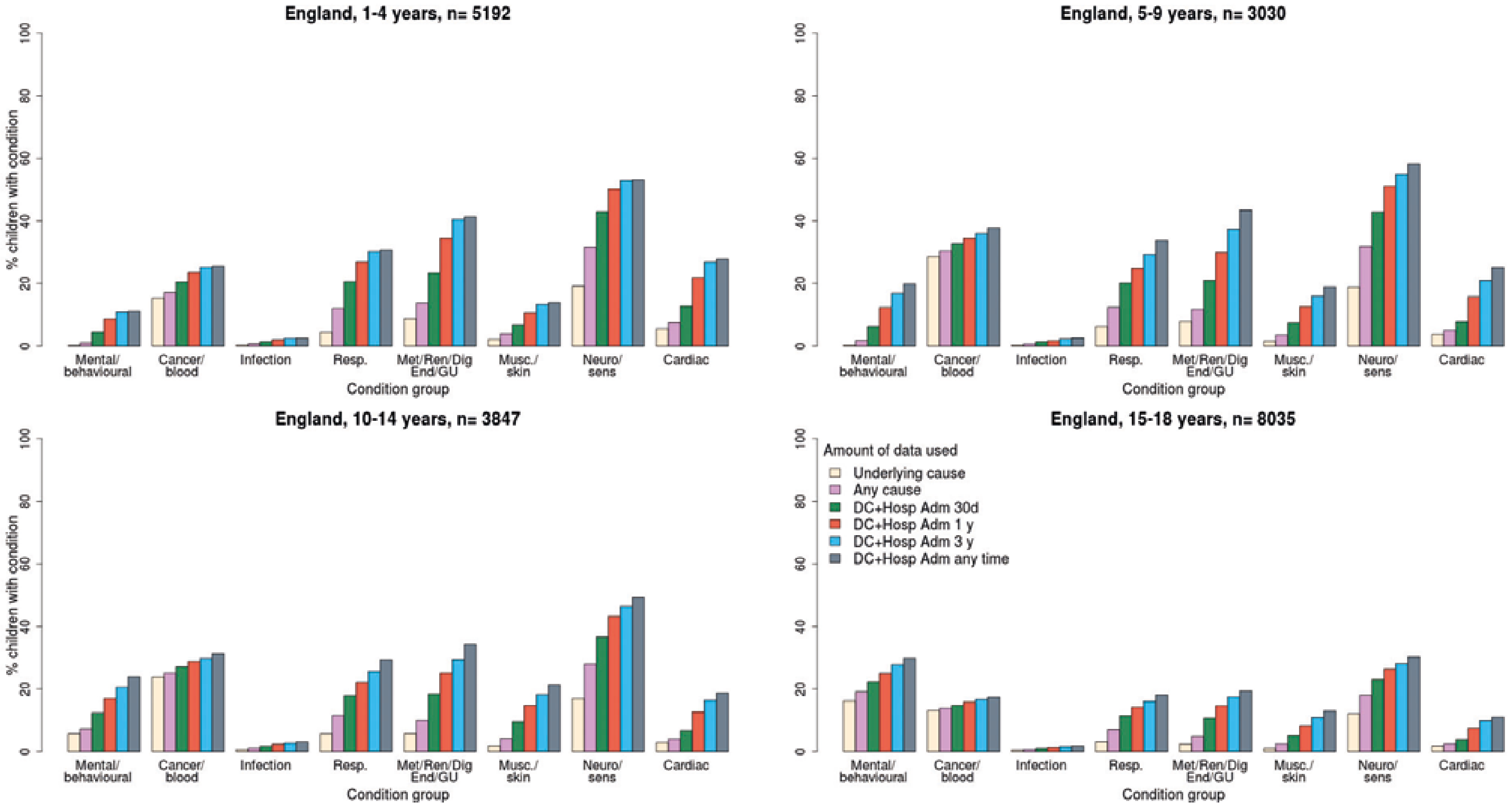
Country	Underlying cause on DC	Any mention on DC	DC+ Hospital adm ≤30 days	DC+ Hospital adm up to 1 year before death	DC+ Hospital adm up to 3 years before death	DC+ Hospital adm until first available record
England ***(n=20104)***	56.7 *(56.0, 57.4)*	65.9 *(65.3, 66.6)*	69.6 *(69.0, 70.3)*	71.2 *(70.6, 71.9)*	72.7 *(72.1, 73.3)*	74.2 *(73.6, 74.8)*
Scotland ***(n=2391)***	58.2 *(56.2, 60.2)*	64.1 *(62.1, 66.0)*	66.4 *(64.5, 68.2)*	68.0 *(66.1, 69.8)*	69.6 *(67.7, 71.4)*	72.2 *(70.4, 73.9)*
Wales ***(n=943)***	51.0 *(47.8, 54.2)*	58.6 *(55.5, 61.7)*	63.3 *(60.2, 66.3)*	65.9 *(62.8, 68.8)*	68.1 *(65.0, 71.0)*	70.6 *(67.6, 73.4)*

DC=death certificate, adm=admission

Data for England and Scotland covers deaths occurring 2001-2010, data for Wales covers deaths occurring 2003-2010

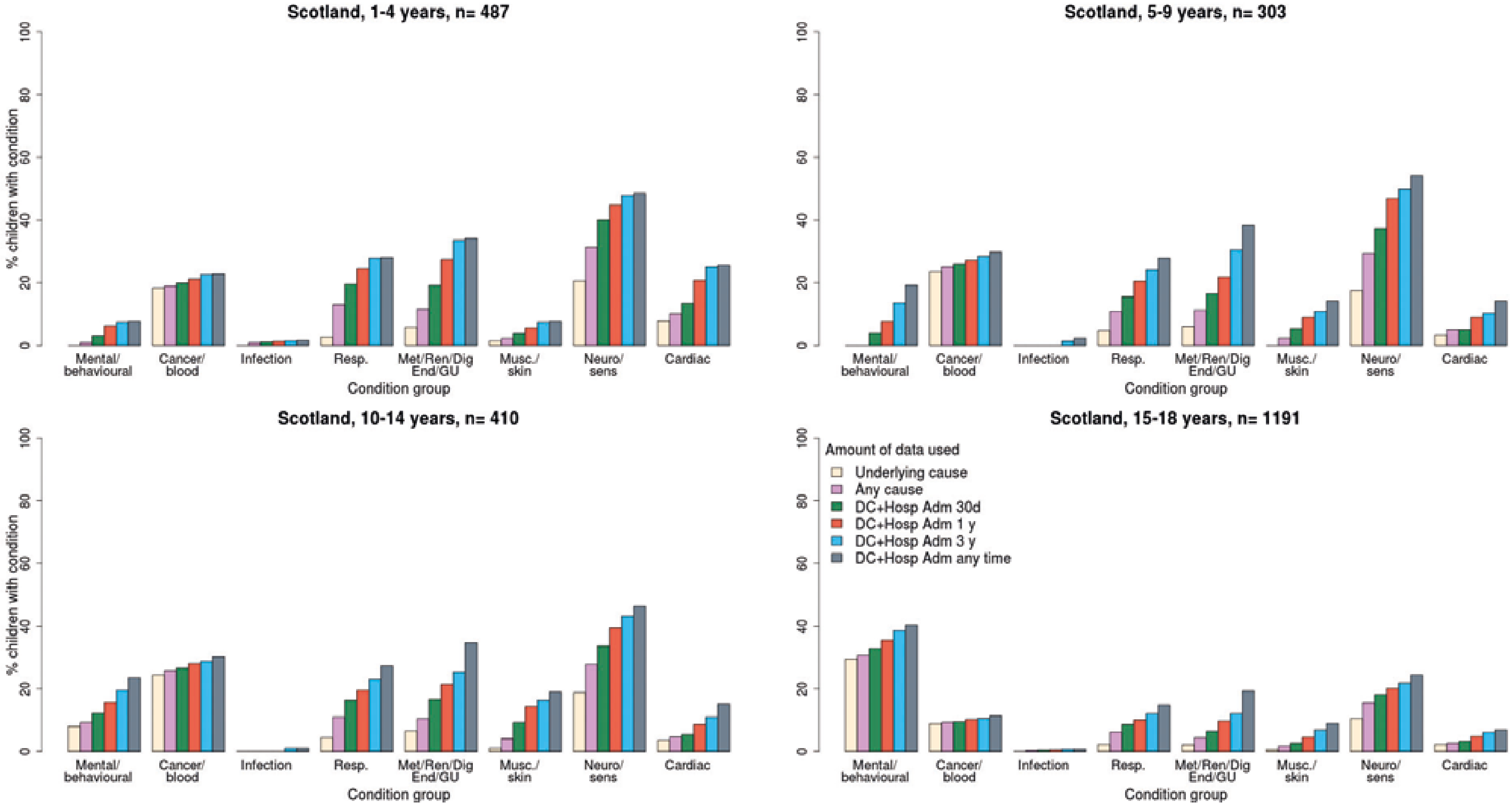
The proportion of children categorised as having a chronic condition when they died also varied according to the type of condition with which a child died (Figure 6.4, Figure 6.5, Figure 6.6). Death certificates captured most children who ever had cancer or a blood disorder recorded in their hospital trajectory: between 56% and 85% of children were identified from death certificates. In contrast, death certificates captured less than a third of children who ever had a metabolic/endocrine/renal condition recorded in their hospital trajectory (Figure 6.4, Figure 6.5, Figure 6.6). A similar pattern of increasing proportions of children affected by a chronic condition as more of their hospital trajectory was included was found for musculoskeletal/skin conditions, cardiac conditions, neurological/sensory conditions and respiratory conditions. These patterns were similar in England, Scotland and Wales, and between boys and girls.

Figure 6.4: Proportion of children who died with a chronic condition in England, 2001-2010, by type of chronic condition, age group, and amount of data included from the hospital trajectory



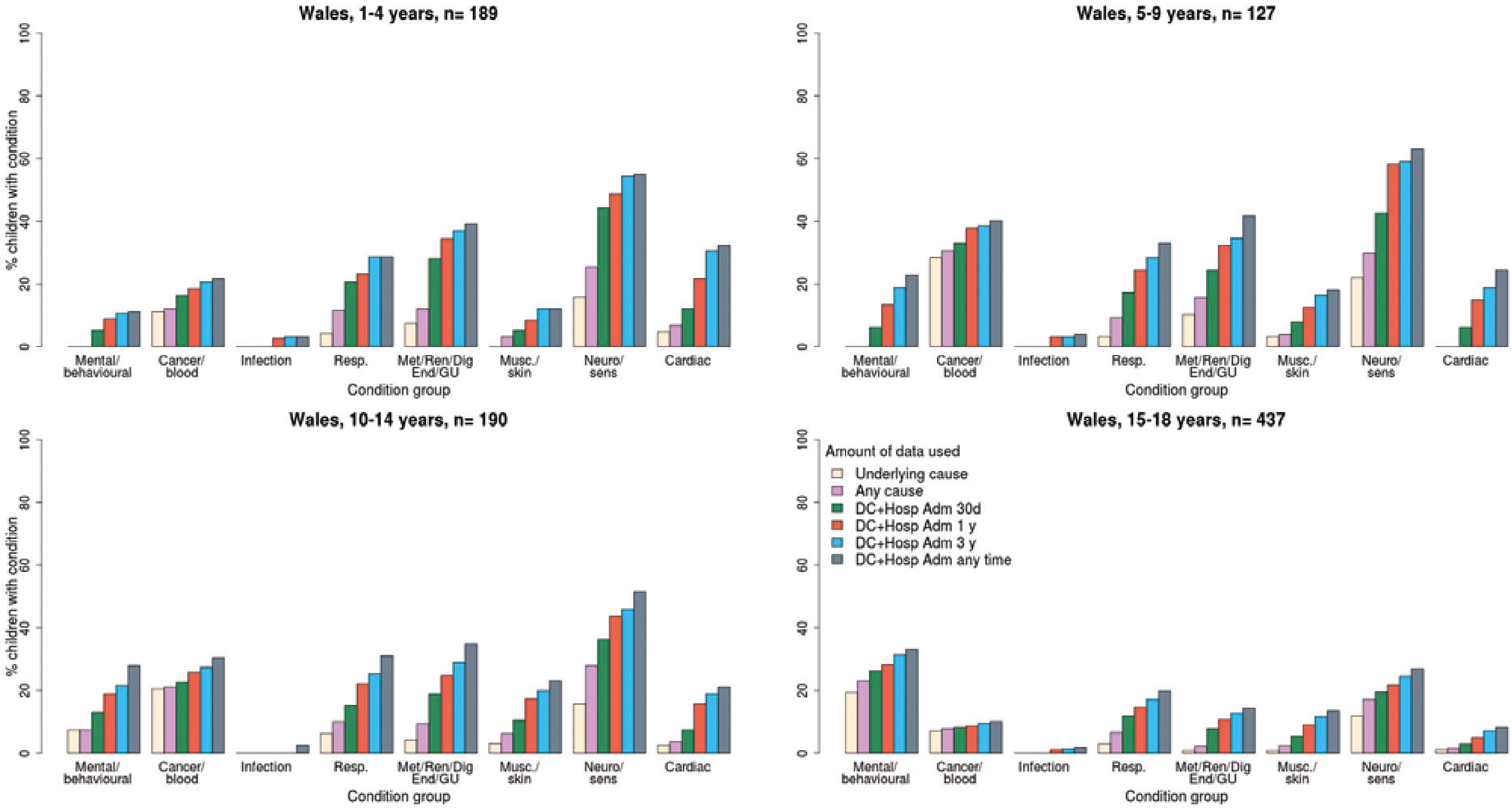
Note if the count in any group is less than or equal to 3, this has been set to 0. Groups are not mutually exclusive and children may be affected by conditions from multiple condition groups

Figure 6.5: Proportion of children who died with a chronic condition in Scotland, 2001-2010, by type of chronic condition, age group, and amount of data included from the hospital trajectory



Note if the count in any group is less than or equal to 3, this has been set to 0. Groups are not mutually exclusive and children may be affected by conditions from multiple condition groups

Figure 6.6: Proportion of children who die with a chronic condition in Wales, 2003-2010, by type of chronic condition, age group, and amount of data included from the hospital trajectory

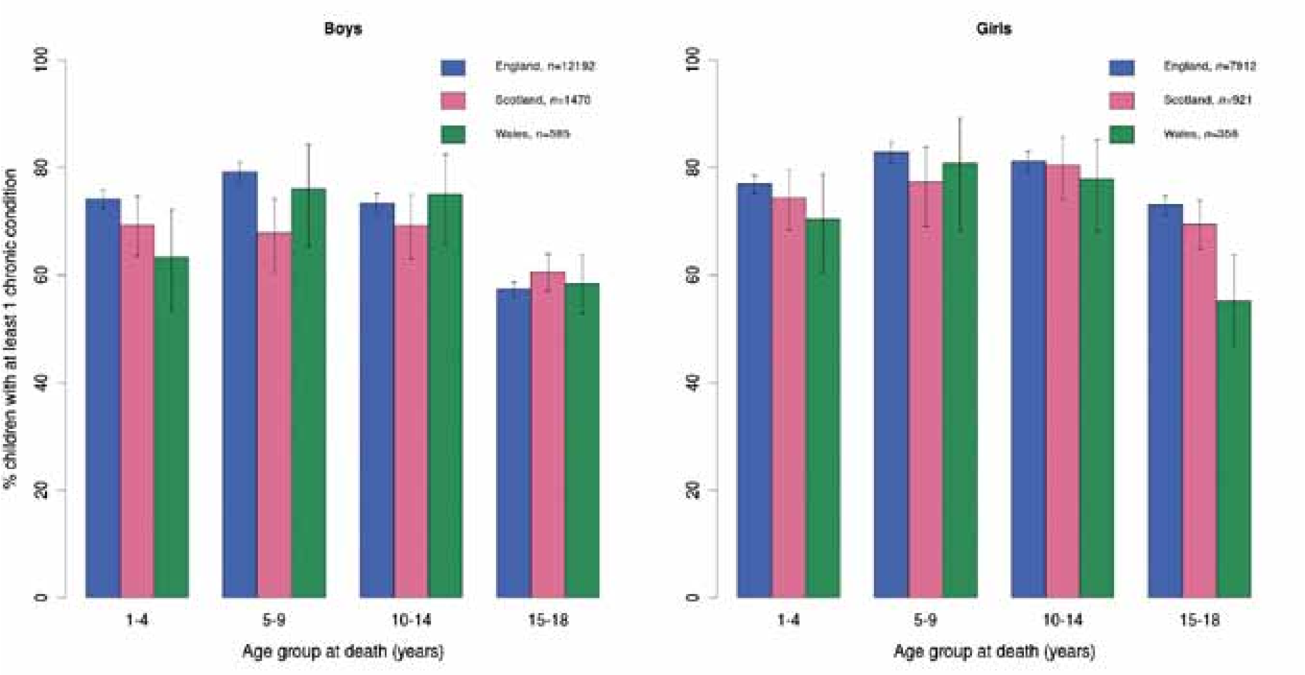


Note if the count in any group is less than or equal to 3, this has been set to 0. Groups are not mutually exclusive and children may be affected by conditions from multiple condition groups

6.3.3 Proportion of children affected by a chronic condition

Using information on all conditions mentioned on death certificates and hospital records up to one year before death, the proportion of children with at least one chronic condition was highest among children aged one to 15 years (Figure 6.7). The overall proportion of children with chronic conditions was highest in England; however CIs for Scotland and particularly Wales are wide. A higher proportion of girls had a chronic condition than boys.

Figure 6.7: Proportion of children who died with at least one chronic condition (based on death certificates and admissions < 1 year before death), by age group, sex and country



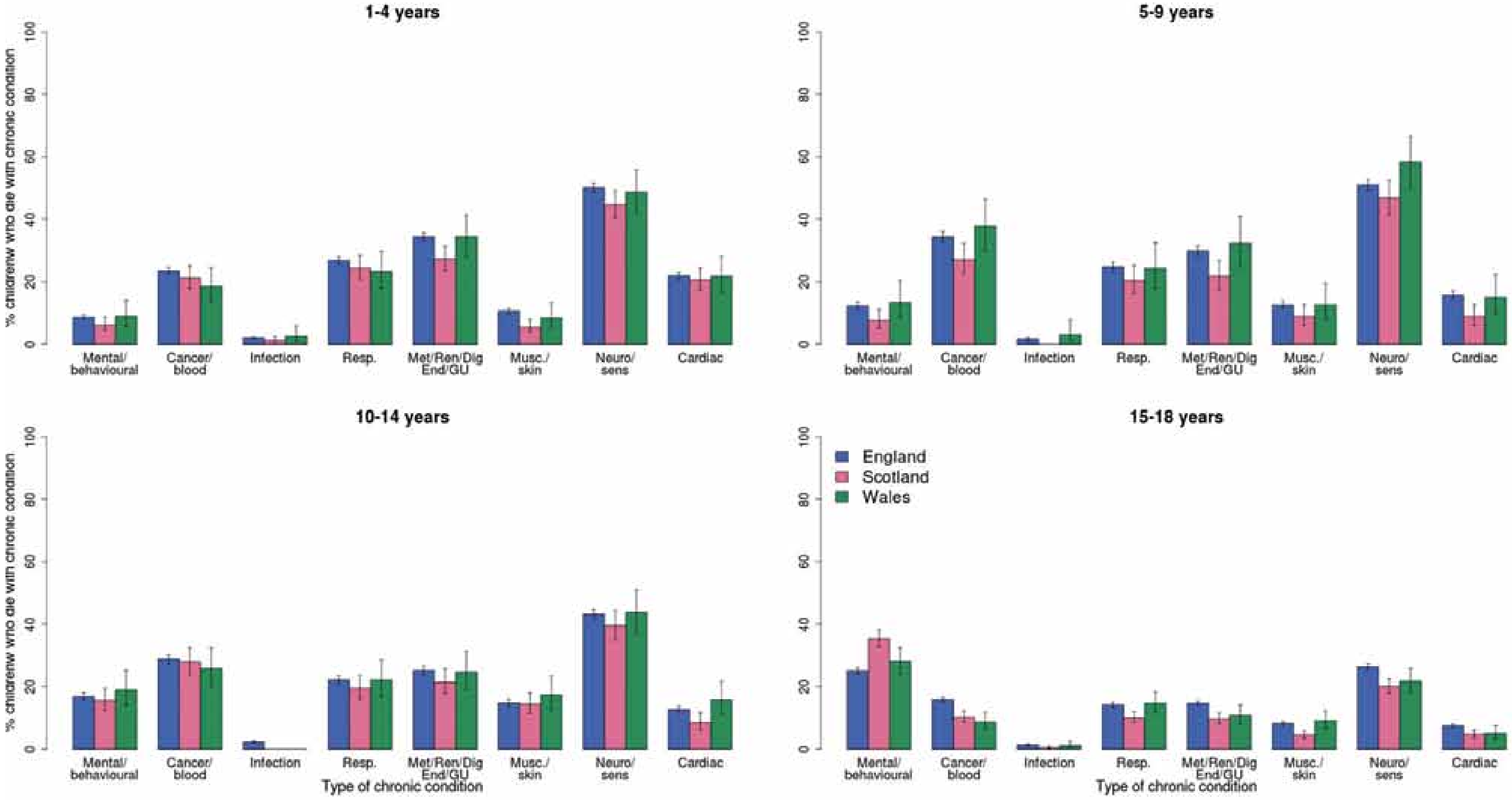
Data for England and Scotland covers deaths occurring 2001-2010, data for Wales covers deaths occurring 2003-2010

Overall, the most frequent group of chronic conditions affecting children who died were neurological/sensory conditions. Figure 6.8 shows the proportion of children with a condition from one or more of the eight groups of chronic conditions by age group and country based on death certificate and hospital admission data in the year before death. If the entire trajectory of health care is considered, 44.0% of children in England (95% CI 43.3%, 44.7%), 36.8% of children in Scotland (95% CI 34.9%, 38.8%) and 42.4% of children in Wales (95% CI 39.3%, 45.6%) died with a neurological/sensory condition, as recorded on death certificates or on any linked hospital records.

Mental/behavioural conditions were the most frequently recorded group of chronic conditions in children aged 15 to 18 years; 29.8% of children in England (95% CI 28.8%, 30.8%), 40.4% of children in Scotland (95% CI 37.6%, 43.2%) and 33.1% of children in Wales (95% CI 28.9%, 37.7%) in this age group died with a mental/behavioural condition, as recorded on death certificate or in their entire hospital admission records.

Scotland had a higher proportion of children aged 15 to 18 years with mental/behavioural conditions than England and Wales: 35.4% of children aged 15 to 18 years in children in Scotland had a mental/behavioural condition recorded as their underlying cause of death compared to 25.0% in England and 28.1% in Wales (Figure 6.8). This difference could be due to a higher proportion of children affected by mental/behavioural conditions in Scotland, better recognition and diagnosis of these conditions, or a difference in coding practices on death certificates.

Figure 6.8: Proportion of children who died with a chronic condition (based on death certificates and admissions < 1 year before death) by country, age group and type of chronic condition



Data for England and Scotland covers deaths occurring 2001-2010, data for Wales covers deaths occurring 2003-2010

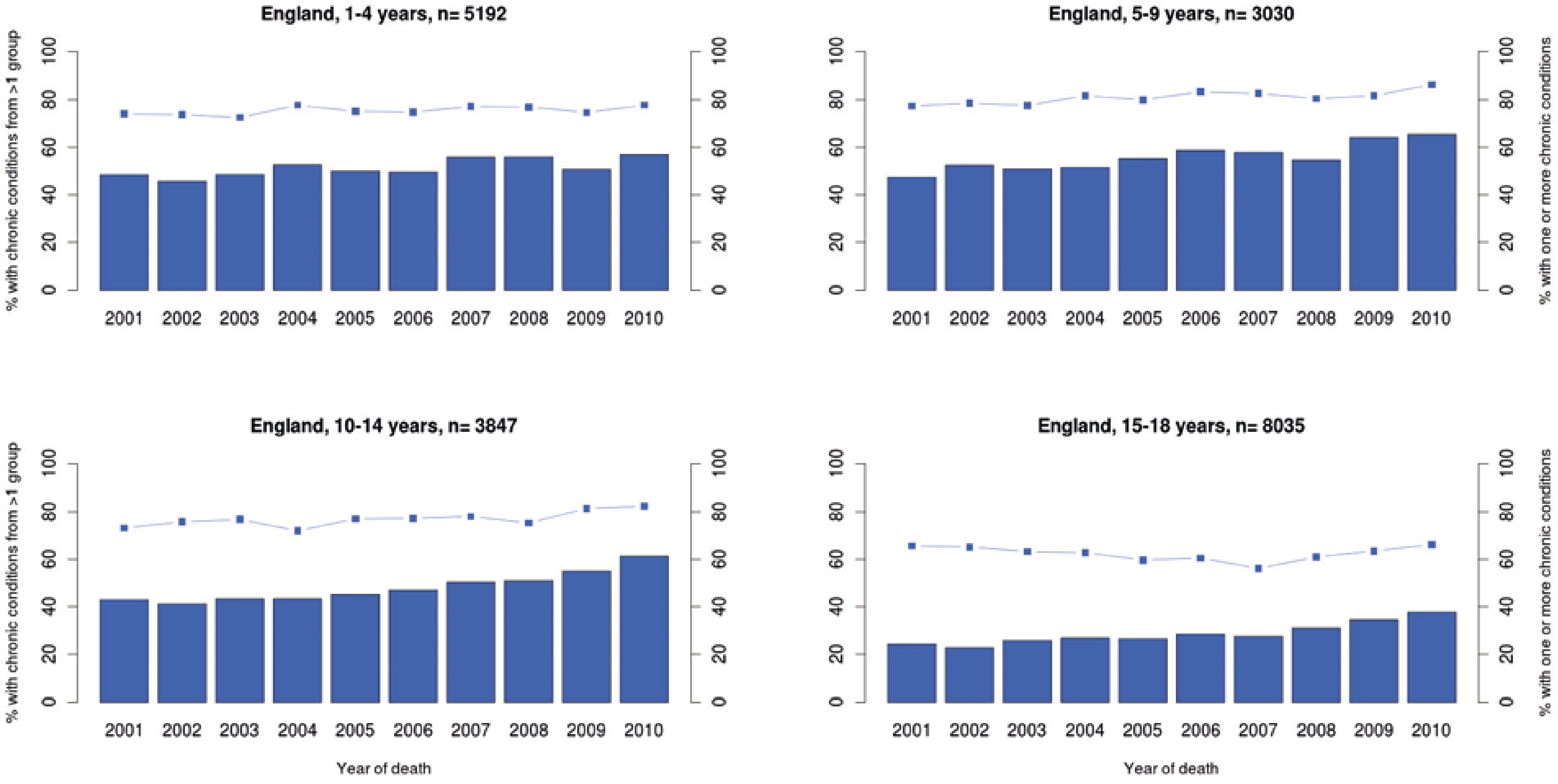
6.3.4 Trends over time in the proportion of children who died with a chronic condition

The proportion of children who died with one or more chronic conditions increased significantly[B] in England between 2001 and 2010 only among children aged five to 14 years (Wald test $p= 0.002$ and 0.003 respectively) (Figure 6.9). The increase in the proportion of children who died with chronic conditions from more than one of the eight condition groups was statistically significant in England (Wald test $p<0.001$) for all age groups (Figure 6.9). This increase was seen for both boys and girls.

In Scotland (Figure 6.10), and Wales (Figure 6.11) we found no evidence of a statistically significant increase in the proportion of children who died with one or more chronic condition, or in the proportion of children who died with two or more chronic conditions from more than one condition group.

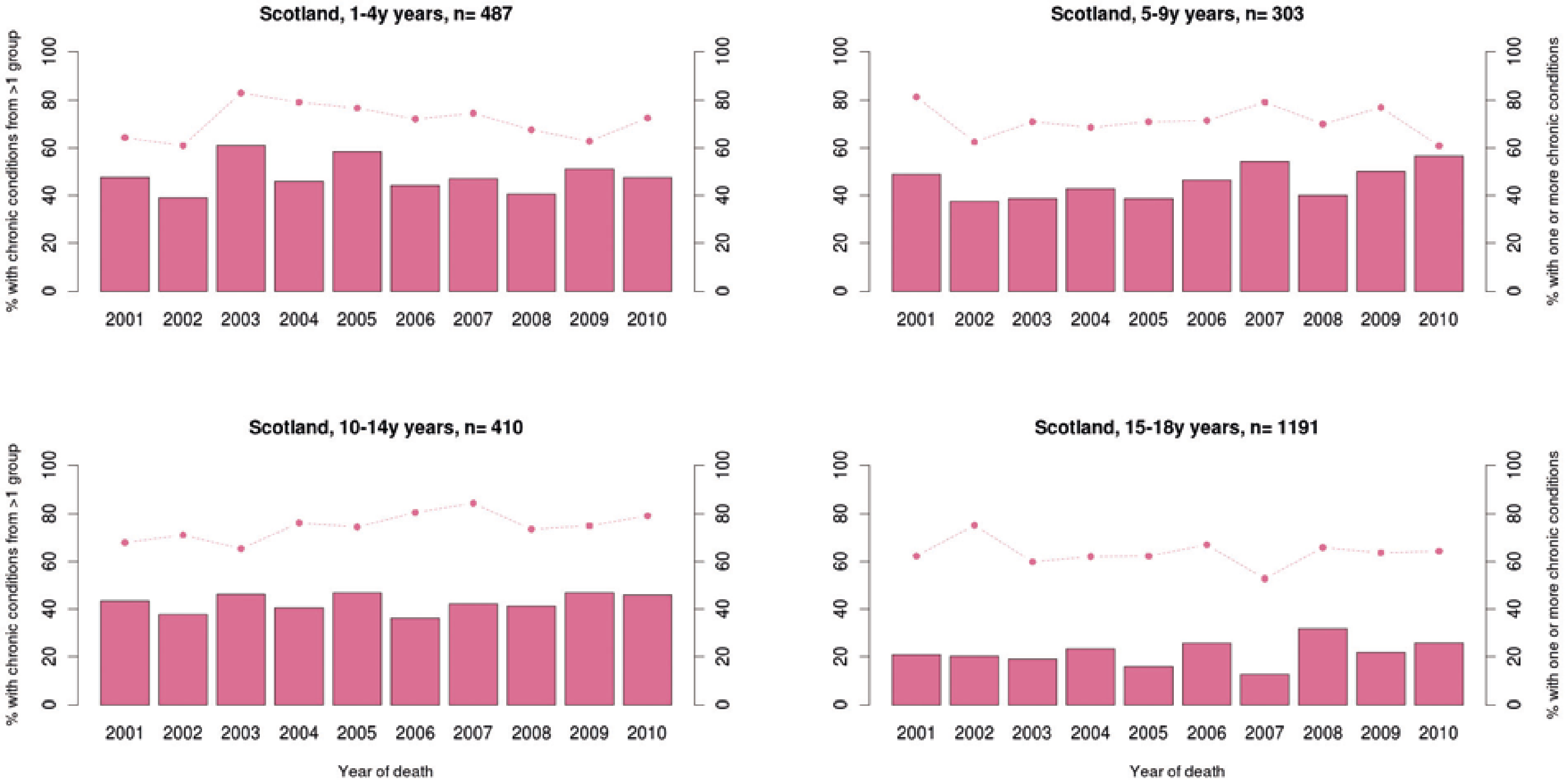
[B] We tested whether there had been an increase in the proportion of children with chronic conditions by fitting logistic regression models with sex and year of death as independent variables, and presence of one or more chronic conditions as the dependent variable. We expected a linear increase in the proportion of children who died with a chronic condition; therefore year of death was included as a linear term. A Wald test p value <0.05 for the linear year of death parameter was taken as evidence of a statistically significant linear trend.

Figure 6.9: Proportion of children resident in England with one (lines) and two or more (bars) chronic conditions, 2001-2010



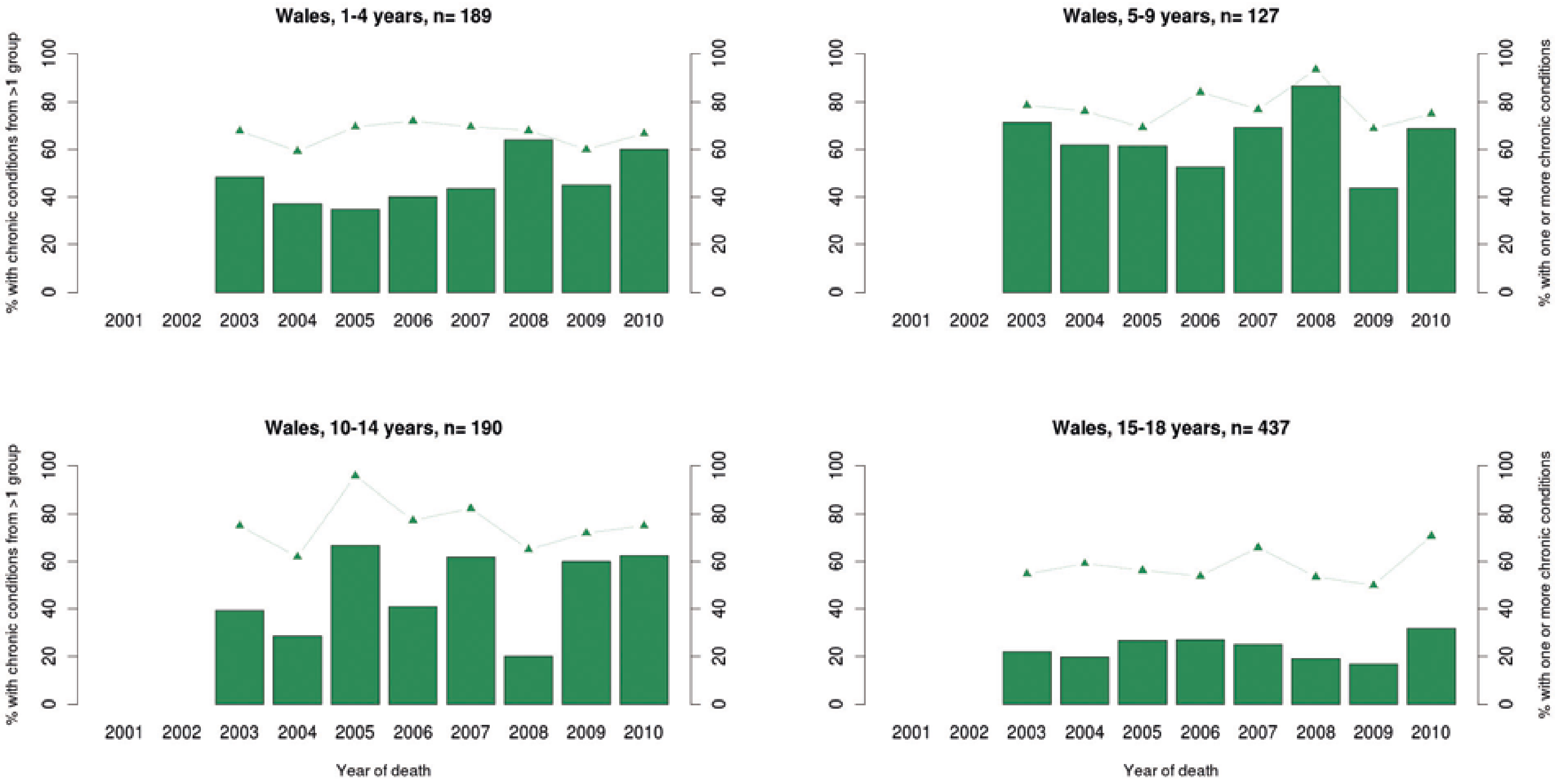
Presence of chronic conditions identified from death certificates or on hospital admission records up to one year before death. Two or more chronic conditions are counted only if they are from different condition groups.

Figure 6.10: Proportion of children resident in Scotland with one (lines) and two or more (bars) chronic conditions, 2001-2010



Presence of chronic conditions identified from death certificates or on hospital admission records up to one year before death. Two or more chronic conditions are counted only if they are from different condition groups.

Figure 6.11: Proportion of children resident in Wales with one (lines) and two or more (bars) chronic conditions, 2003-2010



Presence of chronic conditions identified from death certificates or on hospital admission records up to one year before death. Two or more chronic conditions are counted only if they are from different condition groups.

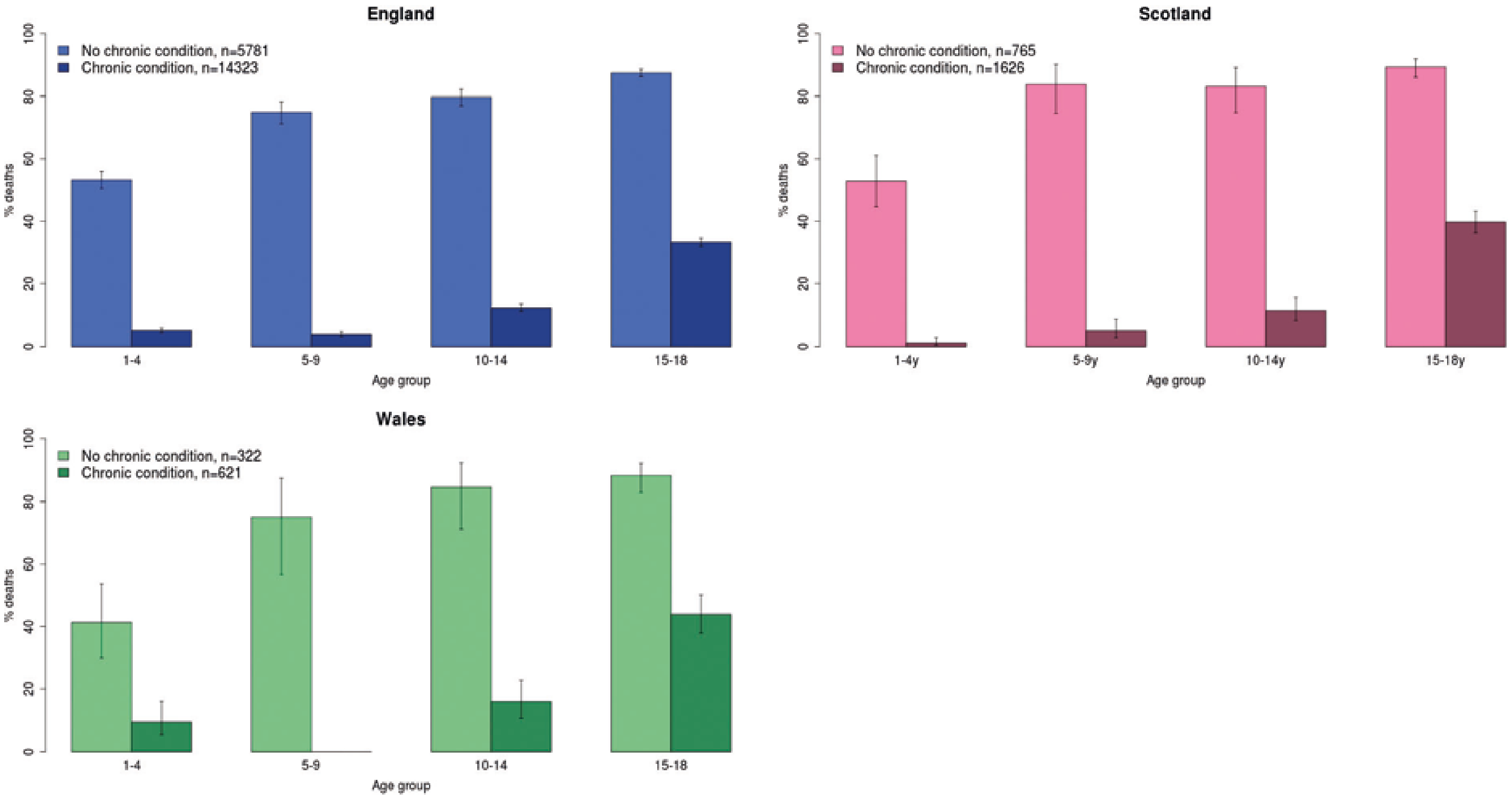
6.3.5 Chronic conditions in children who died of injury

Overall, a minority of children with a chronic condition died of injury. The dark bars in Figure 6.12 show that around 10% of one to four year olds with a chronic condition died of injury. In contrast, among 15 to 18 year olds with a chronic condition (defined using data from death certificates and hospital admission records up to one year before death), 33.2% of children in England (1665/5013, 95% CI 31.9%, 34.5%), 39.7% (300/756, 95% CI 36.3%, 43.2%) in Scotland and 43.8% (110/251 95% CI 37.8%, 50.0%) of children in Wales died of injury.

The higher proportion of children aged 15 to 18 dying of injury could largely be explained by high injury mortality rates among children with mental/behavioural disorders. In England for example, 69.7% of children who died aged 15 to 18 years with a mental/behavioural condition (defined using data from death certificates and hospital admission records up to one year before death) died of injury (1406/2012 children), compared to 2.0% of children of the same age who died with cancer/blood conditions (26/1271 children) and 11.9% of children with neurological conditions (252/2119 children).

Among children who died aged 10 to 14 years with a mental and behavioural disorder, 37.2% died of injury (242/650 children). Similar proportions of children dying of injury according to age group and type of chronic condition were observed in Scotland and Wales where respectively 65.6% (277/422 children) and 75.6% (93/123) of 15 to 18 year olds who died with mental/behavioural conditions died of injury.

Figure 6.12: Proportion of children who died: a) with a chronic condition who died of injury (dark bars); b) with no chronic condition who died of injury (light bars), by age group and country



Presence of chronic conditions identified from death certificates or on hospital admission records up to one year before death

Conversely, of all injury deaths, 34.2%, 36.0% and 37.3% occurred in children with chronic conditions in England (2329/6803 children, 95% CI 33.1%, 35.4%), Scotland (350/971 children, 95% CI 33.1%, 39.1%) and Wales (148/397 children, 95% CI 32.7%, 42.1%) respectively. These proportions are lower than the overall rate of 60% to 70% of children who died with a chronic condition based on health care records within the past year.

6.4 Discussion

6.4.1 Proportion of children who died with a chronic condition

We found that overall, 60% to 70% of children who died had a chronic condition. This proportion was higher in girls and in children aged less than 10 years; these are also the groups in which injury mortality is generally lower (see chapter 3).

Of the eight chronic condition groups, the most common type of chronic conditions children died with was neurological/sensory conditions. In children aged 15 to 18 years, who accounted for the majority of deaths in children aged one to 18 years, mental and behavioural conditions were the most common type of condition children died with.

The majority (50% to 60%) of children aged less than 15 years who died had two or more conditions from more than one chronic condition group. This implies their health problems were complex, requiring input from more than one specialist. Among the 15 to 18 year age group, the proportion of children who died with two conditions from more than one of the eight groups was lower, at around 20% to 40%.

The proportion of children with two or more chronic conditions appeared to be increasing in England but not in the other UK countries. This may be due to the increasing number of codes used for each admission during the study period (Appendix 6.1). This follows the Payment by Results system, introduced in England in 2004, which encourages more detailed coding of hospital admissions. However, we found no evidence to suggest fraudulent 'up-coding' in England.[58] Although not formally analysed, coding across multiple records appeared to be consistent. This finding may therefore indicate coding becoming more sensitive to detecting the true underlying proportion of children with chronic conditions who are admitted to hospital.

6.4.2 Injuries as a cause of death in children who died with chronic conditions

Injury deaths are the single most common underlying cause of death in children. Between 33% and 37% of these deaths occur in children with a chronic condition. The proportion of children with chronic conditions who died of injuries was less than 10%, apart from in the oldest age group, where around 30% of deaths in children with chronic conditions were due to injury.

6.4.3 Maximising the added value of linked data from children's hospital trajectory

Using only death certificates would have underestimated the proportion of children who died with a chronic condition. This was true for most of the eight groups of conditions, but less so for cancer/blood conditions and for mental/behavioural conditions affecting children aged 15 to 18 years.

In future, the accumulation of years of good quality hospital administrative data will add information about events in early childhood for children who die in late adolescence. In Scotland, this is already possible as hospital administrative data are available from 1981. However, cross-mapping of ICD-9 to ICD-10 codes is required to capture past information about chronic conditions in a standardised way. One limitation is that hospital administrative data misses those children with chronic conditions who are predominantly managed in primary care, such as children with asthma, diabetes or mental health problems. Furthermore, for children with chronic conditions captured in hospital data, there may be important problems recorded only in general practice data. For example, a recent overview of epilepsy deaths in young people and adults found that mental health problems, which are mainly managed by primary care services, were an important comorbidity and a major factor contributing to premature death.[59]

Future linkage between longitudinal trajectories of primary care records, mental health services, and hospital and death certification data will lead to more accurate estimates of the proportion of children who die with these conditions. Such linkage would also provide valuable information on the contribution of primary care to the management of children prior to death. In the longer term, linkage to other services relevant to children with chronic conditions, such as education, children's social care, and youth justice, would improve understanding of antecedent care and events and thereby generate hypotheses about how such deaths might be prevented or end of life care improved.

7. Place of death in children (2001-2010)

Key findings

- Around two thirds of children who died of non-injury related causes in England, Scotland (2001-2010) or Wales (2003-2010) died in hospital.
- Around half the children died during a hospital admission, one third died out of hospital, and one fifth died in hospital but not during an admission.
- There has been a small but consistent decrease in the proportion of children who died during an admission and concurrent increases in the proportion of children who died out of hospital.
- The decrease in the proportion of deaths occurring during an admission was largest for children with cancer/blood conditions.

Implications

- The increase over time in the proportion of children who died outside hospital suggests that policy and practice can make a difference and reflects the need to ensure choice for children and families regarding place of death.
- Policies and practices within children's cancer services offer one model for increasing the proportion of expected deaths that occur outside hospital.
- Further research is needed to determine whether improved hospital care could prevent or delay death in children admitted to hospital at the time of death.

7.1 Background

Where children die is determined by their cause of death. Children who die from acute injury or acute illness usually die in hospital or before they can be taken to hospital. On the other hand, for children with life limiting chronic conditions, the place of death can be an active choice as part of end of life care. According to a recent systematic review, research into what parents and children want regarding place of death has largely focused on children with cancer who make up just 15% of children with life-limiting chronic conditions.[60] The studies of children with cancer had extensive provision for palliative care at home. It is not clear that these findings can be extrapolated to conditions without such home support. In addition, preference for dying in a hospice was not captured by the studies included in the review. On the other hand, a consultation in England with providers, commissioners and users of children's palliative care services concluded that death at home is considered desirable by parents yet the majority of children with life-limiting conditions die in hospital.[61]

Despite this mismatch between what happens, the lack of adequate research evidence and what consultations conclude to be desirable, the proportion of child deaths that occur at home has increased steadily in England and Wales since 2004, with around 21% of deaths in children aged five to 15 years occurring at home in 2010.[62] This rise may be partly influenced by initiatives such as the Core Care Pathway and Advance Care Plans.[63] For children who die with cancer, a growing proportion die in a hospice.[64] As more of children who are expected to die are cared for at home or in a hospice, an increasing proportion of child deaths in hospital occur in intensive care units, among those who are acutely ill.[65]

We examined how place of death in children who died in England, Scotland and Wales has changed between 2001 and 2010. We excluded children in whom injury was recorded as the underlying cause as alternatives to hospital would rarely be an option for these children.

Key questions

- What proportion of children die during an admission?
- What proportion of children die outside hospital?
- How has this proportion changed over time?

7.2 Methods

7.2.1 Study population

We analysed resident children in England and Scotland who died between 2001 and 2010, and children from Wales who died between 2003 and 2010. We excluded children who died from injury (see criteria in Appendix 3.4). We analysed place of death according to country, age group at death and chronic condition. Chronic condition was based on information on the death certificate or hospital records up to one year before death.

7.2.2 Defining place of death

We classified place of death based on information from the death certificate about the place of death (hospital or elsewhere) using information from hospital records to determine whether death occurred during an admission or not. We did not investigate place of death outside hospital (eg: home or hospice) as recording differed in the three countries (Appendix 6.1).

We analysed the following exclusive categories:

- Deaths during admission according to duration of admission before death:
    1. Long admission (>48 hours)
    2. Short admission (≤48 hours)
- Deaths in hospital but not admitted, categorised according to previous admission:
    1. Recent (≤30 days)
    2. Long ago (>30 days or never)
- Deaths outside hospital and timing of previous admission:
    1. Recent (≤30 days)
    2. Long ago (>30 days or never)

Cautious interpretation of findings on place of death is needed as the results depend on accurate linkages between hospitalisation and death certification data and correct recording on the death certificate where there were mismatches in data. If children had no link to a hospital record we assumed that they had not been admitted to hospital before death. We assumed that deaths recorded as being in hospital on the death certificate but not recorded as an admission on hospital records represented children who died in the accident and emergency department. However, it is possible that a small number of children in this category had in fact died during an admission but there had been an error in the linkage procedure resulting in the discrepancy. In a small number of children (178/15267 children in the three countries combined, 1.1%) who died during an admission, there was disagreement between place of death information from hospital records and the death certificates. Some of these may have been discharged to die at home on the same day (information on time of admission and time of death was not available) and some may reflect data discrepancies. In these cases, we assumed the death certificate to be correct, and these children were included in the group who died out of hospital but had an admission up to 30 days before death. We analysed data from all three countries together to ensure sufficient numbers of deaths in each group.

To test for significant declines in the proportion of deaths occurring during an admission, we fitted logistic regression models, with death during admission/death not during admission as the binary outcome variable, and age group, sex and year of death (as a linear term) as explanatory variables. A linear trend was assumed to be significant if the Wald test *p* value for year of death was less than 0.05.

7.3 Results

We analysed 13301 children in England, 1420 children in Scotland and 546 children in Wales who died of causes other than injuries between 2001 and 2010 (2003 and 2010 for Wales). Of these, 8.0% (1068 children) in England, 4.4% (62 children) in Scotland and 8.6% (47 children) in Wales did not have a record of a hospital admission. Having excluded injury deaths from this population, a large majority of the children who died had a chronic condition: 90.2% in England (11994 children), 89.9% in Scotland (1276 children) and 86.6% in Wales (473 children).

7.3.1 Distribution of deaths in and out of hospital according to admission status

According to death certificates, 67.5% of children in England, 63.7% of children in Scotland and 64.7% of children in Wales who died of causes other than injury, died in hospital (Table 7.1).

Table 7.1: Distribution of place of death of children* according to hospital admission status, England, Scotland (2001-2010) and Wales (2003-2010)

	England *n* (% of total deaths)	**Scotland *n*** (% of total deaths)	**Wales *n*** (% of total deaths)	**Total Great Britain *n*** (% of total deaths)
Deaths during admission	**6012 (45.2)**	**642 (45.2)**	**221 (40.5)**	**6875 (45.0)**
Admitted>48 hours	3907 (29.4)	401 (28.2)	140 (25.6)	4448 (29.1)
Admitted≤48 hours	2105 (15.8)	241 (17.0)	81 (14.8)	2427 (15.9)
Deaths in hospital outside an admission	**2966 (22.3)**	**263 (18.5)**	**132 (24.2)**	**3361 (22.0)**
Last admission≤ 30 days before	535 (4.0)	56 (3.9)	25 (4.6)	616 (4.0)
Last admission> 30 days before or never	2431 (18.3)	207 (14.6)	107 (19.6)	2745 (18.0)
Deaths outside hospital	**4323 (32.5)**	**515 (36.3)**	**193 (35.3)**	**5031 (33.0)**
Last admission≤ 30 days before	1895 (14.2)	164 (11.5)	87 (15.9)	2146 (14.1)
Last admission> 30 days before or never	2428 (18.3)	351 (24.7)	106 (19.4)	2885 (18.9)
Total number of deaths due to a non-injury related cause	**13301 (100)**	**1420 (100)**	**546 (100)**	**15267 (100)**

Injury deaths are excluded.

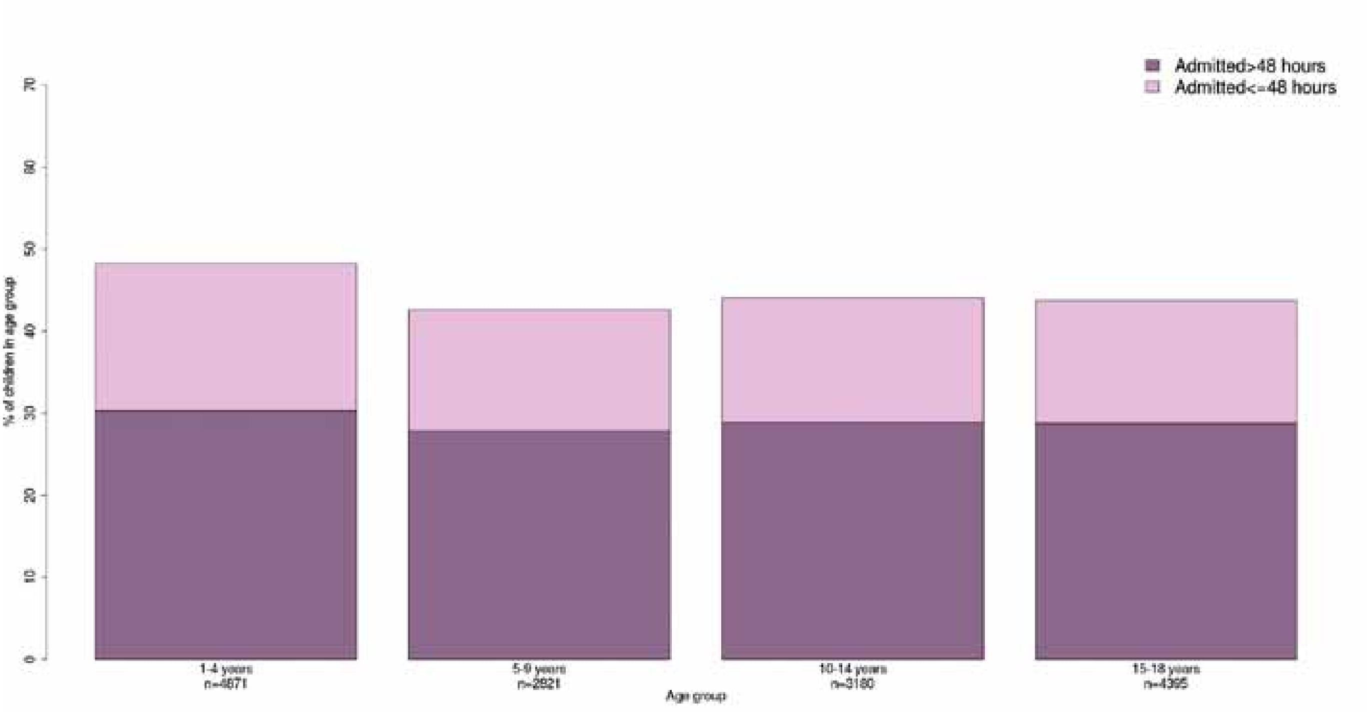
Among the 5031 children across the three countries who died outside hospital, 42.7% had had an admission up to 30 days before death, and a further 35.4% (1779 children) had had a hospital admission up to one year before death.

Among the 3361 children who died in hospital but not during an admission, 18.3% (616 children), had had an admission up to 30 days before death and a further 30.2% (1014 children) had had an admission up to one year before death.

7.3.2 Deaths in hospital and admission status

Among children who died from causes other than injury, 45.2% of children in England, 45.2% of children in Scotland and 40.5% of children in Wales died during a hospital admission. Across the three countries, 6875 children died during a hospital admission and 64.7% of these children had been admitted for more than 48 hours. There were no large variations by age in the proportion of children dying during a hospital admission (Figure 7.1).

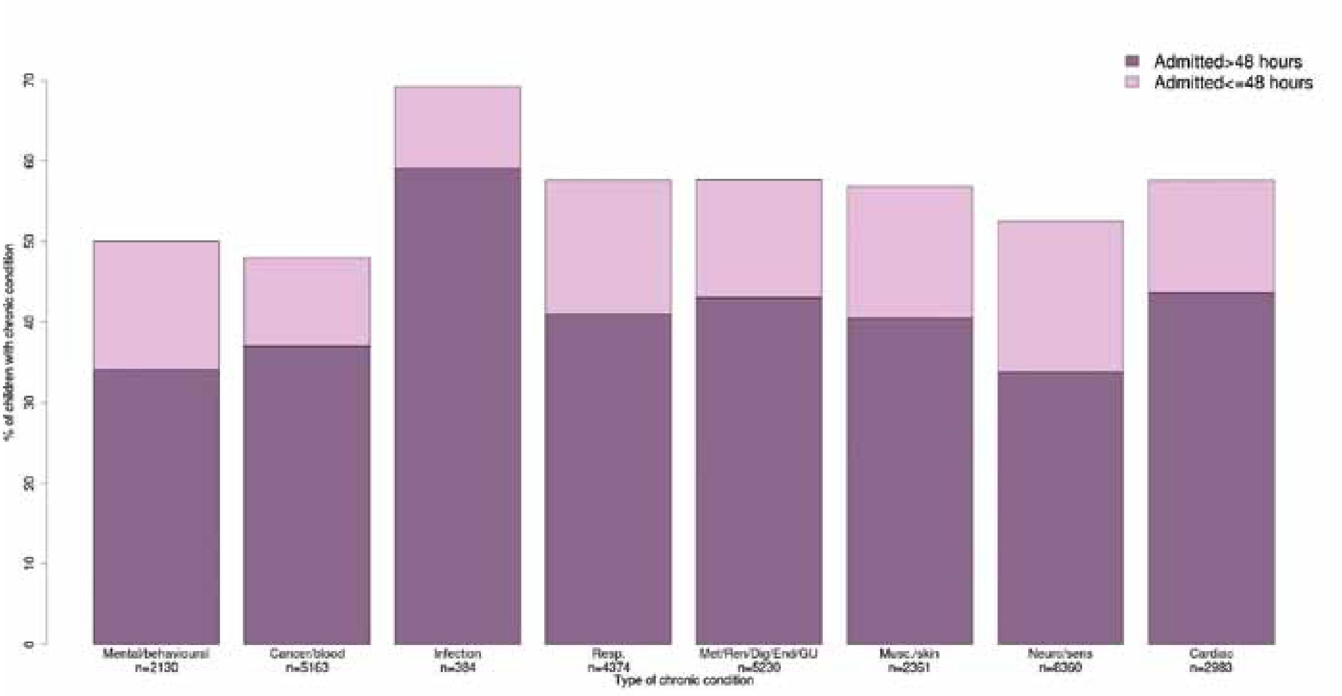
Figure 7.1: Proportion of deaths* where the child died during an admission, by age group at death, according to time since hospital admission, England and Scotland 2001-2010, Wales 2003-2010



*Injury deaths are excluded

For children with a chronic condition, the proportion dying during a hospital admission was marginally higher than for all children who died (48.2% of 11994 children in England, 48.1% of 1276 children in Scotland and 44.2% of 273 children in Wales) but there were differences between chronic conditions. For example, the lowest proportion of deaths during an admission occurred in children with cancer/blood (48.0%), mental/behavioural (50.0%) or neurological/sensory (52.5%) conditions (Figure 7.2; note that chronic condition groups are not mutually exclusive since children may have more than one chronic condition).

Figure 7.2: Proportion of deaths* where the child died during an admission, by chronic condition, according to time since admission, England and Scotland 2001-2010, Wales 2003-2010

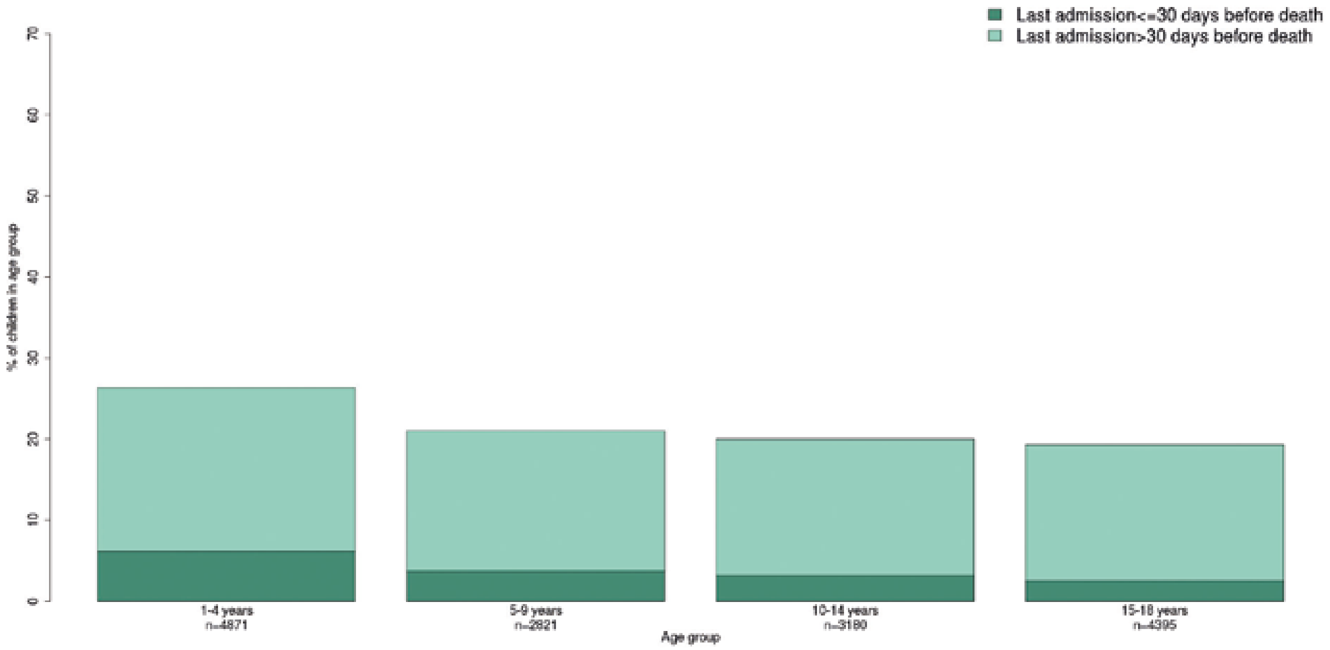


*Injury deaths are excluded

7.3.3 Deaths in hospital but not during admission

Approximately one fifth (22.0%) of children in England, Scotland and Wales who died of non-injury related causes died in hospital, but had not been admitted (Table 7.1). We infer that these children would have died in the emergency department or on the way to hospital. This cannot be verified with the data available. A greater proportion of deaths in young children occurred in hospital outside an admission (26.3% in one to four year olds) compared with the oldest age group (19.3% at 15 to 18 years; Figure 7.3).

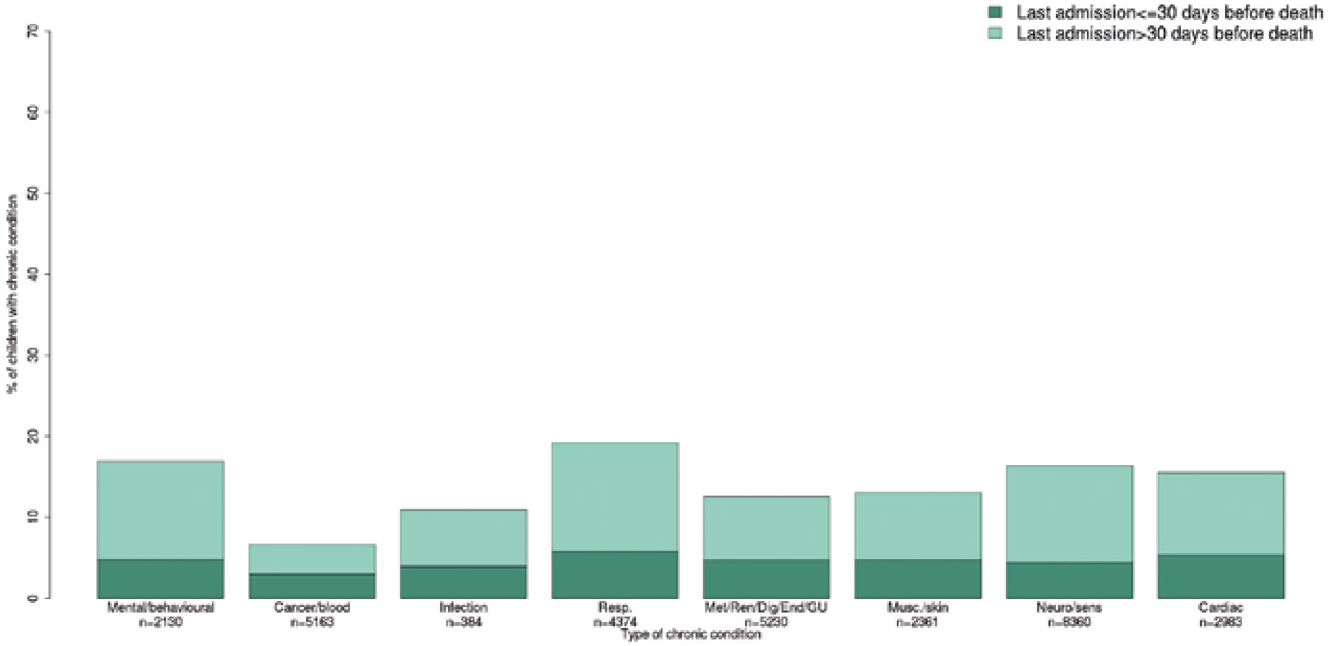
Figure 7.3: Proportion of deaths*, where the child died in hospital but not during an admission, according to time since last admission by age group at death, England and Scotland 2001-2010, Wales 2003-2010



*Injury deaths are excluded

The proportion of children with a chronic condition who died in hospital without being admitted was similar to the average for all non-injury deaths. 2485 children in England, Scotland and Wales with chronic conditions (in total 13743 children) died in hospital but outside an admission (18.1%). Of these 2485 children, 23.7% had been admitted during the last 30 days before death. The proportion of children who died in hospital but outside an admission varied according to the type of chronic condition (Figure 7.4; note that chronic condition groups are not mutually exclusive since children may have more than one chronic condition), and was highest for children with respiratory, mental and behavioural and neurological/sensory conditions.

Figure 7.4: Proportion of deaths*, where the child died in hospital but not during an admission, according to type of chronic condition, England and Scotland 2001-2010, Wales 2003-2010

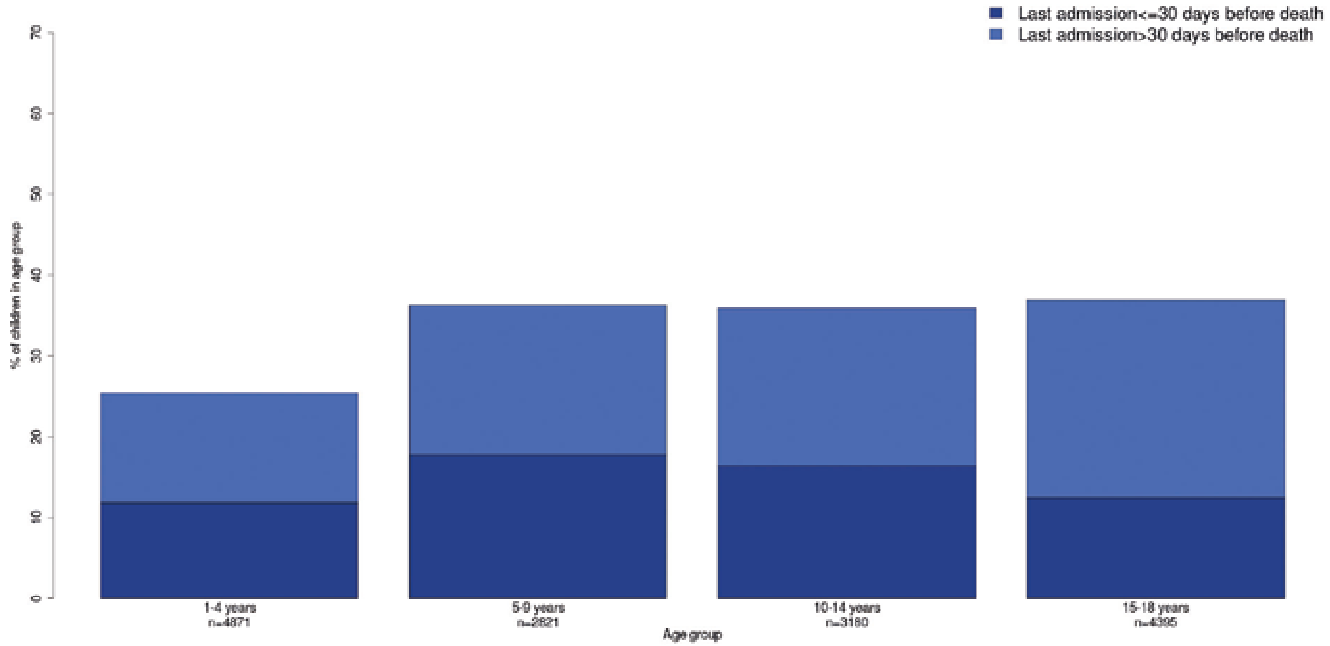


*Injury deaths are excluded

7.3.4 Deaths out of hospital

Across the three countries, around a third of deaths (33.0%) in children who died of non-injury related causes occurred out of hospital (Table 7.1). A higher proportion of children aged five years and older died out of hospital than children aged one to four years: 36.5% of 10396 children compared to 25.4% of 4871 children (Figure 7.5). One third (33.7%) of 15 to 18 year olds and half (46% to 49%) of one to 14 year olds who died outside hospital had been admitted within the preceding 30 days.

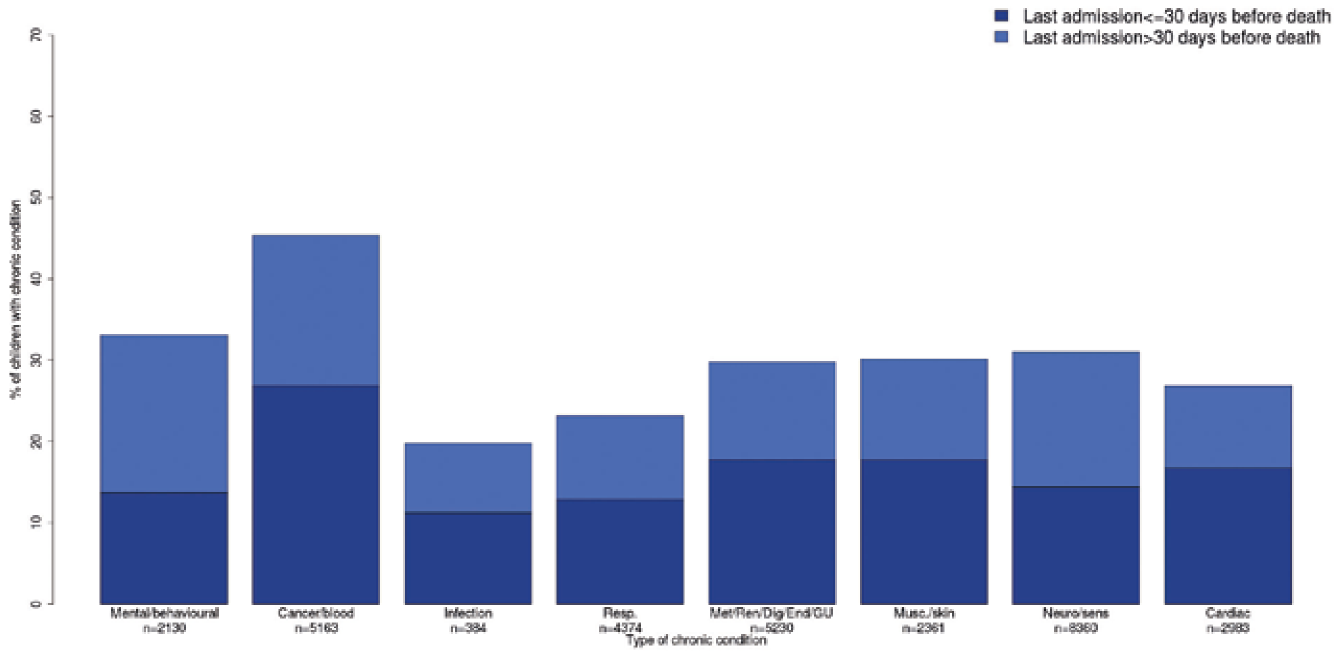
Figure 7.5: Proportion of deaths*, where the child died outside hospital, according to time since last admission, by age group at death, England and Scotland 2001-2010, Wales 2003-2010



*Injury deaths are excluded

A similar proportion (33.8%) of the 13743 children who died with at least one chronic condition in England, Scotland and Wales died outside hospital. Half of these (45.9% of 4652 children) had been admitted within the previous 30 days of death.

Figure 7.6: Proportion of deaths*, where the child died outside hospital, according to time since last admission, by type of chronic condition, England and Scotland 2001-2010, Wales 2003-2010

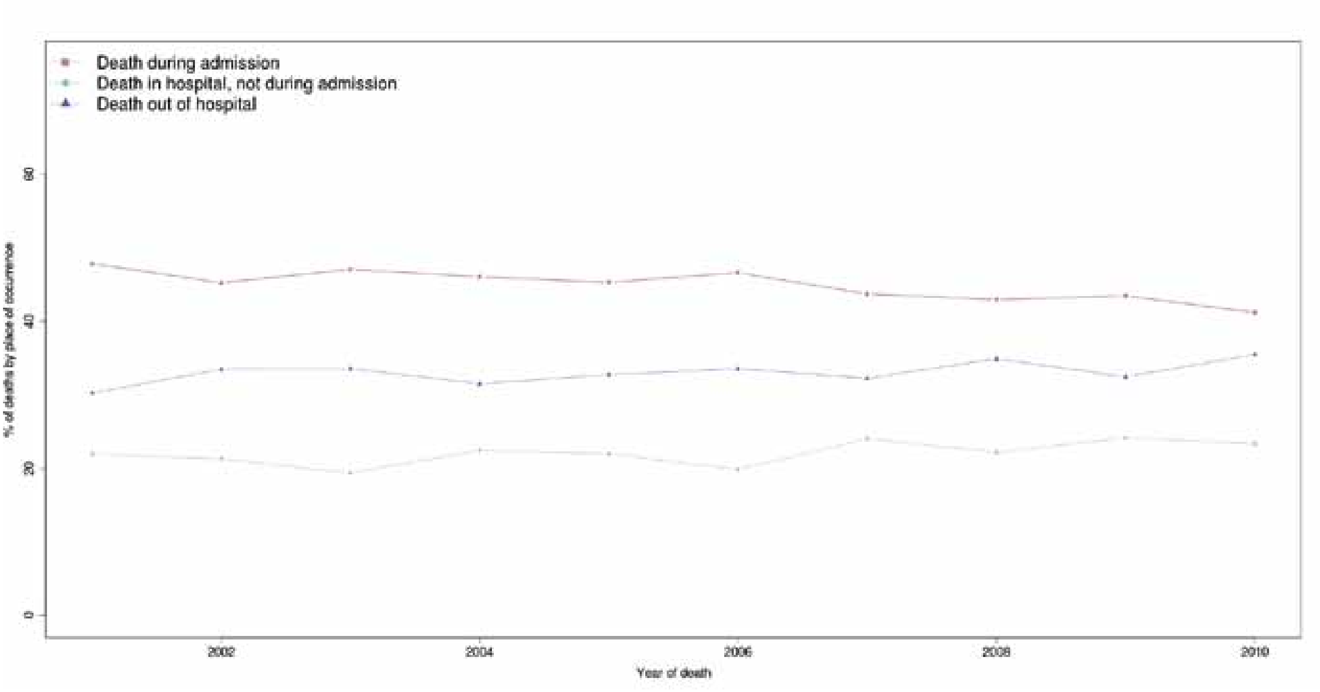


The proportion of children who died outside hospital varied between the chronic conditions groups. Whereas 45.4% of deaths in children with cancer/blood conditions occured out of hospital, this was the case for only 19.8% of children with chronic infections and 23.2% of children with respiratory conditions (Figure 7.6; note that chronic condition groups are not mutually exclusive since children may have more than one chronic condition). On the other hand, the proportion of children who had a hospital admission during the 30 days before death was highest for children with cancer/blood conditions, 59.1% of whom been admitted in the previous 30 days.

7.3.5 Trends over time in the proportion of deaths occurring in and out of hospital

Figure 7.7 shows trends over time in the proportion of children in England, Scotland and Wales combined who died during an admission, in hospital but outside an admission, and out of hospital (note that these three groups are mutually exclusive and add up to 100%). A small but significant decline was observed in the proportion of children who died during a hospital admission during the period (Wald test *p*<0.001). This was mirrored by a concurrent increase in the proportion of children who died outside hospital and in hospital but outside an admission.

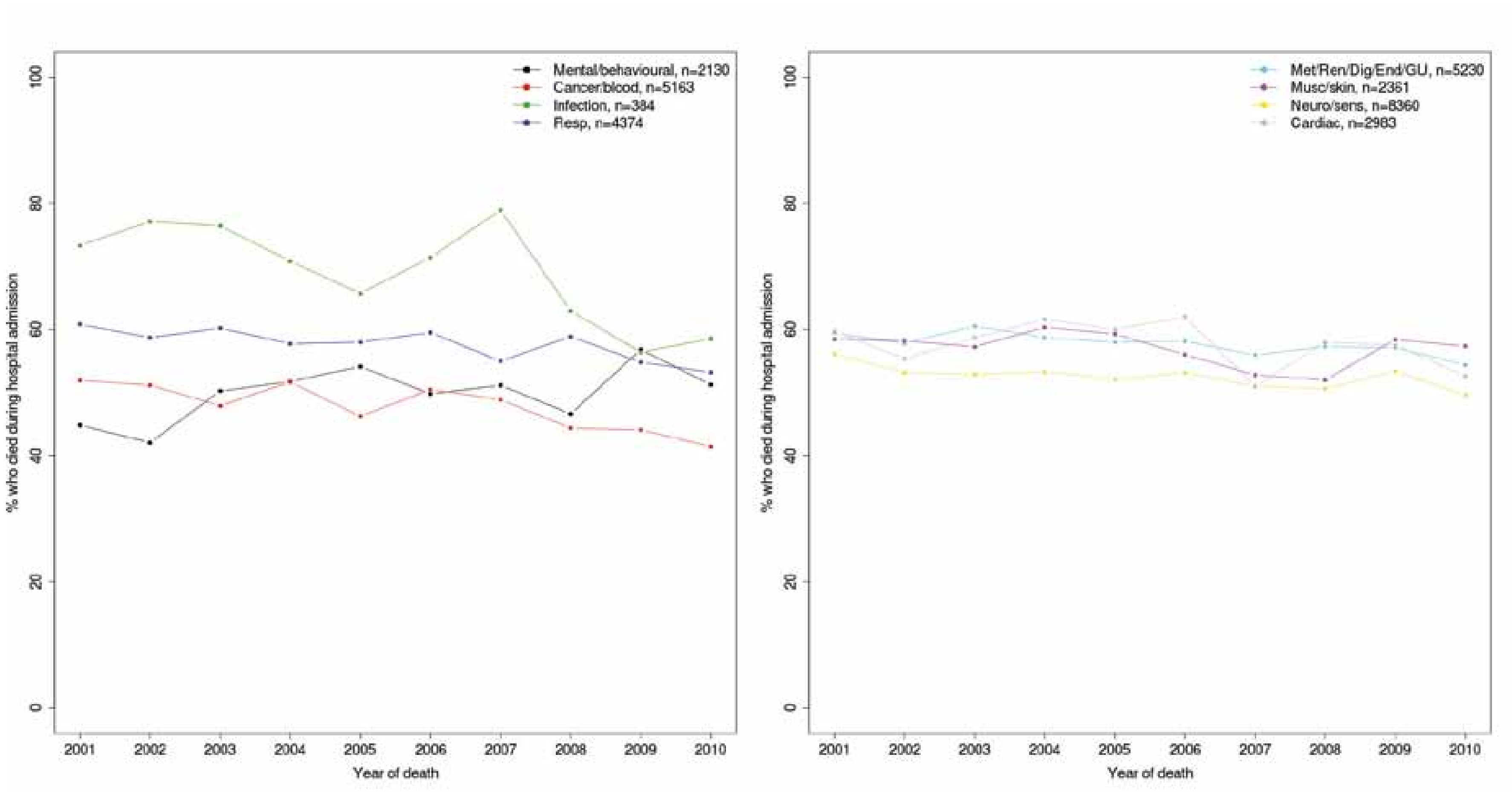
Figure 7.7: Proportion of deaths* where the child died during a hospital admission, in hospital but outside an admission, and outside hospital according to year of death (England, Scotland 2001-2010; Wales 2003-2010)



*Injury deaths are excluded

Significant declines in the proportion of deaths that occurred during an admission were seen for children with cancer/blood (Figure 7.8, Wald test $p<0.001$), respiratory (Wald test $p=0.007$) and neurological/sensory conditions (Wald test $p=0.02$). The proportion of children with chronic infections who died during a hospital admission also declined, from 73.3% in 2001 to 58.5% in 2010, however this group was small and there are therefore large variations in rates from year to year. Note that children may be in more than one chronic condition group and these declines may therefore be related. An exception to these downward trends was found for children with mental/behavioural conditions, where the odds of dying during an admission increased by 3% per year (Wald test $p=0.007$) between 2001 and 2010.

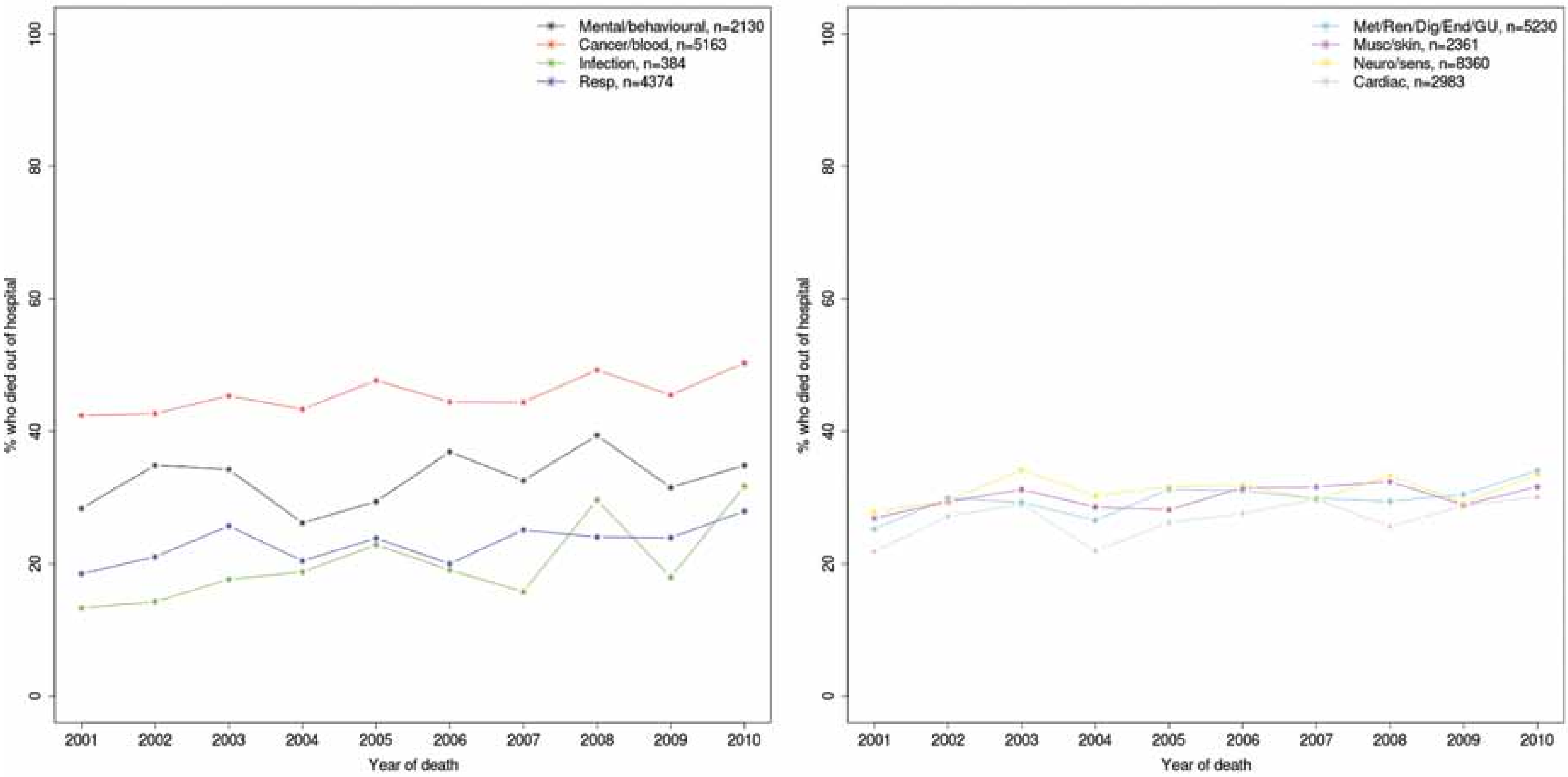
Figure 7.8: For each type of chronic condition, the proportion of deaths* that occurred during a hospital admission, by year of death in England and Scotland 2001-2010, Wales 2003-2010



*Injury deaths are excluded

The proportion of deaths occurring out of hospital increased across all chronic conditions (Figure 7.9).

Figure 7.9: For each type of chronic condition, the proportion of deaths* that occurred outside hospital by year of death in England and Scotland 2001-2010, Wales 2003-2010



*Injury deaths are excluded

7.4 Discussion

Around half of children who died from causes other than injury died during a hospital admission. A further 20% of children died in hospital but were not admitted, and a further third died out of hospital. Less than one-fifth of children (18.9%) died outside hospital and had not been admitted in the previous 30 days. Children with cancer/blood conditions were most likely to die outside hospital.

The proportion of children who died in hospital is decreasing slowly but steadily. The decrease was most marked for children with cancer/blood conditions, and most likely reflects improved palliative care services for these children. Our estimate of the proportion of children with cancer/blood conditions who died during a hospital admission are similar to those presented by Shah et al.[64]

Around 65% of children who died during an admission had been admitted for more than 48 hours before death. These deaths include children with life-limiting conditions, some of whom may have been expected to die, but the child or parents preferred death to occur in hospital.[60] Other deaths in hospital in children with life limiting conditions may reflect intensive treatment to prevent or delay death, which may or may not have been planned. For yet others, death may have been an unexpected outcome of hospital admission. It is not possible to distinguish these three groups using the routine data sources in these analyses. Disentangling preferences and expectations would require survey or qualitative research. More detailed analyses of diagnoses at admission and surgical and medical procedures carried out in hospital immediately preceding death will allow an improved understanding of whether improved hospital care could prevent or delay death in these children.

Further research is needed to examine where deaths outside hospital took place and the extent to which provision of hospice care differs according to type of chronic condition, age and country.

8. Future directions

What do our findings mean for policy?

Our study shows variation in mortality rates between UK countries, over time and according to maternal age. These differences suggest that some child deaths could be prevented, assuming there are modifiable factors related to children's environment or in the way their family or health services care for them. We highlighted key factors that affected substantial proportions of children who died in the UK.

- The continuing importance of injuries as a cause of death in childhood and the lack of decrease in deaths due to intentional injury for children aged 10 to 18 since 1980.
- The persisting effect of young maternal age as a risk factor for child death throughout early childhood, despite accounting for birth weight.
- The high proportion of children who died with chronic conditions.
- The small but consistent decrease in the proportion of children with a chronic condition who died during hospital admission.

These findings highlight groups for whom policies have the potential to reduce child deaths: children exposed to injury, children of young mothers, and children with chronic conditions. These groups are affected by policies that impact on risk factors such as health care services, family living standards and inequalities, parental capacity to care for their child, risk taking behaviour by adolescents, and exposure to violence, alcohol, drugs, or environmental hazards.[14;18;66;67] Our study did not detect, and was not designed to detect, sub-optimal hospital care as a factor contributing to child deaths. However, evidence from adults suggests that a very small proportion of hospital deaths are potentially preventable (around 5%).[68;69] The big gains are made from public health interventions. On the other hand, these findings highlight the need to consider patterns of health care for the growing proportion of children affected by chronic conditions. Most of the care for these children is likely to be provided in the home by their parents, supported by services in the community.[70] Future child health reviews need to characterise how services outside hospital address the needs of children who die and their families.

Synergy between population-based overviews and case note reviews

Our findings of the importance of community exposures for a large proportion of child deaths have implications for future child death overviews. Population-based overviews of deaths remain essential to characterise which children die, what they die with, and how this varies between countries and over time. Inferences about preventable deaths are a secondary aim and depend on finding substantial variations between similar populations and on assumptions about the effectiveness of interventions or policies. Administrative health data offer a comprehensive, rich, reliable, complete, and low cost resource to address these purposes, but are too crude to meaningfully tease out important aspects of complex pathways of care.

The complexity of care will continue to require case note review to capture processes that culminate in death or serious morbidity. This is particularly important when the proportion of deaths that are preventable is small, as is the case for deaths in hospital.[68] Case note reviews are expensive, suffer from incomplete ascertainment, and can be viewed as inquisitorial.[71;72] However, they can be a powerful way to understand the processes, context, and circumstances in which children die.[73] For example, among children with chronic conditions, qualitative methods as part of case note review could help to distinguish children, conditions and circumstances in which deaths were expected or allowed, from those where health care was intended to prevent death.

These dual approaches are complementary and can be synergistic. Linking children included in case note reviews to their trajectory of administrative health care data could minimise data collection for case note reviews and enable examination of differences between the review sample and all deaths with similar characteristics. This approach would also help to standardise data collection and might reduce associated costs. For example, an overview of serious case reviews, where abuse or neglect is a factor in a child's death or serious outcome, found that data collection on health care services was variable and important factors, such as contact with a GP, were often not recorded.[74]

An alternative approach is for the population-based analyses to guide the focus of a case note review, for example by identifying hospitals or regions with contrasting patterns of care and/or outcomes, where better understanding of organisational, clinician and patient characteristics could be informative.[72]

Future population-based overviews of child deaths

Our study has given some examples of how the growing resource of administrative healthcare data can be used to characterise children who die. Here, we outline directions for future studies.

Improving understanding of events prior to death

Linked death registration and hospital admission datasets used for this study could be used to describe the timing and frequency of acute events leading to hospital admission in the 30 days before death. Such analyses could be combined with case note review. Of particular interest is the frequency of infections and respiratory problems in children with chronic conditions, and frequency of adverse health care events in children undergoing elective procedures in hospital.[1;75]

Using other health care databases

Our study was limited to linkage between death records and hospital admissions or birth records. Further linkages within health care to emergency department attendances, and most importantly, to national-level primary care data, would offer much more information about children who die. For example, linkage with primary care data would capture information on past adversity, including maltreatment,[76;77] mental illness,[78] and chronic conditions such as asthma, all of which would be recognised and treated mainly in the community. Linkage to primary care data would also provide information on family risk factors, such as mental illness,[79] violence, or drug or alcohol misuse, where parents have consulted for these conditions, are registered with the same GP and live in the same household. A recent study into ischaemic heart disease highlighted the importance of linkage between primary and secondary care data for ascertaining cases and validating diagnoses.[80] For hospitalised children, further information on what care they receive would be provided by linkage to data captured by the Paediatric Intensive Care Audit Network (PICANet)[81] or the Intensive Care

National Audit Research Centre (ICNARC) databases.[82] Such links between primary care and hospital datasets would allow analyses of the child's complete care trajectory and more detailed analyses of patterns of care preceding death.

Using data outside health care

The recent government initiative to improve access for researchers to linked administrative datasets from different sectors through an Administrative Data Research Network opens up the possibility of establishing linked, anonymised datasets that include information from education, crime and social care data.[2] Characteristics such as special educational needs, school failure, and being looked after in the care system, are well established risk factors for injury in adolescents and for other adverse outcomes such as teenage pregnancy.[29;83-85] How these characteristics cluster in children who die in the UK is not known, but is highly relevant to how services work together to support vulnerable children. Such data could be ascertained from administrative data linked across sectors.

Which ages should be included in child death overviews?

In the future, the age group included in child death overviews could be based on consideration of the following principles. First, childhood is a period of development towards maturation as an adult. Reproductive maturation is increasingly at odds with neurological and psychological maturation, aspects of which are not fully mature, on average, until the mid-twenties.[86]

Second, services have different cut-offs for children. Paediatric intensive care units admit children under 16 years of age, whereas some cancer services do not hand children over to adult services until the age of 25 years. These varied definitions of children suggest the influence of sector boundaries and budgets rather than health care needs. Child death reviews can usefully measure care either side of these boundaries.

Third, the rising rate of injury deaths in late adolescence continues into the early twenties.[15] As risk factors and policy solutions are likely to be similar across this age range, excluding young people in their early twenties may limit understanding of the problem.

Lastly, a major problem facing adolescents with chronic conditions is transition to adult services.[87;88] As children with chronic conditions survive longer, overviews need to address the quality of care provided by services at all ages. Currently there is inadequate evidence for policy makers on how services meet the changing needs across the child to young adult life course and how these patterns vary across the UK. Quantitative, population-based analyses using administrative health care data offer a low cost, comprehensive resource to track how antecedent health care differs across the transition in children, adolescents and young people who die. The UK department of health should consider extending future overviews to include children across the entire age range and young people up to their mid-twenties.

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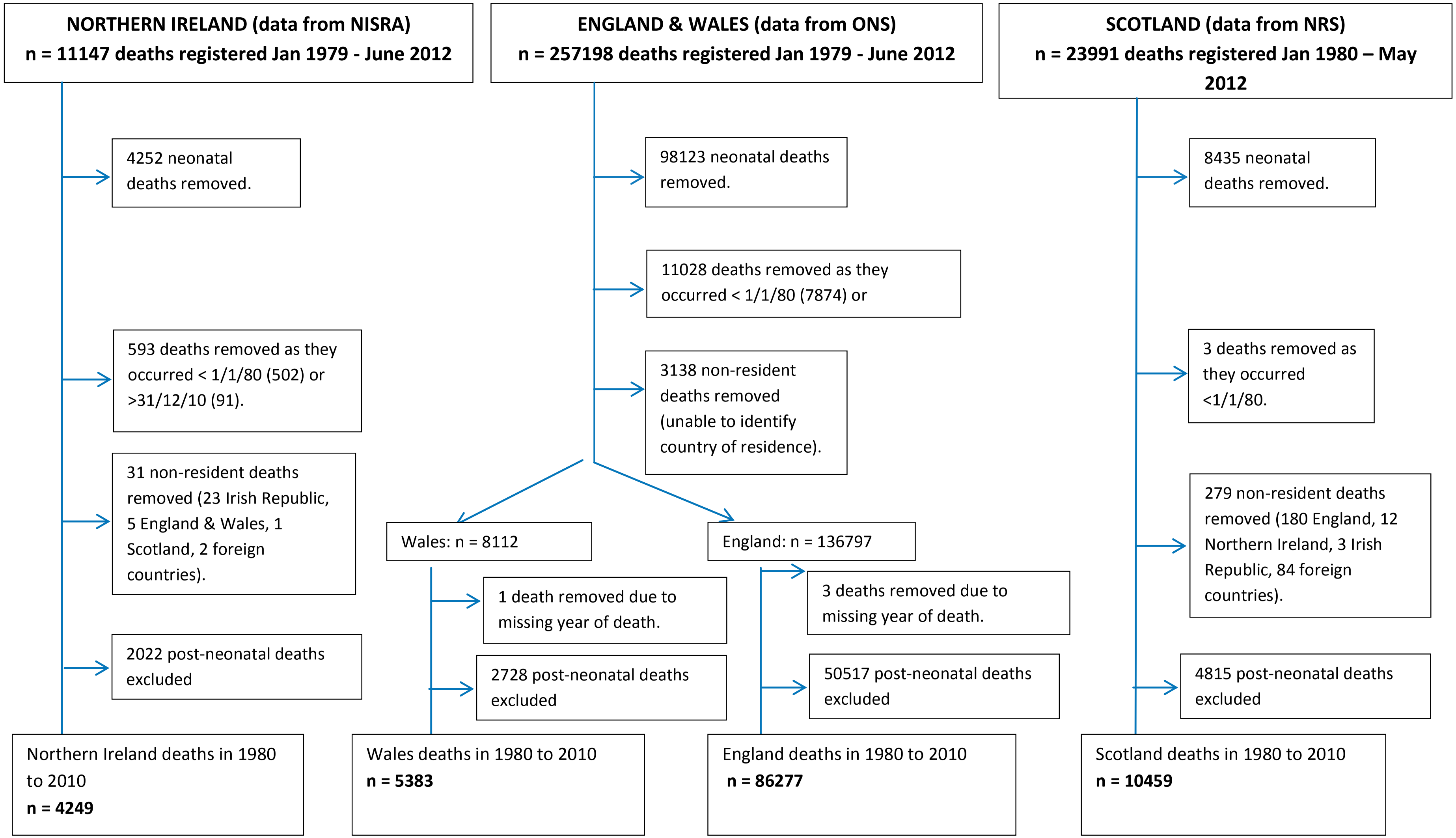
Appendix 3.1: Data cleaning and exclusions for death certificate data for deaths that occurred in 1980 and 2010 in children aged one to 18 years



Appendix 3.2A: Injury mortality rates, rate ratios and rate differences (per 100,000 population) comparing Scotland, Wales and Northern Ireland with England, by age group and time period: boys

1-9 years	England	Scotland	Wales	Northern Ireland
1980-84				
Number of deaths/pop.	1,620/13,340,424	273/1,514,089	95/814,538	109/607,960
Mortality rate	12.14 (11.57, 12.75)	18.03 (16.01, 20.3)	11.66 (9.54, 14.26)	17.93 (14.86, 21.63)
Rate ratio cf. England†	-	1.48 (1.31,1.69)	0.96 (0.78,1.18)	1.48 (1.22,1.79)
Rate difference cf. England‡	-	5.89 (3.67, 8.11)	-0.48 (-2.9, 1.94)	5.79 (2.37, 9.2)
1993-97				
Number of deaths/pop.	835/14,657,369	113/1,478,677	59/872,979	58/599,173
Mortality rate	5.70 (5.32, 6.1)	7.64 (6.36, 9.19)	6.76 (5.24, 8.72)	9.68 (7.48, 12.52)
Rate ratio cf. England†	-	1.34 (1.10,1.63)	1.19 (0.91,1.54)	1.70 (1.3,2.22)
Rate difference cf. England‡	-	1.95 (0.48, 3.41)	1.06 (-0.71, 2.83)	3.98 (1.46, 6.50)
2006-10				
Number of deaths/pop.	352/13,847,428	41/1,268,767	25/770,743	13/533,954
Mortality rate	2.54 (2.29, 2.82)	3.23 (2.38, 4.39)	3.24 (2.19, 4.8)	2.43 (1.41, 4.19)
Rate ratio cf. England †	-	1.27 (0.92,1.76)	1.28 (0.85,1.91)	0.96 (0.55,1.67)
Rate difference cf. England‡	-	0.69 (-0.33, 1.71)	0.70 (-0.60, 2.00)	-0.11 (-1.46, 1.24)
10-18 years				
1980-84				
Number of deaths/pop.	5,057/17,038,295	694/1,990,010	315/1,021,930	241/676,702
Mortality rate	29.68 (28.87, 30.51)	34.87 (32.37, 37.57)	30.82 (27.60, 34.42)	35.61 (31.39, 40.41)
Rate ratio cf. England†	-	1.17 (1.09, 1.27)	1.04 (0.93, 1.16)	1.20 (1.05, 1.37)
Rate difference cf. England‡	-	5.19 (2.47, 7.91)	1.14 (-2.36, 4.64)	5.93 (1.36, 10.50)
1993-97				
Number of deaths/pop.	2,412/13,535,473	359/1,443,819	196/833,699	189/591,838
Mortality rate	17.82 (17.12, 18.55)	24.86 (22.42, 27.57)	23.51 (20.44, 27.04)	31.91 (27.69, 36.82)
Rate ratio cf. England†	-	1.40 (1.25, 1.56)	1.32 (1.14, 1.53)	1.79 (1.55, 2.08)
Rate difference cf. England‡	-	7.04 (4.38, 9.71)	5.69 (2.32, 9.06)	14.11 (9.51, 18.72)
2006-10				
Number of deaths/pop.	1,711/14,841,629	277/1,427,116	140/880,184	120/575,449
Mortality rate	11.53 (10.99, 12.09)	19.41 (17.25, 21.84)	15.91 (13.48, 18.77)	20.85 (17.44, 24.94)
Rate ratio cf. England†	-	1.68 (1.48, 1.91)	1.38 (1.16, 1.64)	1.81 (1.50, 2.18)
Rate difference cf. England‡	-	7.88 (5.53, 10.23)	4.38 (1.69, 7.07)	9.32 (5.55, 13.10)

*Numbers in brackets indicate 95% CI

†$\text{Rate}_{\text{Country}}$/ $\text{Rate}_{\text{England}}$

‡$\text{Rate}_{\text{Country}}$- $\text{Rate}_{\text{England}}$

Appendix 3.2B: Injury mortality rates, rate ratios and rate differences (per 100,000 population) comparing Scotland, Wales and Northern Ireland with England, by age group and time period: girls

1-9 years	**England**	**Scotland**	**Wales**	**Northern Ireland**
1980-84				
Number of deaths/pop.	871/12,652,914	133/1,438,915	61/769,491	59/577,358
Mortality rate	6.88 (6.44, 7.36)	9.24 (7.8, 10.96)	7.93 (6.17, 10.19)	10.22 (7.92, 13.19)
Rate ratio cf. England†	-	1.34 (1.12,1.61)	1.15 (0.89,1.49)	1.48 (1.14,1.93)
Rate difference cf. England‡	-	2.36 (0.72, 4.00)	1.04 (-1.00, 3.08)	3.34 (0.69, 5.98)
1993-97				
Number of deaths/pop.	480/13,999,255	71/1,413,419	34/831,045	33/569,384
Mortality rate	3.43 (3.14, 3.75)	5.02 (3.98, 6.34)	4.09 (2.92, 5.73)	5.8 (4.12, 8.15)
Rate ratio cf. England†	-	1.47 (1.14,1.88)	1.19 (0.84,1.69)	1.69 (1.19,2.41)
Rate difference cf. England‡	-	1.59 (0.39, 2.8)	0.66 (-0.75, 2.07)	2.37 (0.37, 4.37)
2006-10				
Number of deaths/pop.	242/13,214,483	21/1,210,054	15/730,564	16/506,308
Mortality rate	1.83 (1.61, 2.08)	1.74 (1.13, 2.66)	2.05 (1.24, 3.41)	3.16 (1.94, 5.16)
Rate ratio cf. England †	-	0.95 (0.61,1.48)	1.12 (0.67,1.89)	1.73 (1.04,2.86)
Rate difference cf. England‡	-	-0.10 (-0.87, 0.68)	-0.22 (-0.84, 1.29)	1.33 (-0.24, 2.89)
10-18 years				
1980-84				
Number of deaths/pop.	1,550/16,169,129	204/1,903,575	102/980,248	65/641,636
Mortality rate	9.59 (9.12, 10.08)	10.72 (9.34, 12.29)	10.41 (8.57, 12.63)	10.13 (7.94, 12.92)
Rate ratio cf. England†	-	1.12 (0.97, 1.29)	1.09 (0.89, 1.33)	1.06 (0.82, 1.35)
Rate difference cf. England‡	-	1.13 (-0.42, 2.68)	0.82 (-1.26, 2.89)	0.54 (-1.96, 3.05)
1993-97				
Number of deaths/pop.	887/12,968,872	113/1,393,253	52/800,942	54/573,896
Mortality rate	6.84 (6.40, 7.30)	8.11 (6.74, 9.75)	6.49 (4.95, 8.52)	9.41 (7.21, 12.29)
Rate ratio cf. England†	-	1.19 (0.97, 1.44)	0.95 (0.72, 1.26)	1.38 (1.05, 1.81)
Rate difference cf. England‡	-	1.27 (-0.29, 2.83)	-0.35 (-2.17, 1.47)	2.57 (0.02, 5.12)
2006-10				
Number of deaths/pop.	611/14,170,350	89/1,357,250	49/841,004	46/547,202
Mortality rate	4.31 (3.98, 4.67)	6.56 (5.33, 8.07)	5.83 (4.40, 7.71)	8.41 (6.30, 11.22)
Rate ratio cf. England†	-	1.52 (1.22, 1.90)	1.35 (1.01, 1.81)	1.95 (1.44, 2.63)
Rate difference cf. England‡	-	2.25 (0.84, 3.65)	1.51 (-0.15, 3.18)	4.09 (1.64, 6.55)

*Numbers in brackets indicate 95% CI

†$\text{Rate}_{\text{Country}}$/ $\text{Rate}_{\text{England}}$

‡$\text{Rate}_{\text{Country}}$- $\text{Rate}_{\text{England}}$

Appendix 3.3: Information on death registration data used in analyses

	Death certificate data			
Unit of analysis	Child death occurring during calendar year			
Age groups	1-4 , 5-9 , 10-14 and 15-18 completed years			
Study period	1980-2010			
UK countries	**England**	**Wales**	**Northern Ireland**	**Scotland**
Data source	Office for National Statistics		Northern Ireland Statistics and Research Agency	National Records of Scotland (Information Services Division, Scotland)
Data source weblink	http://www.ons.gov.uk/ons/index.html		http://www.nisra.gov.uk/	http://www.nrscotland.gov.uk/
Denominator population	Mid-year population estimates by age and sex - ONS; 2002-2010 estimates updated using 2011 census		Mid-year population estimates by age and sex - NISRA	Mid-year population estimates by age and sex- NRS
Denominator population (unrevised) weblink	http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/population-estimates-timeseries-1971-to-current-year/rft---table-2-quinary-age-groups-constituent-countries.zip		www.nisra.gov.uk/archive/demography/population/midyear/NI_Home_Pop_sya(1961_2011).xls	http://www.gro-scotland.gov.uk/files2/stats/time-series/pop-est-time-series-council-areas-1981-2011.xls
Automated coding of underlying cause of death	1993		1997	1996
Number of causes listed on death certificate	2001		2001	2000
Year ICD-10 coding introduced (ICD-9 used prior to this)	1979-84 & 1988-92 (0); 1985-87 (up to 8); 1993-2010 (up to 15)		1979-85 (up to 1); 1986-2004 (up to 4); 2005-08 (up to 10); 2009 (up to 12); 2010 (up to 20)	1980-95 (up to 3); 1996-2010 (up to 10)
Date of registration information available	2006-2010		1997-2010	1980-2010
Last date of registration	27th June 2012		18th June 2012	3rd May 2012
Resident status information available	1980-		1997-	1980-
Information on UK country of residence for non-country residents	Does not state country of residence for non resident deaths		1997-	1980-
Year automated coding of underlying cause of death introduced	1993		1997	1996
Are causes of death in file updated following coroner's verdict	No		Yes	Yes
Link to information on death registration process	https://www.gov.uk/after-a-death/register-the-death		http://www.nidirect.gov.uk/registering-a-death	http://www.gro-scotland.gov.uk/statistics/theme/vital-events/general/weekly-monthly-births-death-data/weekly/index.html

Appendix 3.4: Information on codes used for ICD-9 and ICD-10 chapter groupings based on death certificate data

Codes used for ICD chapter groupings	
Injury deaths: ICD-9 codes for underlying cause	**Unintentional injuries E800-E949;** Transport accidents: E800-E846-E848; E9290, E9291 Other accidents: E850-E928; E9292-E9299; E930-E949 **Intentional injuries: E950-E989** Suicide: E950-E959; Homicide: E960-E969; Legal intervention: E970-E978; E990-E999 Undetermined intent: E980-E989
Injury deaths ICD-10 codes for underlying cause	**Unintentional injuries: V01-X59, Y40-Y86, Y88;** Transport accidents: V01-V99;W00-X59; Y85 Other accidents: W00-X59; Y40-Y84; Y86; Y88 **Intentional injuries: X60-Y36, Y87, Y89, U50.9** Suicide: X60-X84; Y870 Assult/homicide: X85-Y09; Y871 Legal intervention: Y35-Y36; Y890, Y89 Undetermined intent: Y10-Y34 (excl.Y339); Y872 Inquest delayed (England and Wales only): Y339, U509
ICD-9 chapter group for coding based solely on death certificates	Injuries: as above Congenital anomalies: 740-759 Respiratory: 460-519 Endocrine/metabolic/GU/pregnancy: 240-279, 520-676 Symptoms/cardiovascular: 390-459, 780-799 Infections: 001-139 Cancer/blood: 140-289 Mental health: 290-319 Neurological/perinatal/sensory/skin/musculoskeletal:320-389, 680-709, 710-739, 760-779
ICD-10 chapter group for coding based solely on death certificates	Injuries: as above Congenital anomalies: Q00-Q99 Respiratory: J00-J99 Endocrine/metabolic/GU/pregnancy: E00-E90, K00-K93, N00-N99, O00-O99 Symptoms/cardiovascular: I00-I99, R00-R99 Infections: A00-B99 Cancer/blood: C00-D89 Mental health: F00-F99 Neurological/perinatal/sensory/skin/musculoskeletal: G00-G99, H00-H95, L00-L99, M00-M99, P00-P96

Appendix 3.5: Information on sources for population denominator estimates by country

Population Estimates			
Mid-year population estimates by age and sex	1971-2010	1961-2011	1981-2011
Web link	http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/population-estimates-timeseries-1971-to-current-year/rft---table-2-quinary-age-groups-constituent-countries.zip	www.nisra.gov.uk/archive/demography/population/midyear/NI_Home_Pop_sya(1961_2011).xls	http://www.gro-scotland.gov.uk/files2/stats/time-series/pop-est-time-series-council-areas-1981-2011.xls
Revised population estimates for 2002-2010 based on 2011 Census	http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-england-and-wales/mid-2002-to-mid-2010-revised--subnational-/stb---mid-2002-to-mid-2010-subnational-population-estimates-revised.html	Not available at time of analyses	Not available at time of analyses

Appendix 3.6A: Transport accident mortality rates (per 100,000 population) with 95% CI by country, age group and time period

1-9 years	England	Scotland	Wales	Northern Ireland
1980-84				
Number of deaths/pop.	1,112/ 25,993,3381,112/ 25,993,338	189/ 2,953,004189/ 2,953,004	61/ 1,584,02961/ 1,584,029	98/ 1,1853,1898/ 1,1853,18
Rate/100000 pop (95% CI) Rate/100000 pop (95% CI)	4.28 (4.03,4.54)4.28 (4.03,4.54)	6.4 (5.55,7.38)6.4 (5.55,7.38)	3.85 (3.00,4.95)3.85 (3.00,4.95)	8.27 (6.78,10.08)8.27 (6.78,10.08)
1993-97				
Number of deaths/pop.	-	75/ 2,892,09675 /2,892,096	-	57/ 1,168,55757/ 1,168,557
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)		2.59 (2.07,3.25)2.59 (2.07,3.25)		4.88 (3.76,6.32)4.88 (3.76,6.32)
2006-10				
Number of deaths/pop.	174/ 27,061,911174/ 27,061,911	31/ 2,478,82131/ 2,478,821	11/ 1,501,30711/ 1,501,307	16/ 1,040,26216/ 1,040,262
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	0.64 (0.55,0.75)0.64 (0.55,0.75)	1.25 (0.88,1.78)1.25 (0.88,1.78)	0.73 (0.41,1.32)0.73 (0.41,1.32)	1.54 (0.94,2.51)1.54 (0.94,2.51)
10-18 years				
1980-84				
Number of deaths/pop.	4,324/33,207,424	534/3,893,585	224/2,002,178	183/1,318,338
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	13.02 (12.64, 13.42) 13.02 (12.64, 13.42)	13.71 (12.60, 14.93)13.71 (12.60, 14.93)	11.19 (9.82, 12.75)11.19 (9.82, 12.75)	13.88 (12.01, 16.05)13.88 (12.01, 16.05)
1993-97				
Number of deaths/pop.	-	212/2,837,072	-	115/1,165,734
Rate/100000 pop (95% CI)		7.47 (6.53, 8.55)		9.87 (8.22, 11.84)
2006-10				
Number of deaths/pop.	1,124/29,011,979	166/2,784,366	76/1,721,188	69/1,122,651
Rate/100000 pop (95% CI)	3.87 (3.65, 4.11)	5.96 (5.12, 6.94)	4.42 (3.53, 5.53)	6.15 (4.83, 7.78)

Note that mortality rates according to accident type for England and Wales in 1993-97 were not calculated due to a large number of deaths from traffic accidents were coded as unspecified other accidents in this period. Please note that this does not affect calculation of total unintentional injury mortality rates.

Appendix 3.6B: Mortality rates for other unintentional injuries (not transport accidents; per 100,000 population) with 95% CI by country, age group and time period

1-9 years	England	Scotland	Wales	Northern Ireland
1980-84				
Number of deaths/pop.	1,128/25,993,3381,128/25,993,338	194/2,953,004194/2,953,004	83/1,584,02983/1,584,029	65/1,185,31865/1,185,318
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	4.34 (4.09,4.60)4.34 (4.09,4.60)	6.57 (5.71,7.56)6.57 (5.71,7.56)	5.24 (4.23,6.5)5.24 (4.23,6.5)	5.48 (4.3,6.99)5.48 (4.3,6.99)
1993-97				
Number of deaths/pop.	-	71/2,892,09671/2,892,096	-	32/1,168,55732/1,168,557
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)		2.45 (1.95,3.1)2.45 (1.95,3.1)		2.74 (1.94,3.87)2.74 (1.94,3.87)
2006-10				
Number of deaths/pop.	283/27,061,911283/27,061,911	22/2,478,82122/2,478,821	15/1,501,30715/1,501,307	9/1,040,2629/1,040,262
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	1.05 (0.93,1.17)1.05 (0.93,1.17)	0.89 (0.58,1.35)0.89 (0.58,1.35)	1.00 (0.60,1.66)1.00 (0.60,1.66)	0.87 (0.45,1.66)0.87 (0.45,1.66)
10-18 years				
1980-84				
Number of deaths/pop.	1,429/33,207,424	219/3,893,585	136/2,002,178	64/1,318,338
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	4.30 (4.09, 4.53)4.30 (4.09, 4.53)	5.62 (4.93, 6.42)5.62 (4.93, 6.42)	6.79 (5.74, 8.04)6.79 (5.74, 8.04)	4.85 (3.80, 6.20)4.85 (3.80, 6.20)
1993-97				
Number of deaths/pop.	-	74/2,837,072	-	54/1,165,734
Rate/100000 pop (95% CI)		2.61 (2.08, 3.28)		4.63 (3.55, 6.05)
2006-10				
Number of deaths/pop.	424/29,011,979	42/2,784,366	50/1,721,188	25/1,122,651
Rate/100000 pop (95% CI)	1.46 (1.33, 1.61)	1.51 (1.11, 2.04)	2.90 (2.20, 3.83)	2.23 (1.50, 3.30)

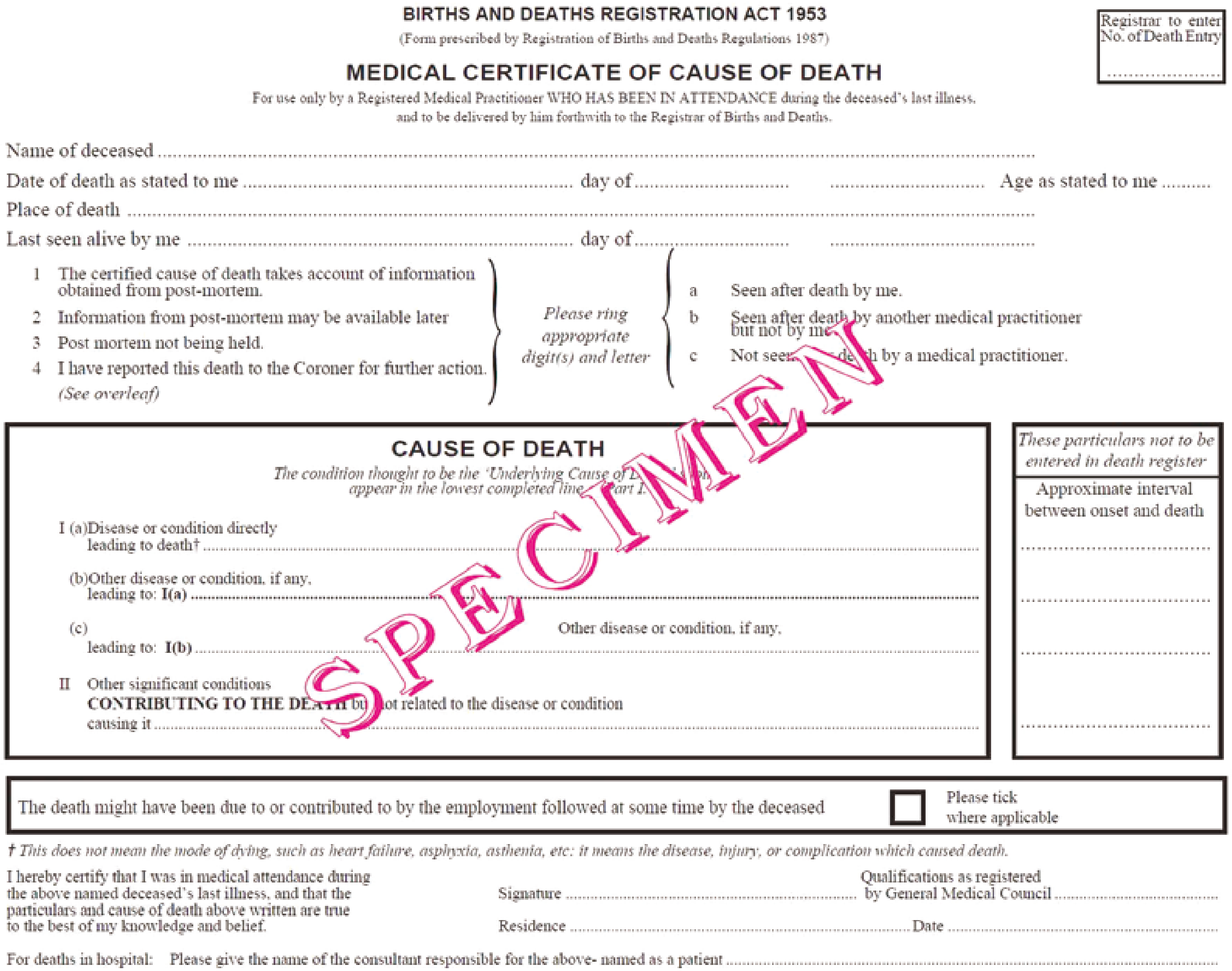
Note that mortality rates according to accident type for England and Wales in 1993-97 were not calculated due to a large number of deaths from traffic accidents were coded as unspecified other accidents in this period. Please note that this does not affect calculation of total unintentional injury mortality rates.

Appendix 3.6C: Mortality rates for intentional injuries (per 100,000 population) with 95% CI by country, age group and time period

1-9 years	England	Scotland	Wales	Northern Ireland
1980-84				
Number of deaths/pop.	251/25,993,338251/25,993,338	23/2,953,00423/2,953,004	12/1,584,02912/1,584,029	5/1,185,3185/1,185,318
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	0.97 (0.85,1.09)0.97 (0.85,1.09)	0.78 (0.52,1.17)0.78 (0.52,1.17)	0.76 (0.43,1.33)0.76 (0.43,1.33)	0.42 (0.18,1.01)0.42 (0.18,1.01)
1993-97				
Number of deaths/pop.	200/28,656,624200/28,656,624	38/2,892,09638/2,892,096	11/1,704,02411/1,704,024	-/1168557*-/1168557*
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	0.70 (0.61,0.80)0.70 (0.61,0.80)	1.31 (0.96,1.81)1.31 (0.96,1.81)	0.65 (0.36,1.17)0.65 (0.36,1.17)	
2006-10				
Number of deaths/pop.	137/27,061,911137/27,061,911	9/2,478,8219/2,478,821	14/1,501,30714/1,501,307	4/1,040,2624/1,040,262
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	0.51 (0.43,0.6)0.51 (0.43,0.6)	0.36 (0.19,0.7)0.36 (0.19,0.7)	0.93 (0.55,1.57)0.93 (0.55,1.57)	0.38 (0.14,1.02)0.38 (0.14,1.02)
10-18 years				
1980-84				
Number of deaths/pop.	854/33,207,424	145/3,893,585	57/2,002,178	59/1,318,338
Rate/100000 pop (95% CI)Rate/100000 pop (95% CI)	2.57 (2.40, 2.75)2.57 (2.40, 2.75)	3.72 (3.16, 4.38)3.72 (3.16, 4.38)	2.85 (2.20, 3.69)2.85 (2.20, 3.69)	4.48 (3.47, 5.78)4.48 (3.47, 5.78)
1993-97				
Number of deaths/pop.	789/26,504,345	186/2,837,072	59/1,634,641	74/1,165,734
Rate/100000 pop (95% CI)	2.98 (2.78, 3.19)	6.56 (5.68, 7.57)	3.61 (2.80, 4.66)	6.35 (5.05, 7.97)
2006-10				
Number of deaths/pop.	774/29,011,979	158/2,784,366	63/1,721,188	72/1,122,651
Rate/100000 pop (95% CI)	2.67 (2.549, 2.86)	5.67 (4.86, 6.60)	3.66 (2.86, 4.69)	6.41 (5.09, 8.08)

* Number of deaths is ≤5 in this group and the count and rate are therefore suppressed to avoid disclosure

Appendix 4.1: Medical certificate of cause of death



BIRTHS AND DEATHS REGISTRATION ACT 1953

(Form prescribed by Registration of Births and Deaths Regulations 1987)

Registrar to enter No. of Death Entry ....

MEDICAL CERTIFICATE OF CAUSE OF DEATH

For use only by a Registered Medical Practitioner WHO HAS BEEN IN ATTENDANCE during the deceased's last illness, and to be delivered by him forthwith to the Registrar of Births and Deaths.

Name of deceased ....

Date of death as stated to me .... day of .... Age as stated to me ....

Place of death ....

Last seen alive by me .... day of ....

1 The certified cause of death takes account of information obtained from post-mortem.
2 Information from post-mortem may be available later
3 Post mortem not being held.
4 I have reported this death to the Coroner for further action.
(See overleaf)

Please ring appropriate digit(s) and letter

a Seen after death by me.
b Seen after death by another medical practitioner but not by me.
c Not seen after death by a medical practitioner.

CAUSE OF DEATH

The condition thought to be the 'Underlying Cause of Death' should appear in the lowest completed line of Part I.

These particulars not to be entered in death register

Approximate interval between onset and death

I (a) Disease or condition directly leading to death† ....

(b) Other disease or condition, if any, leading to: I(a) ....

(c) Other disease or condition, if any, leading to: I(b) ....

II Other significant conditions CONTRIBUTING TO THE DEATH but not related to the disease or condition causing it ....

The death might have been due to or contributed to by the employment followed at some time by the deceased ☐ Please tick where applicable

† This does not mean the mode of dying, such as heart failure, asphyxia, asthenia, etc: it means the disease, injury, or complication which caused death.

I hereby certify that I was in medical attendance during the above named deceased's last illness, and that the particulars and cause of death above written are true to the best of my knowledge and belief.

Signature .... Qualifications as registered by General Medical Council ....

Residence .... Date ....

For deaths in hospital: Please give the name of the consultant responsible for the above- named as a patient ....

Appendix 4.2: ICD-10 code lists for acute respiratory conditions

Acute respiratory conditions	
ICD-10 Codes	**Type of condition**
J00-J06	Acute upper respiratory infections
J09-J18	Influenza and pneumonia
J20-J22	Other acute lower respiratory infections
J30-J39	Other diseases of upper respiratory tract
J60-J70	Lung diseases due to external agents
J80-J84	Other respiratory diseases principally affecting the interstitium
J85-J86	Suppurative and necrotic conditions of lower respiratory tract
J90-J94	Other diseases of pleura
J95-J99	Other diseases of the respiratory system

Appendix 5.1: Information on birth registrations linked to death certificate and live birth denominator data for singleton live births, England and Wales, and Scotland

Births linked to deaths data		
Unit of analsysis	Number of child deaths by year of birth	
UK countries	**England & Wales**	**Scotland**
Age groups	0-27 & 28-364 days; 1-4, 5-9 & 10-14 completed years	0-27 & 28-364 days; 1-4, 5-9, 10-14 & 15-18 completed years
Data source	Office for National Statistics	National Records of Scotland (Information Services Division, Scotland)
Year of birth interval	1993-2010	1980-2010
Last date of death registrations received	30th September 2012	3rd May 2012
Multiple births included?	No	No
Maternal age groups analysed	Under 20, 20-24, 25-29, 30-34, 35+	Under 20, 20-24, 25-29, 30-34, 35+
Birthweight groups analysed	500-1499, 1500-2499, 2500+ grams	500-1499, 1500-2499, 2500+ grams
Live births		
Number of live births	By grouped maternal age, birth weight and sex	By grouped maternal age and birth weight
Maternal age groups	Under 18, 18-19, 20-24, 25-29, 30-34, 35-39, 40+	Under 18, 18-19, 20-24, 25-29, 30-34, 35-39, 40+
Birth weight groups	Under 1000, 1000-1499, 1500-1999, 2000-2499, 2500-2999, 3000-3499, 3500-3999, 4000+ grams	Under 500, 500-999, 1000-1499, 1500-1999, 2000-2499, 2500-2999, 3000-3499, 3500-3999, 4000+ grams
Year of birth	1993-2010	1981-2010

Appendix 5.2: Details of data cleaning and statistical methods used in Chapter 5

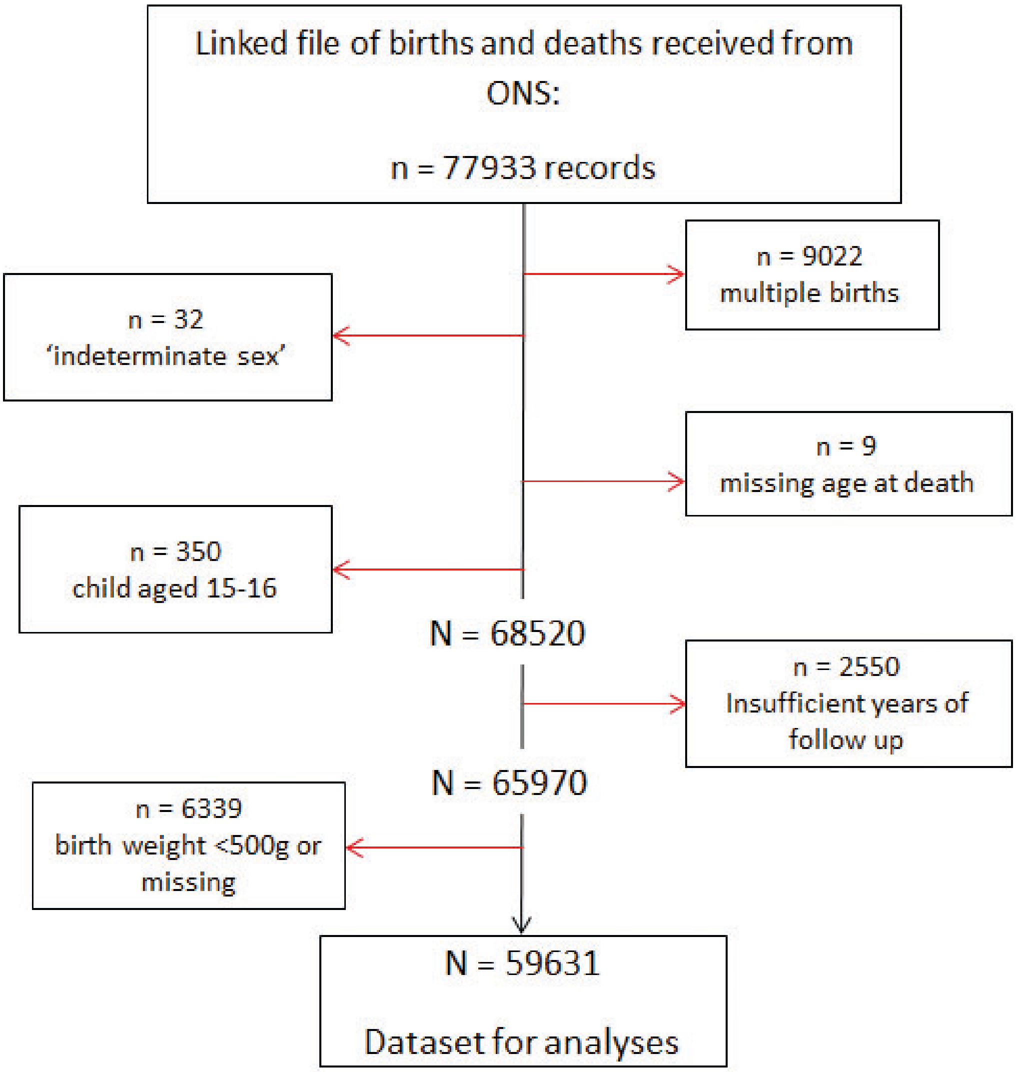
1. England & Wales: data cleaning

1.1 Introduction

ONS provided a linked dataset of birth registrations and death certificates for children who were born in 1993 up to 2010 and who died between 1993 and 2012. Age at death was given in the following categories: zero to six days, seven to 27 days, and then by month up to 11 months and then by year. In total the original dataset contained linked records for 77933 children who died aged up to 16 years.

1.2 Deriving a cohort of birth registrations linked to death certificates

Figure APPX 5.2.1: England and Wales: derivation of dataset for analysis of birth registrations linked to death certificates



1.2.1 Years of follow up

Figure APPX 5.2.1 shows how the dataset for analysis was derived and the number of cases excluded. We restricted analyses to ensure that all children born in each calendar year had sufficient follow up to be included in each age group at death. For example, children born in 2008 would be captured in death certification data for 2009 and 2010 if they died before the age of two, but children born in 2008 who died at age three or four years would be missing from the one to four years age at death group. We therefore restricted analyses for deaths in the one to four year age group to births in 2002-2006. Using the same reasoning, we analysed deaths in children aged 10 to 14 year who were born in 1993-1996 inclusive. We excluded children who died aged 15 to 16 years due to insufficient numbers and years of follow up. This approach was applied to all birth cohorts and resulted in 2550 death records being excluded. An exception to this approach was the analysis of births in 2002-2010 where we considered any neonatal or post-neonatal death that occurred in 2002-2010. A total of 65970 deaths were included in analyses that did not involve birth weight.

1.2.2 Birth weight

We excluded 6339 death records based on their birth weight. 2262 children had a birth weight recorded as 0g, while 4077 children had a recorded birth weight between 1-499g. In total, 6370 records were treated as having missing birth weight. Many of the birth weights under 500g were obviously incorrect (eg. impossibly low birth weights such as 2 or 3g). Because we were unable to distinguish between errors and genuine extremely low birth weights, we decided to exclude all children with a birth weight less than 500g. A total of 59631 deaths were included in analyses involving birth weight.

1.2.3 Socio-economic status

The linked file included a variable for socio-economic status (NSSEC - National Statistics Socio-economic Classification operational category for father of child), recorded between 2001 and 2010 on the birth registration. As only 8% of children had a non-missing entry we did not pursue analyses involving socio-economic status for England and Wales.

1.3 Denominator tables

ONS provided denominators in the form of live births tables by year of birth, birth weight and maternal age. The denominator population was split by maternal age into: <18 years, 18 to 19 years, 20 to 24 years, 25 to 29 years, 30 to 34 years, 35 to 39 years and 40 years+. Due to small numbers we analysed maternal age in groups of: <20 years, 20 to 24 years, 25 to 29 years, 30 to 34 years and 35+ years.

1.3.1 Years of follow up

We derived denominator populations for birth cohorts with complete follow-up for each age at death group. Therefore, denominators from 2007 onwards for one to four years, 2002 onwards for five to nine years and 1997 onwards for 10 to 14 years were set to 0.

Denominators for neonates were taken directly from the live births tables. Denominators for older age at death groups were adjusted to account for deaths that had occurred in previous age at death groups (e.g. for one to four years the neonates and post-neonates who have already died were deducted from the number of live births).

1.3.2 Birth weight

For birth weight we received denominators in the following groups: <1000g, 1000-1499g, 1500-1999g, 2000-2499g, 2500-2999g, 3000-3499g, 3500-3999g and 4000g+. The lowest denominator birth weight category ONS were willing to provide was <1000g due to concerns regarding data quality. As our lowest birth weight category started at 500g it was necessary to adjust these <1000g denominators to remove babies with birth weight less than 500g. This was implemented by calculating the proportion of Scottish births <1500g that were <500g and adjusting the denominator for births <1500g in England and Wales.

2. Scotland: data cleaning

2.1 Introduction

Scotland Information Services Division (ISD) provided birth registration data linked to delivery records (SMR02), neonatal admission records (SBR) and birth registration data (GRO births) for children born 1974-2010 who died in 1979-2010 and had their death registered in 1980-2012.

2.2 Deriving a cohort of birth registrations linked to death certificates

We combined delivery records (SMR02) with neonatal admissions (SBR file) for singleton births with death certificates and birth registration data. A large number (*n*=6734) of unmatched death registration records related to children with birth records before 1980. We excluded cases with no birth registration (*n*=124) . Births before 1981 (*n*=2545) were excluded because denominator data for Scotland were provided for births only from 1981 onwards. We extracted year of birth and socio-economic status from the birth registration dataset. All files contained a unique identifier so that information belonging to the same child could be linked across different datasets.

2.2.1. Years of follow up

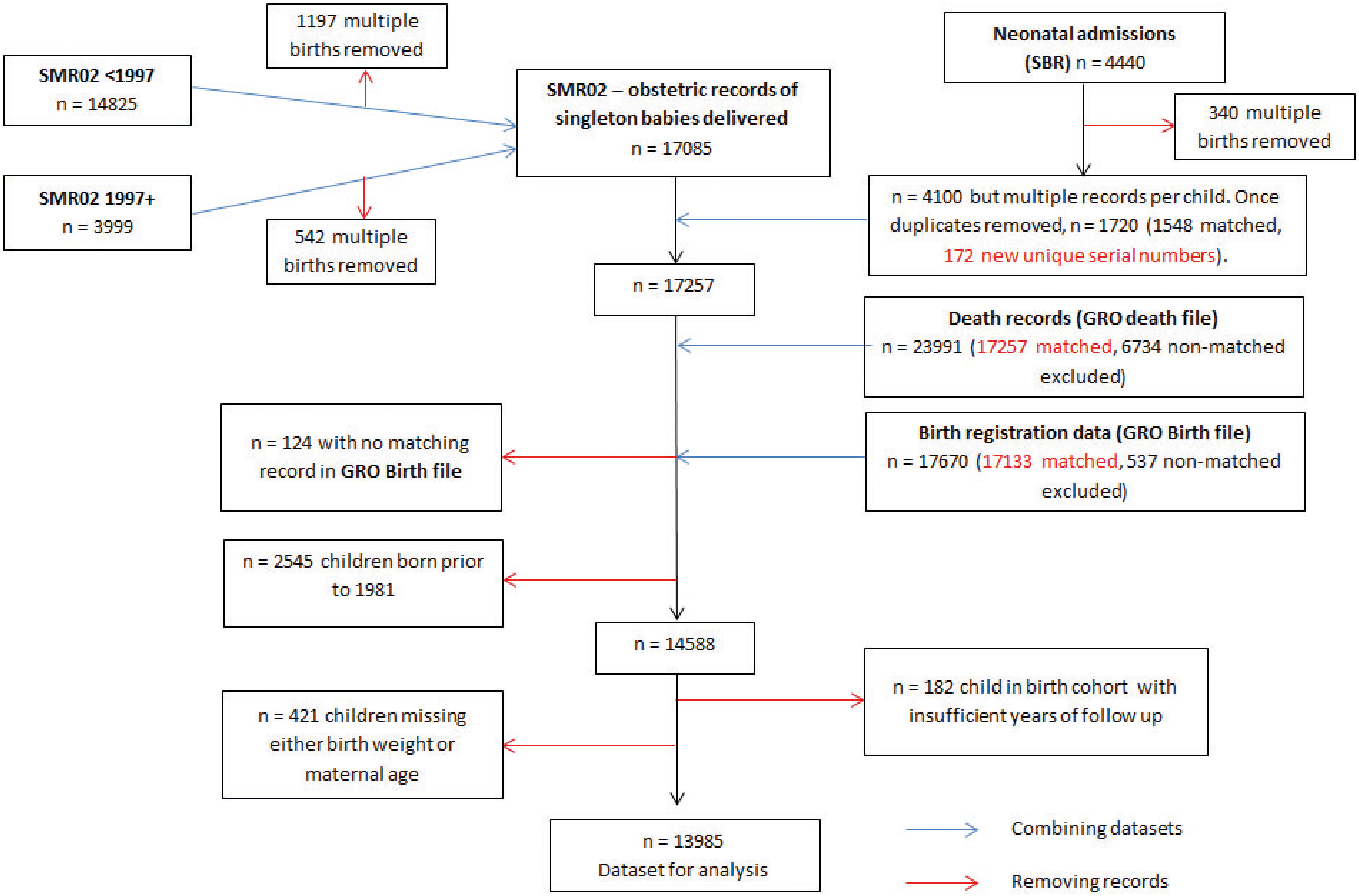
We excluded deaths from birth cohorts with insufficient years of follow up for all children within the birth cohort (excludes 182 records). Because Scotland provided deaths for children born in 1981 onwards, we were able to analyse deaths up to 18 years old in children born in 1981-1992.

2.2.2. Birth weight

We extracted birth weight and maternal age from the delivery (SMR02) and neonatal records (SBR). Where there was a conflict we accepted the SBR birth entry. 200 children had birth weight recorded as missing, while 195 children had a recorded birth weight between 1-499g.

Analyses were based on 13985 linked records.

Figure APPX 5.2.2: Scotland: derivation of dataset for analysis of birth registrations linked to death certificates



2.3 Denominator tables

The ISD Scotland provided denominators in the form of tables of live births by year of birth, birth weight, maternal age and socio-economic status. For birth weight we received denominators in the following groups: <500g, 500-999g, 1000-1499g, 1500-1999g, 2000-2499g, 2500-2999g, 3000-3499g, 3500-3999g and 4000g+. For maternal age the denominators were split into: <18 years, 18 to 19 years, 20 to 24 years, 25 to 29 years, 30 to 34 years, 35 to 39 years and 40 years+. Denominator tables were constructed in the same way as for England and Wales.

Birth registration data for Scotland included socio-economic status based on father's occupation for births from 2001 onwards. Completenes for this variable was very good, with only 1 missing value. Groupings were higher management, intermediate, routine & manual, unemployed, not stated and missing. These data were not used in the present report because comparable data were not available for England and Wales.

Statistical models to adjust for the effect of birth weight and calculation of the mortality difference for children of mothers under 30 years compared with those aged 30 to 34 years.

We fitted Poisson regression models, taking into account overdispersion where present, to determine the relative effect of maternal age on mortality whilst adjusting for the effect of birth weight. To ensure that results applied to the most recent period while taking account of the differing periods of follow up by child age at death, we constructed separate models for deaths in infancy (based on births 2002-2010), at one to four years of age (based on births 2002-2006), five to nine years (based on births 1993-2001) and 10 to 14 years of age (based on births in 1993 to 1996). For age groups where inclusion of a term for maternal age significantly improved the fit of the model (ie. the likelihood ratio (LR) test $p<0.05$ comparing models with birth weight only and birth weight and maternal age), we calculated population attributable risks and rate differences in the number of deaths compared with children born to mothers aged 30 to 34 years (based on births in the latest calendar period with complete follow-up). Rate differences were calculated only if the 95% confidence interval for the rate difference did not cross 0. We divided the difference in the number of deaths for children born in the most recent birth cohort by the number of calendar years to estimate differences in the number of deaths in a single year.

Appendix 5.3A: Number of deaths, mortality rates and rate ratios by age at death, time period and birth weight: England and Wales

		1981-1992			1993-2001			2002-2010			
Age at death	**Birth weight**	**Deaths**	**Rate/100,000 children (95% CI)**	**Rate ratio (95% CI)**	**Deaths**	**Rate/100,000 children (95% CI)**	**Rate ratio (95% CI)**	**Deaths**	**Rate/100,000 children (95% CI)**	**Rate ratio (95% CI)**	**% reduction: 2002+-2010 vs. 1993-2001**
0-27 days 0-27 days	500-1499g	n/a	n/a	n/a	8183	16106 (15758, 16456)16106 (15758, 16456)	145.42 (140.75, 150.24)145.42 (140.75, 150.24)	6496	12297 (11998, 12596)12297 (11998, 12596)	133.48 (128.77, 138.36)133.48 (128.77, 138.36)	↓24%
	1500-2499g				2579	925 (889, 960)925 (889, 960)	8.35 (7.97, 8.74)8.35 (7.97, 8.74)	2304	805 (772, 838)805 (772, 838)	8.74 (8.32, 9.18)8.74 (8.32, 9.18)	↓13%
	2500g+				5710	111 (108, 114)111 (108, 114)	1	4983	92 (90, 95)92 (90, 95)	1	↓17%
28-364 days 28-364 days	500-1499g	n/a	n/a	n/a	1685	3953 (3765, 4142)3953 (3765, 4142)	33.13 (31.42, 34.93)33.13 (31.42, 34.93)	1681	3628 (3455, 3802)3628 (3455, 3802)	41.50 (39.29, 43.85)41.50 (39.29, 43.85)	↓8%
	1500-2499g				1803	652 (622, 682)652 (622, 682)	5.47 (5.19, 5.76)5.47 (5.19, 5.76)	1507	531 (504, 558)531 (504, 558)	6.07 (5.73, 6.43)6.07 (5.73, 6.43)	↓19%
	2500g+				6145	119 (116, 122)119 (116, 122)	1	4724	87 (85, 90)87 (85, 90)	1	↓27%
1-4 years 1-4 years	500-1499g	n/a	n/a	n/a	205	501 (432, 569)501 (432, 569)	5.77 (5.01, 6.63)5.77 (5.01, 6.63)	134	300 (249, 351)300 (249, 351)	8.03 (6.75, 9.57)8.03 (6.75, 9.57)	↓40%
	1500-2499g				695	253 (234, 272)253 (234, 272)	2.91 (2.69, 3.16)2.91 (2.69, 3.16)	350	124 (111, 137)124 (111, 137)	3.32 (2.96, 3.72)3.32 (2.96, 3.72)	↓50%
	2500g+				4467	87 (84, 89)87 (84, 89)	1	2017	37 (36, 39)37 (36, 39)	1	↓57%
5-9 years 5-9 years	500-1499g	n/a	n/a	n/a	77	189 (147, 231)189 (147, 231)	4.12 (3.28, 5.16)4.12 (3.28, 5.16)	n/a	n/a	n/a	n/a
	1500-2499g				264	96 (85, 108)96 (85, 108)	2.10 (1.85, 2.38)2.10 (1.85, 2.38)				
	2500g+				2360	46 (44, 48)46 (44, 48)	1				
10-14 years 10-14 years	500-1499g	n/a	n/a	n/a	32	79 (51, 106)79 (51, 106)	3.64 (2.56, 5.17)3.64 (2.56, 5.17)	n/a	n/a	n/a	n/a
	1500-2499g				119	43 (36, 51)43 (36, 51)	2.01 (1.66, 2.43)2.01 (1.66, 2.43)				
	2500g+				1111	22 (20, 23)22 (20, 23)	1				

Data n/a for E&W in 1981-1992 because we did not receive data for this time period

Data n/a for children aged 5-9 & 10-14 in 2002-2010 because birth cohort prevents full coverage of these age groups in this time period

Appendix 5.3B: Number of deaths, mortality rates and rate ratios by age at death and birth weight: Scotland

		1981-1992			1993-2001			2002-2010			
Age at death	Birth weight	Deaths	Rate/100,000 children (95% CI)	Rate ratio (95% CI)	Deaths	Rate/100,000 children (95% CI)	Rate ratio (95% CI)	Deaths	Rate/100,000 children (95% CI)	Rate ratio (95% CI)	% reduction: 2002+-2010 vs. 1993-2001
0-27 days 0-27 days	500-1499g	1412	26447 (25067, 27826)26447 (25067, 27826)	166.44 (154.71, 179.06)166.44 (154.71, 179.06)	652	12212 (11275, 13149)12212 (11275, 13149)	145.42 (140.75, 150.24)145.42 (140.75, 150.24)	457	8560 (7775, 9344)8560 (7775, 9344)	163.32 (142.91, 186.64)163.32 (142.91, 186.64)	↓30%
	1500-2499g	713	1925 (1784, 2066)1925 (1784, 2066)	12.12 (11.04, 13.29)12.12 (11.04, 13.29)	246	664 (581, 747)664 (581, 747)	8.35 (7.97, 8.74)8.35 (7.97, 8.74)	199	537 (463, 612)537 (463, 612)	10.25 (8.64, 12.17)10.25 (8.64, 12.17)	↓19%
	2500g+	1149	159 (150, 168)159 (150, 168)	1	537	74 (68, 81)74 (68, 81)	1	379	52 (47, 58)52 (47, 58)	1	↓30%
28-364 days 28-364 days	500-1499g	206	5246 (4529, 5962)5246 (4529, 5962)	20.25 (17.60, 23.31)20.25 (17.60, 23.31)	163	3478 (2944, 4012)3478 (2944, 4012)	33.13 (31.42, 34.93)33.13 (31.42, 34.93)	113	2315 (1888, 2741)2315 (1888, 2741)	45.58 (36.99, 56.18)45.58 (36.99, 56.18)	↓33%
	1500-2499g	344	947 (847, 1047)947 (847, 1047)	3.66 (3.26, 4.10)3.66 (3.26, 4.10)	174	473 (403, 543)473 (403, 543)	5.47 (5.19, 5.76)5.47 (5.19, 5.76)	126	342 (282, 402)342 (282, 402)	6.74 (5.50, 8.24)6.74 (5.50, 8.24)	↓28%
	2500g+	1870	259 (247, 271)259 (247, 271)	1	576	80 (73, 86)80 (73, 86)	1	367	87 (85, 90)87 (85, 90)	1	↓36%
1-4 years 1-4 years	500-1499g	26	699 (430, 967)699 (430, 967)	5.48 (3.72, 8.08)5.48 (3.72, 8.08)	15	332 (164, 499)332 (164, 499)	5.77 (5.01, 6.63)5.77 (5.01, 6.63)	11	231 (94, 367)231 (94, 367)	10.22 (5.55, 18.81)10.22 (5.55, 18.81)	↓30%
	1500-2499g	121	336 (276, 396)336 (276, 396)	2.64 (2.18, 3.19)2.64 (2.18, 3.19)	71	194 (149, 239)194 (149, 239)	2.91 (2.69, 3.16)2.91 (2.69, 3.16)	37	101 (68, 133)101 (68, 133)	4.47 (3.13, 6.38)4.47 (3.13, 6.38)	↓48%
	2500g+	918	127 (119, 136)127 (119, 136)	1	362	50 (45, 55)50 (45, 55)	1	163	23 (19, 26)23 (19, 26)	1	↓54%
5-9 years 5-9 years	500-1499g	5	135 (17, 254)135 (17, 254)	2.10 (0.87, 5.07)2.10 (0.87, 5.07)	3	67 (0, 142)67 (0, 142)	4.12 (3.28, 5.16)4.12 (3.28, 5.16)	n/a	n/a	n/a	n/a
	1500-2499g	54	151 (110, 191)151 (110, 191)	2.34 (1.77, 3.10)2.34 (1.77, 3.10)	22	60 (35, 85)60 (35, 85)	2.10 (1.85, 2.38)2.10 (1.85, 2.38)				
	2500g+	463	64 (59, 70)64 (59, 70)	1	221	31 (27, 35)31 (27, 35)	1				
10-14 years 10-14 years	500-1499g	6	163 (32, 293)163 (32, 293)	2.44 (1.09, 5.45)2.44 (1.09, 5.45)	4	89 (2, 176)89 (2, 176)	6.10 (2.25, 16.55)6.10 (2.25, 16.55)	n/a	n/a	n/a	n/a
	1500-2499g	45	126 (89, 162)126 (89, 162)	1.89 (1.39, 2.56)1.89 (1.39, 2.56)	8	22 (7, 37)22 (7, 37)	1.50 (0.73, 3.09)1.50 (0.73, 3.09)				
	2500g+	479	67 (61, 73)67 (61, 73)	1	105	15 (12, 17)15 (12, 17)	1				
15-18 years 15-18 years	500-1499g	10	271 (103, 440)271 (103, 440)	1.78 (0.96, 3.32)1.78 (0.96, 3.32)	n/a	n/a	n/a	n/a	n/a	n/a	n/a
	1500-2499g	84	235 (185, 285)	1.54 (1.23, 1.92)							
	2500g+	1095	152 (143, 161)	1							

Data n/a where birth cohort does not allow for full coverage in age group/time period

Appendix 5.4A: Number of deaths, mortality rates and rate ratios by age at death and maternal age – England and Wales

		1981-1992			1993-2001			2002-2010			
Age at death	**Maternal age years**	**Deaths n**	**Rate/100,000 children (95% CI)**	**Rate ratio (95% CI)**	**Deaths n**	**Rate/100,000 children (95% CI)**	**Rate ratio (95% CI)**	**Deaths n**	**Rate/100,000 children (95% CI)**	**Rate ratio (95% CI)**	**% reduction: 2002+-2010 vs. 1993-2001**
5-9 years	<20 yrs	n/a	n/a	n/a	261	66 (58, 74)	1.56 (1.35, 1.80)	n/a	n/a	n/a	n/a
	20-24 yrs				612	57 (53, 62)	1.35 (1.21, 1.51)				
	25-29 yrs				880	51 (48, 54)	1.21 (1.09, 1.34)				
	30-34 yrs				657	42 (39, 45)	1				
	35+ yrs				321	43 (39, 48)	1.03 (0.90, 1.17)				
10-14 years	<20 yrs	n/a	n/a	n/a	110	28 (23, 33)	1.34 (1.08, 1.66)	n/a	n/a	n/a	n/a
	20-24 yrs				296	28 (24, 31)	1.33 (1.14, 1.56)				
	25-29 yrs				422	24 (22, 27)	1.18 (1.02, 1.36)				
	30-34 yrs				323	21 (18, 23)	1				
	35+ yrs				140	19 (16, 22)	0.91 (0.75, 1.11)				

Data n/a for E&W in 1981-1992 because we did not receive data for this time period.

Data n/a for children aged 5-9 & 10-14 in 2002-2010 because birth cohort prevents full coverage of these age groups in this time period.

Appendix 5.4B: Number of deaths, mortality rates and rate ratios by age at death and maternal age – Scotland

		1981-1992			1993-2001			2002-2010			
Age at death	Maternal age years	Deaths n	Rate/100,000 children (95% CI)	Rate ratio (95% CI)	Deaths n	Rate/100,000 children (95% CI)	Rate ratio (95% CI)	Deaths n	Rate/100,000 children (95% CI)	Rate ratio (95% CI)	% reduction: 2002+-2010 vs. 1993-2001
5-9 years	<20 yrs	55	77 (57, 98)	1.42 (1.00, 2.00)	28	70 (44, 96)	1.61 (1.03, 2.52)	n/a	n/a	n/a	n/a
	20-24 yrs	198	89 (77, 102)	1.63 (1.26, 2.11)	62	66 (50, 83)	1.52 (1.07, 2.17)				
	25-29 yrs	162	61 (51, 70)	1.11 (0.85, 1.45)	68	43 (33, 53)	0.99 (0.70, 1.40)				
	30-34 yrs	80	55 (43, 67)	1	62	43 (33, 54)	1				
	35+ yrs	28	55 (35, 76)	1.01 (0.66, 1.55)	26	41 (25, 57)	0.95 (0.60, 1.50)				
10-14 years	<20 yrs	62	87 (66, 109)	1.52 (1.10, 2.11)	11	28 (11, 44)	1.27 (0.64, 2.52)	n/a	n/a	n/a	n/a
	20-24 yrs	167	75 (64, 87)	1.31 (1.01, 1.70)	21	22 (13, 32)	1.03 (0.59, 1.80)				
	25-29 yrs	179	67 (57, 77)	1.17 (0.90, 1.51)	42	27 (19, 35)	1.23 (0.77, 1.95)				
	30-34 yrs	84	57 (45, 70)	1	31	22 (14, 29)	1				
	35+ yrs	37	73 (49, 96)	1.27 (0.86, 1.87)	12	19 (8, 30)	0.87 (0.45, 1.70)				
15-18 years	<20 yrs	132	186 (154, 218)	1.49 (1.19, 1.87)	n/a	n/a	n/a	n/a	n/a	n/a	n/a
	20-24 yrs	440	198 (180, 217)	1.59 (1.34, 1.89)							
	25-29 yrs	373	140 (125, 154)	1.12 (0.94, 1.34)							
	30-34 yrs	182	125 (106, 143)	1							
	35+ yrs	64	126 (95, 157)	1.01 (0.76, 1.35)							

Data n/a where birth cohort does not allow for full coverage in age group/time period

Appendix 5.5: Estimated average difference in the number of child deaths in one year, by age at death and birth weight* comparing mothers less than 30 years with mothers aged 30 to 34 years

Child age at death	Birth weight	Number of excess deaths according to maternal age group			Average number of excess deaths in 1 year	Average number of deaths in 1 year
		<20 years	20-24 years	25-29 years		
		Births in 2002-2010				
0-27 days	500-1499g	18	12	0	30	773
	1500-2499g	0	0	0	0	278
	2500g+	12	17	15	44	596
28-364 days	500-1499g	5	0	0	5	199
	1500-2499g	9	13	6	28	181
	2500g+	48	77	32	157	566
		Births in 2002 to 2006				
1-4 years	all	26	37	22	85	542
		Births in 1993-2001				
5-9 years	all	12	20	15	47	337
Total		130	176	90	396	3472

*Analyses based on birth cohorts from the most recent calendar period with complete follow up

Comparing mortality rates in children of other maternal age groups against children born to 30-34 year old mothers

Appendix 5.6: Differences in mortality rates for children born to mothers aged less than 30 compared with mothers aged 30 to 34 years, by age at death, birth weight*

		Rate difference per 100,000 (95% CI) comparing each maternal age group to mothers aged 30 to 34 yrs:		
Age at death	**Birth weight**	**<20 yrs**	**20-24 yrs**	**25-29 yrs**
		Births in 2002-2010		
NN	**500-1499g**	3053 (1865, 4240)	964 (103, 1825)	603 (-206, 1412)
	1500-2499g	-1 (-123, 121)	6 (-86, 98)	-20 (-108, 67)
	2500g+	28 (17, 39)	13 (6, 21)	9 (2, 15)
PNN	**500-1499g**	926 (229, 1623)	157 (-337, 651)	34 (-429, 498)
	1500-2499g	295 (184, 407)	172 (97, 247)	69 (0, 137)
	2500g+	110 (97, 124)	62 (55, 70)	19 (13, 24)
		Births in 2002-2006		
1-4 yrs	**ALL**	54 (39, 69)	29 (20, 39)	13 (5, 22)
		Births in 1993-2001		
5-9 yrs	**ALL**	24 (15, 32)	16 (10, 21)	8 (3, 12)

Shading indicates rate differences where 95% confidence interval does not include 0

*Analyses based on birth cohorts from the most recent calendar period with complete follow up

Comparing mortality rates in children of other maternal age groups against children born to 30-34 year old mothers

Appendix 6.1: Details of death registration data linked to hospital records by country

	England	Scotland	Wales
Basic unit of hospital data	Finished consultant episode (FCE), linked to admissions as described in Appendix 6-2.	Admission (linked to provide comparable admissions to England and Wales as described in Appendix 6-2)	Finished consultant episode (FCE), linked to admissions as described in Appendix 6-2.
Linked hospital records available from	FCEs ending 1st April 1997 onwards	Admissions ending 1st Jan 1981 onwards	Consultant episodes ending 1st January 1998 onwards
Linked mortality->hospital admission data available from	Deaths registered 1st January 1998 onwards	Deaths registered 1st Jan 1980 onwards (linked to hospital birth records) Deaths registered 1st Jan 1981 onwards (linked to hospital inpatient records)	Deaths registered 1st January 1998 onwards
Number of diagnoses/episode or admission	1997-2001: up to 7/FCE 2002-2006: up to 14/FCE 2007-2010: up to 20/FCE	Up to 6/admission (up to 12/ admission in SMR11)	Up to 14/episode
Number of ICD-10 coded causes of death in linked data	Up to 15 mentions	Up to 11 mentions	Underlying cause of death only (January 1998-February 2003) Up to 8 mentions (February 2003 onwards)
Date ICD-10 coding introduced on hospital records	FCEs ending 1st April 1997 onwards	Admissions ending 1st April 1996	FCEs ending 1st January 1998
Date ICD-10 coding introduced on death registration data	Deaths registered 1st January 2001 onwards	Deaths registered 1st January 2000 onwards	Deaths registered 1st January 2001 onwards
Linked hospital birth records available from	1st April 1997 onwards (births count as inpatient admissions) All birth admissions have a maternity tail with information on the baby and mother.	Births occurring 1st January 1975 onwards: Diagnostic information available 1st Jan 1975-31st March 2003 ICD-10 diagnoses on birth records available for children admitted to SCBUs only between 1st April 1996 and 31st March 2003	Birth records only included if the child is admitted to hospital (in which case counts as an FCE). Death certificates have been linked to maternity record.
Mean number of non-missing diagnoses/ admission in study dataset (admissions ending in 2001)	3.1	3.4	3.5

Mean number of non-missing diagnoses/ admission in study dataset (admissions ending in 2010)	6.2	4.3	6.2
Variables used for linkage to death registration records	Hierarchical alogrithm based on combinations of: NHS number, date of birth, sex, postcode *	Probablistic linkage based on CHI number, NHS number, dates of birth and death, names, postcode and other unique identifiers	NHS number
Variables used for linkage of hospital records across time	Hierarchical alogrithm based on combinations of: NHS number, date of birth, sex, postcode, provider, local patient ID**	CHI number	NHS number
Last date of death occurrence	31st December 2010	31st December 2010	31st December 2010
Last date of registration	7th August 2012	3rd May 2012	9th December 2011
Definition of death in hospital from hospital records	dismeth=4 OR date of death≤last date of discharge	disch_to=”00” OR date of death≤last date of discharge	discharge_method=”Patient died” OR date of death≤ last date of discharge
Place of death coding on death certificates	Coded as ‘home’, ‘elsewhere’ or in a communal establishment, where communal establishment can be further subdivided into NHS establishments (such as NHS acute or community trusts) or non-NHS establishments (such as non-NHS hospices and care homes, hostels and special schools)	Coded into an 11-category variable (hospital, clinic, GP surgery, non-NHS maternity, private or voluntary nursing homes paid for by health board, nursing homes, prisons, residential homes, children’s homes/convalescent homes and non-institutions). Place of occurrence available for deaths due to injury.	As for England

* Linkage methodology can be found on page 7 of the HES-ONS mortality data guide:

http://www.hscic.gov.uk/media/11668/HES-ONS-Mortality-Data-Guide/pdf/guide_to_linked_ONS_HES_mortality_data_V4_040613.pdf

** Methodology for linking hospital episode records over time can be found in the old HES User guide from HSCIC

Appendix 6.2: Derivation of datasets for analyses: death certificates linked to hospital admission data in England, Scotland and Wales

1. England

1.1 Introduction

Death records (provided by ONS) and HES hospital admission records were linked by the Trusted Data Linkage Service of the HSCIC using a hierarchical, deterministic algorithm.[48]

It is possible to link HES records over time for the same individual for admissions ending on 1st April 1997 onwards. Each person is identified using an encrypted identifier (hesid). HES can be linked to death records for deaths registered on the 1st January 1998 onwards.

We received the linked data in three separate files:

1. Linked death records (75088 death records)
2. Linked hospital records (hospital records for the children in 1); file included 557,344 finished consultant episodes)
3. Unlinked death records (17289 death records)

No identifying information, such as name, date of birth or NHS number was supplied. Instead individuals were identified using the encrypted id 'hesid'. Methods for identifying individuals on HES and linking admissions to persons have been described elsewhere[89].

1.1.1 Checking link between matched records

The HES and ONS records were linked using the hesid identifier. 3247 of the 75088 records in the matched death records file could not be linked to a HES record. These were moved to the 'unmatched' ONS file (see below).

1.2 Cleaning the linked dataset

1.2.1 Basic structure of HES

The HES inpatient dataset is based on finished consultant episodes (FCEs). One FCE represents time in hospital under the continuous care under one consultant. Therefore if a patient is transferred between consultants during an admission, this admission will include more than one episode. If a patient is transferred to a different hospital during an admission, a new episode and admission starts. We assumed all episodes within a unique admission have the same admission date.

1.2.2 Exclusions

We excluded the following children:

- Children who died aged less than one year of age (excludes 105854 episodes, 47284 hesids)
- 57109 episodes for 2064 children who died on or after 1st January 2011 were excluded
- 138 children with a date of death before 1st January 1998. Complete linkage to death records are only available for deaths registered on or after this date. (245 episodes)

- One episode without a primary diagnosis recorded was also deleted
- 774 non-English resident children (5547 episodes)
- Two episodes for two hesids where the discharge method=5 (still births) The other records for these two hesids were retained.

In some cases, children were entered as having died in hospital in HES (dismeth=4), but no matching death record from ONS can be identified. This could be due to a failure in the linkage process, ie. the child died but could not be linked to a death record with the current linkage algorithm. Alternatively, it could be an incorrect entry in the electronic hospital record. These children can be identified in HES using the variable matchrank; all children who have a record of death in HES but no linked death record have a matchrank value of 0. Their date of death registration is also unknown.

To be included in the study cohort, all children required a death record from ONS; therefore we excluded all children without a linked death record. (658 hesids, 3386 episodes).

1.2.3 Completion of date variables

Dates of hospital admission and discharge, and episode start and end dates are key variables in HES. Dates are provided in day/month/year format. Time of admission or episode started or ended is not available. Any dates before 1st Jan 1930 were set to missing (*n*=4). Missing episode start dates were replaced with the admission date if this was the first episode in the admission (*n*=1). Ten episodes with missing episode end dates and discharge dates were removed since these appeared to be duplicate episodes. Discharge dates were used for eight episodes with missing episode end dates.

There were 371 episodes with missing admission dates; these were replaced with the episode start dates as there were only one episode for these admissions. Discharge dates were checked against episode end dates. There was one episode for which the admission date was greater than the discharge date. The admission date was changed to the episode start date in this instance (it was the first episode of the admission)

1.2.4 Duplicate removal

We removed 1447 duplicate episodes based on hesid, financial year, episode start date, episode end date, episode order, all diagnoses codes, procedure codes and operation status code.

1.2.5 Validating the link between death and hospital records

In a small number of cases, the ONS death record indicated the death of a child aged between one and 18 years who died in 1998 onwards, but where the linked hospital record indicated the link could not be correct. For these records, the hospital record was removed and the resulting unlinked death record was moved to the unlinked death record file. We applied this to the following cases:

- 35 children whose age at admission in at least one instance was more than 18 years (351 episodes)
- 17 children who had more than one admission subsequent to their death date (283 episodes)
- 19 children who had one more admission after their date of death and whose date of death was only available on the ONS mortality record (that, is the date of death could not be confirmed using hospital records) (310 episodes).

- In some cases of multiple births, more than one child had been allocated the same hesid. For example, children born before 2005 were not allocated a unique NHS number at birth, and therefore the hesids for these children would have been based on variables which would not uniquely identify each child in cases of multiple birth. In these cases, it is impossible to tell which of the children died and whom the hospital records refer to. Therefore, these death records were also unlinked from the hospital record: 47 hesids (1295 episodes)

We deleted a further seven episodes in cases where children appeared to have died in hospital (as the difference between their date of death from HES and their date of death from the death record was two days or less) but they had more than one more admission after their death date. This could be resulting from a hesid being applied to more than one person.

1.2.6 Linking episodes into admissions

A child's hospital admissions could be identified through the admission date variable (admidate): any episodes with the same admission date were assumed to belong to the same admission. A number of children appeared to have admissions that overlapped in time; in other words they appeared to be admitted to more than one hospital at the same time. To overcome this issue, and to ensure the definition of a hospital admissions was comparable across countries, we redefined hospital admissions and re-linked HES episodes. In this study, a hospital admission included all episodes/admissions where the difference between the admission date and the previous discharge date was less than or equal to 0. This means all transfers between hospitals were considered part of one admission. Two admissions for children discharged and then readmitted on the same day were also counted as one admission.

1.3 Cleaning unlinked death records

There were 17289 records in the unlinked death records file. The 3217 unlinked records from the linked death record file were added to this (excluding 30 records where the matchrank variable was equal to 0, ie. there was no death record from ONS), as were the death records from the 118 hesids where the link between death and hospital records were deemed to be incorrect.

We then excluded the following records:

- Children aged less than one year at death (*n*=11754)
- Deaths occurring before 1st January 1998 or after 31st December 2010 (*n*=791).
- Non-English residents (*n*=1670)

C Cases where a number of children had the same hesid were identified by more than one birth episode for one hesid. A birth episode was identified as an admission where at least one diagnosis code was equal to Z38 (birth code) and the age at the start of admission was less than one day and the episode order was equal to one. Note that this is a specific definition as the aim was to detect duplicate children who had been allocated the same hesid.

1.4 De-duplication and creation of final dataset for analyses

We appended the 381497 records for the 20805 children from the linked death records file to the 6409 linked records, creating a file of 387906 observations for 27214 children. The last date of registration was 7th August 2012.

We compared this dataset against a dataset of death records for resident children who died in England aged one to 18 years from 1979 onwards, obtained separately from the ONS. In this dataset, there were only 27139 resident children aged one to 18 years who died in England between 1998 and 2010. The last date of registration in this dataset was 27th June 2012.

We therefore checked for duplicates on death records in the death records obtained from the HSCIC, based on date of death, date of registration, PCT of residence, gender, communal establishment code and any mention of cause of death. 137 duplicates were identified using this method (0.5%). In the dataset obtained from the ONS, there were only 34 duplicate values among 27139 records (0.1%). For all but one of these duplicates, the underlying cause was an injury.

To remove duplicates in the linked dataset, it was assumed that ‘unlinked’ death records (ie those where there was no link to a hospital record) were not duplicated. All remaining duplicates where the underlying cause was not an injury (*n*=80 hesids, 197 episodes) were dropped. For the remaining duplicates, the linked hospital admission records were removed.

Finally, we removed 7030 children who died before 1st January 2001, since their death records were not coded using ICD-10. Our analysis dataset therefore included 20104 children. Of their death records, 15960 had been linked to one or more hospital records (79.4%)

2. Scotland

2.1 Introduction

Scottish death records (from the National Records of Scotland, previously the General Register Office for Scotland) and Scottish Morbidity Records for inpatients (SMR-01) and birth records (SMR-11) or Scottish Birth Records (SBRs) were linked by Information Services Division Scotland using algorithms described elsewhere.[49]

SMR-01 data contain diagnostic and procedure information for hospital admissions ending on the 1st January 1981 onwards, which may be linked to death records for deaths registered from January 1981 onwards. Some birth records, available for births occurring 1975 onwards also contain diagnostic information. Before 1996, SMR-11 covered all births, but after this date, only children admitted to Special Care Baby Units (SCBUs) were covered by SMR-11. Some diagnostic information is available for these children (although not children born 1996-2002 who were not admitted to a SCBU). From 2003 onwards, all births are covered in Scottish Birth Records, but no diagnostic information is included.

We received the following data:

- 23991 death records
- 96258 hospital admissions for 10936 children
- 19922 birth records, of which 13299 contain some diagnostic information on conditions present at birth or recorded while the baby was in a SCBU

As in HES, no personal identifiers were included, and individuals were identified using the anonymised identifier serialno.

2.1.1 Checking link between death and hospital records

All the 109557 hospital admissions were linked to a death certificate record; 6391 death records were not linked to a hospital admission.

2.2 Cleaning the linked dataset

2.2.1 Structure of SMR-01/SMR-11

An admission is the basic unit of the SMR-01. Each admission can be identified from the admission date. In some cases, children did appear to have multiple admissions on the same date; these were either excluded as duplicates, or linked together with other admissions based on the algorithm described in section 1.2.6, to ensure the way admissions were counted was comparable between the three countries.

2.2.2 Exclusions

We excluded the following records:

- Children who died before or after the start or end of the period of complete death record data, ie. 1st January 1980-31st December 2010 (11 admissions, 10 children)
- Children who died aged less than one year (21218 admissions, 13327 children)
- Non-Scottish residents at death (218 admissions, 195 children)

2.2.3 Date completion and checking

Date of admission and date of discharge are key variables in hospital admission data. As in HES, we did not have time of admission or discharge.

We did not identify any missing or discrepant records (such as discharge date occurring before the corresponding admission date).

We also compared the date of death and the date of last discharge from hospital, to determine whether the link between hospital and death records appeared correct.
The date of discharge was later than the date of death for 85 children; for 78 of these the difference between death and discharge was one day, with a maximum difference of six days. These records were still assumed to be correctly linked. Unlike in HES, there were no children with admission dates after the death date.

2.2.4 Removing duplicates

Forty seven duplicate records, based on serial number, date of admission, date of discharge, all diagnoses, all operations, all operation dates, reason for admission, admission from and consultant specialty, were identified and deleted.

2.2.5 Re-linking admissions

Using the same algorithm as for HES, admissions were linked so that any admissions where the difference between the admission date and the previous discharge date was less than one day were counted as one admission.

3. Creation of final dataset for analyses

We finally excluded 55650 records for 8068 children who died before 1st January 2001 (to ensure death records were coded in ICD-10 and make the study period comparable to that in England), leaving 38741 records for 2391 children.

3. Wales

3.1 Introduction

The Patient Episode Database for Wales (PEDW) contains linked data on all hospital admissions in Welsh NHS hospitals. For this study, records for deaths registered 1st January 1998 onwards have been linked to PEDW by the NHS Wales Informatics Service using a deterministic algorithm using the NHS number. PEDW records ending 1st January 1998 onwards can be linked over time to create longitudinal records for an individual.

We received the following data:

- 1757 unlinked death records
- 20257 PEDW episodes for 2016 children which had been successfully linked to a death record.

Only anonymised data were received. Records for a particular individual could be identified using the anonymised identifier nhsno_pseudo. Eight children did not have a valid nhsno_pseudo value; we created a temporary ID variable for these children. The nhsno_pseudo variable was also duplicated on two death certificate entries in the unlinked file. These four records were given new, unique, temporary id variables.
Unlike HES, 861 of these episodes lacked diagnostic information or data on procedures carried out (4.3%). However, only a small minority of children lacked diagnostic information for all their linked PEDW episodes (see section 3.2.5 below).

3.2 Cleaning the linked dataset

3.2.1 Basic structure of PEDW

Like in HES, the basic unit of PEDW is a finished consultant episode. PEDW comprises inpatient admissions, day cases, regular attenders and maternity records. Dates of admission, discharge and episode start dates and end dates are key variables in PEDW. As in HES, a unique admission can be identified from the admission date (we assumed all episodes in one admission had the same admission date).

3.2.2 Exclusions

We excluded the following:

- Five children who died during 2010 (registered during 2011) aged <1 year who had duplicate records to some older children whose deaths were registered before 2011 (seven episodes)
- 625 children (4934 episodes) who died before 1st January 2003 –mentions of multiple causes on the linked death record were not available before this date in the Welsh data
- 660 children who died before their first birthday (1759 episodes) Note that the data extract we were given related to Welsh residents only, so no exclusions were made based on country of residence.

3.2.3 Date completion and checking

Admission dates and episode end dates were complete. 108 episodes lacked an episode start date. We replaced the episode start dates with the admission dates if the episode order was equal to one (indicating that the episode was the first in the admission, for 37 episodes), and with the previous episode end date in the remaining 72 episodes.

Discharge dates were missing for 15 episodes. In these cases, the last episode end date was set as the discharge date.

3.2.4 Removing duplicates

117 duplicate episodes, based on nhsno_pseudo, episode start and episode end dates, episode order, diagnoses and operations were removed.

3.2.5 Identifying incorrectly linked death and hospital admission data

As in the HES dataset, a number of children were identified for which the linkage between death and hospital admission records did not appear correct.

- One person apparently aged over 20 years when admitted (1 nhs id, 47 episodes)
- Four children were apparently linked to a hospital record, but no diagnoses or procedures were recorded for these children for any of their admissions. (4 children, 7 episodes).

In these cases, we retained the death records but unlinked them from the hospital record. Three children had admissions beginning apparently after their deaths, but there was agreement between the diagnostic information on the death and hospital admission records. The episodes starting after their date of death were therefore removed (n=4 episodes).

3.2.6 Linking episodes into admissions

Admissions were linked over time using the same algorithm as for Scotland and England (section 1.2.6) to ensure comparability between datasets.

3.3 Cleaning unlinked records

We appended the five children for whom the link between death records and PEDW were uncertain to the unlinked records. We then removed the following children from the file containing unlinked records:

- 1252 unlinked records were for children aged less than one year at death
- 293 records from children who died before the 1st January 2003 were also excluded.

4. Creation of final dataset

The 13195 episodes from the 726 children with linked PEDW data were appended to the 217 unlinked records giving a file of 13412 records for 943 children. The last date of registration in the linked file was 9th December 2011. This is identical to the number of children in the separately received ONS dataset for children who died aged one to 18 years, resident in Wales whose deaths occurred between 2003 and 2010 and were registered up to the end of December 2011.

Appendix 6.3: Development of coding clusters for chronic conditions using data from death certificates linked to hospital admissions

1. Definition of a chronic condition

We developed a sensitive definition of chronic conditions in children who die in routine mortality and hospital admission data. We aimed to group the chronic conditions according to the type of medical specialism, level of health care, or clinical pathway required for management, eg. hospital-based procedures, Child and Adolescent Mental Health Services (CAMHS) or speech and language therapy.

In the UK routine hospital databases are coded using the ICD-10. Table APPX 6.3.1 shows a number of previous approaches to identifying children with long term health problems in routine health databases using ICD codes.

APPX 6.3.1: Published coding systems for chronic conditions in children

Reference	Definition	Coding system
Tai et al[90]	Conditions significantly predicting 1-year mortality following hospital discharge	ICD-9
Agency for Healthcare Research and Quality[91] (also includes adults)	- more than 12 months duration AND - limits self-care, independent living or social interactions OR -requires need for ongoing intervention w medicinal products or services	ICD-9
Feudtner et al[45]	-several organ systems OR -one organ system severely enough to require specialist paediatric care and admission to tertiary hospital	ICD-9, ICD-10[57]
Edwards et al[5]6	Same as Feudtner et al[45] but with revised list, eg. including mental health conditions	ICD-9

Unlike these previous examples, our aim was to use a sensitive definition of a chronic condition to determine the extent to which a child was likely to have had previous contact with health services. We defined a chronic condition as:

Any health problem requiring medical follow-up for more than 12 months in 50% or more of cases

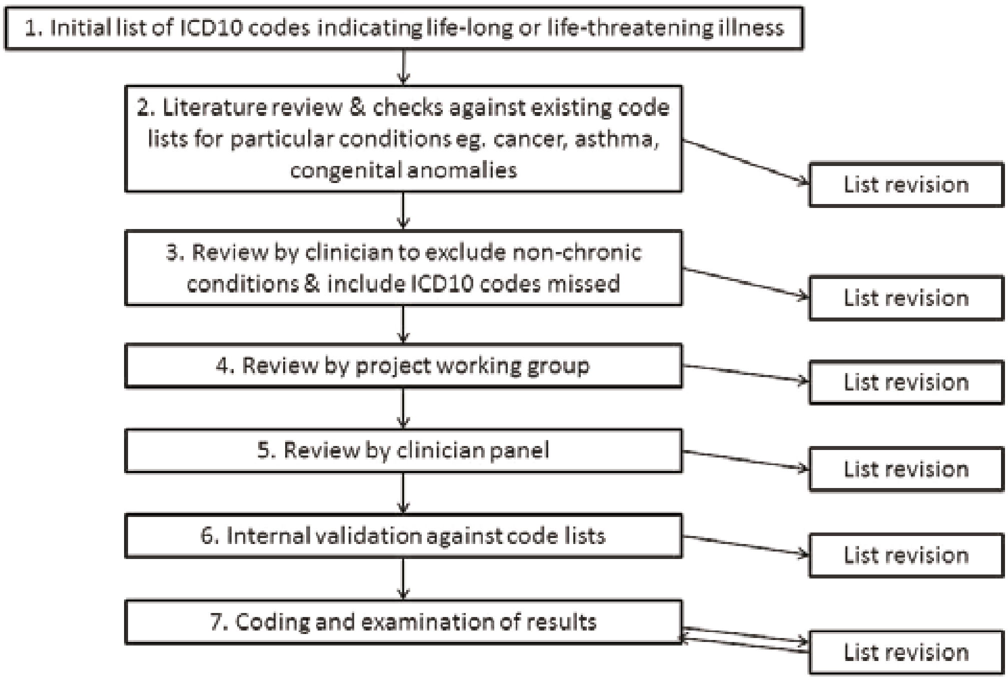
Medical follow-up was defined as

- repeated hospital admission OR
- specialist follow-up through outpatient department visits OR
- use of support services such as physiotherapy or speech and language therapy.

2. Development of an ICD-10 coding list for chronic conditions

Our approach to developing a list of clinical codes to identify children with chronic conditions is summarised in Figure APPX 6.3.1.

Figure APPX 6.3.1: Steps for developing ICD-10 coding cluster for chronic conditions in children who died



2.1 Development of initial list

Two of the report authors (PH and RG) initially developed a list of ICD-10 codes indicating life-long illnesses. The list included codes for specific conditions, and codes indicating the presence of a chronic condition through a surgical or medical procedure (such as adjustment and management of cardiac pacemaker indicating chronic heart disease). We also assumed that children who died or had been admitted with injuries resulting from self-harm had a mental health condition.

2.2 Review of existing code lists

We reviewed published code lists (including those mentioned in Table APPX 6.3.1) and included further codes for life limiting conditions,[50] childhood tumours[51], congenital anomalies,[52;53], paediatric inflammatory bowel disease[54] and diabetes[55]. We also obtained a lists of ICD-10 codes from HES admissions in children with cancer from the Childhood Cancer Research Group at Oxford University (Nicole Diggens, personal communication) and causes of death recorded on death certificates for children with congenital heart defects who had undergone cardiac surgery (Rachel Knowles, personal communication).

2.3 Review by clinician and project working group

At this stage, one clinician (Dr Andrew McArdle) checked the list to ensure no acute conditions had been included, and also examined the ICD-10 manual to determine whether conditions fitting the definition had been excluded. The draft list was then reviewed by the Child Death Overview Working Group.

2.4 Review by clinician panel

As a next step, the codes were reviewed by a panel of four clinicians (Drs Quen Mok, Peter Sidebotham, Mike Sharland and Katja Doerholt). The clinician panel were asked to rate each listed condition as always chronic, chronic with severity criteria (see below) or not a chronic condition. We included conditions in our definition if two or more of the panel agreed on a particular outcome (MS and KD carried out the scoring together). If there was complete disagreement, the code was reviewed again by RG and PH.

2.5 Internal validation of code list

Internal validation of codes was then carried out by extracting all diagnostic codes for children with any of the following:

- 10 or more hospital admissions
- Five or more hospital admissions, one of which mentions a congenital anomaly (ICD-10 code Qxx)
- Five or more hospital admissions, one of which mentions epilepsy (G40.x) or cerebral palsy (G80.x)

These codes were compared against our draft code list to ensure that no codes indicating chronic conditions had been inadvertently excluded.

2.6 Application of coding list in hospital admission and death certificate data

Finally, the list of codes was applied in the linked data and code lists for children classified as having a chronic condition and children without any chronic conditions were scrutinised.

3. Severity criteria

ICD-10 codes alone were not sufficient to determine whether certain conditions, particularly injuries and cardiac conditions, were acute or could lead to chronic sequelae. We therefore developed a set of severity criteria, such that a condition which may be either acute or chronic will be considered as chronic if the following conditions are both met:

- The length of stay of any hospital admission where the ICD-10 code is mentioned is three days or more
- The hospital admission where the ICD-10 code is mentioned finished more than 30 days before death

4. Events of undetermined intent

Events of undetermined intent (where injuries could be due to accident, self-harm or assault), were included with an age criterion. Children aged 10 or over who died or were admitted to hospital with an injury with undetermined intent were classified as having a chronic condition, since a substantial number of suicides are recorded as events of undetermined intent in children.[92]

Table APPX 6.3.2 lists all ICD-10 codes included under each condition group. Note that the groups are not mutually exclusive and a child may have a number of conditions from different chronic condition groups.

Table APPX 6.3.2: ICD-10 codes for chronic conditions in children who died

Type of chronic condition	Categories	Codes
Mental health/behavioural	Substance abuse	E24.4, F10-F19, F55*, G24.0*, G31.2, G40.5, G62.1, G72.0, G72.1, I42.6, K29.2, K70, K85.2, K85.3, K86.0, O35.4, R78.1*-R78.5*, Y47, Y49, Z50.2, Z50.3, Z71.4, Z71.5, Z72.2*, Z86.4
	Self-harm	X60-X84, Y10-Y34†, Y87.0, Y87.2†, Z91.5
	Other mental health problems	F00-F01, F02.8, F03-F09, F20-F48, F50, F53, F54, F59*, F60-F69, F99*, Z09.3*, Z50.4*, Z86.5, Z91.4*
	Behavioural/developmental disorders	F70-F79, F80.0-F80.2, F80.8, F80.9, F81-F84, F88, F89, F90-F98
Cancer/blood disorders	Neoplasms	C00-C97, D00-D02, D05-D09, D12, D13, D14.1-D14.4, D15, D20, D32-D35, D37-D48, D63.0, E34.0, E88.3, G13.0, G13.1, G53.3, G55.0, G63.1, G73.1, G73.2, G94.1, M36.0, M36.1, M49.5, M82.0, M90.6, M90.7, N08.1, N16.1, Y43.1-Y43.3, Y84.2, Z08, Z51.0-Z51.2, Z54.1, Z54.2, Z85, Z86.0, Z92.3
	Immunological disorders	D80-D84, G53.2, Q98.0
	Anaemia and other blood disorders	D50*, D56.0-D56.2, D56.4, D56.8, D56.9, D57.0-D57.2, D57.8, D58, D61.0, D61.9, D64*, D66, D67, D68.0-D68.2, D68.4-D68.9, D69, D70-D76, M36.2-M36.4, M90.4, N08.2, Z86.2
Chronic infections	HIV	B20-B24, F02.4, R75, Z21
	Tuberculosis	A15-A19, E35.0, K23.0, K67.3, K93.0, M01.1, M49.0, P37.0
	Other	A50, A81, B18, B37.1, B37.5, B37.6, B37.7, B38.1, B39.1, B40.1, B44.0, B44.7, B45, B46, B48.7, B50.0, B50.8*, B51.0, B51.8*, B52.8*, B52.0, B55, B57.2-B57.5, B58.0, B59, B67, B69, B73, B74, B78.7, B90-B94, F02.1, K23.1, K93.1, M00, N33.0, P35.0-P35.2, P35.8, P35.9, P37.1
Respiratory	Asthma and chronic lower respiratory disease	J41-J47
	Cystic fibrosis	E84, P75
	Injuries	S17*, S27*, S28*, T27*, T91.4*
	Congenital anomalies	Q30-Q37, Q79.0
	Other	G47.3, J60-J70, J80-J86, J96.1, J98, P27, Y55.6, Z43.0, Z93.0, Z94.2

Metabolic/endocrine/ digestive/ renal/genitourinary	Diabetes	E10-E14, G59.0, G63.2, I79.2, M14.2, N08.3, O24, Y42.3
	Other endocrine	E00, E03.0, E03.1, E07.1, E22.0, E23.0, E25, E26.8, E29.1, E31, E34.1, E34.2, E34.5, E34.8, G13.2, G73.5, Y42.1
	Metabolic	D55, E70-E72, E74-E78, E79.1-E79.9,E80.0-E80.3, E80.5, E80.7, E83, E85, E88.0, E88.1, E88.2*, E88.8, E88.9, G73.6, L99.0, M14.4, M14.3, N16.3
	Digestive	K20, K21.0, K22, K23.8, K25-K28, K29.0, K29.1, K29.3-K29.9, K31, K50-K52, K55, K57, K59.2, K63.0-K63.3, K66, K72-K76, K80-K83, K85.0, K85.1, K85.8, K85.9, K86.1-K86.9, K87.0, K90, M07.4, M07.5, M09.1, M09.2, T86.4, Z43.2-Z43.4, Z46.5, Z90.3, Z90.4, Z93.2-Z93.5
	Renal/GU	D63.8, G63.8, G99.8, I68.8, M90.8, N08.4, N00-N05, N07, N11-N15, N16.0, N16.2, N16.4, N16.5, N16.8, N18, N19, N20-N23, N25, N26, N28, N29, N31, N32, N33.8, N35, N36, N39.1, N39.3, N39.4, N40-N42, N70-N74, N80-N82, N85, N86*, N87,N88, P96.0, T82.4, T83.1, T83.2, T83.4-T83.9, T85.5, T86.1, Y60.2, Y61.2, Y62.2, Y84.1, Z49, Z93.6, Z94.0, Z99.2
	Congenital anomalies of the digestive/ renal/GU system	Q38.0, Q38.3, Q38.4, Q38.6-Q38.8, Q39, Q40.2, Q40.3, Q40.8, Q40.9, Q41, Q42, Q43.1, Q43.3-Q43.7, Q43.9, Q44, Q45, Q50.0, Q51, Q52.0-Q52.2, Q52.4, Q54.0-Q54.3, Q54.8, Q54.9, Q55.0, Q55.5, Q56, Q60.1, Q60.2, Q60.4-Q60.6, Q61, Q62.0-Q62.6, Q62.8, Q63.0-Q63.2, Q63.8, Q63.9, Q64, Q79.2-Q79.5, Q87.8, Q89.1, Q89.2
	Injuries	S36*, S37*, S38*, S39.6*, S39.7*, T06.5*, T28*, T91.5*
	Other/unspecific	E66, G63.3, G99.0, M14.5, N92*, Z86.3, Z93.8
Musculoskeletal/skin	Musculoskeletal/connective tissue	G55.1-G55.3, G63.5, G63.6, G73.7, J99.0, J99.1, L62.0, M05, M06, M07.0-M07.3, M07.6, M08, M09.8, M10-M13, M14.0, M14.6, M14.8, M30-M35, M40-M43, M45-M48,M50-M54, M60-M62, M63.8, M80.1-M80.9, M81.1-M81.9, M82.1, M82.8, M84.0-M84.2, M84.8, M84.9, M85, M86.3-M86.6, M89, M90.0, M91-M94, N08.5, Y45.4
	Skeletal injuries/amputations	S13*, S22.0*-S22.2*, S22.5*, S23*, S32*, S33*, S68.3*, S68.4*, S68.8*, S77*, S78*, S87*, S88*, S97*, S98.0*, S98.2*-S98.4*, T02*, T04*, T05*, T20.3*, T20.7*, T21.3*, T21.7*, T22.3*, T22.7*, T23.2*, T23.3*, T23.6*, T23.7*, T24.3*, T24.7*, T25.2*, T25.3*, T25.6*, T25.7*, T29.3*, T29.7*, T30.3*, T30.7*, T31.2*-T31.9*, T32.2*-T32.9*, T87.3-T87.6, T91.2* T91.8*, T92.6*, T93.1*, T93.4*, T93.6*, T94.0*, T94.1*, T95.0*, T95.1*, T95.4*, T95.8*, T95.9*, Y83.5, Z89.1, Z89.2, Z89.5-Z89.8, Z97.1
	Chronic skin disorders	L10, L11.0, L11.8, L11.9, L12-L14, L28, L40-L45, L57, L58.1, L59, L87, L88, L90, L92, L95, L93, L98.5, M09.0, Q80, Q81, Q87.0-Q87.5, Q89.4
	Congenital anomalies	Q18.8, Q65.0-Q65.2, Q65.8, Q65.9, Q67.5, Q68.2, Q68.3*-Q68.5*, Q71-Q73, Q74, Q75.3-Q75.9, Q76.1-Q76.4, Q77, Q78, Q79.6, Q79.8, Q82.0-Q82.4, Q82.9, Q86.2, Q89.7-Q89.9

Neurological	Epilepsy	F80.3, G40.0-G40.4, G40.6-G40.9, G41, R56.8, Y46.0-Y46.6
	Cerebral palsy	G80-G83
	Injuries of brain, nerves, eyes or ears	S05*-S08*, S12*, S14*, S24*, S34*, S44*, S54*, S64*, S74*, S84*, S94*, T06.0*-T06.2*, T26*, T90.4*, T90.5*, T91.1*, T91.3*, T92.4*
	Chronic eye conditions	H05.1-H05.9, H13.3, H17, H18, H19.3, H19.8, H21, H26, H27, H28.0-H28.2, H31, H32.8, H33, H34, H35, H40, H42.0, H43, H44, H47, H54.0- H54.2, H54.4, T85.2, T85.3, Z44.2
	Chronic ear conditions	H60.2, H65.2-H65.4, H66.1-H66.3, H69.0, H70.1, H73.1, H74.0-H74.3, H75.0, H80, H81.0, H81.4, H83.0, H83.2, H90.0, H90.3, H90.5, H90.6, H91, Z45.3
	Perinatal conditions	P10, P21.0, P52, P57, P90, P91.1, P91.2, P91.6
	Congenital anomalies of neurological or sensory systems	Q00-Q07, Q10.4, Q10.7, Q11-Q12, Q13.0-Q13.4, Q13.8, Q13.9, Q14-Q16, Q75.0, Q75.1, Q85, Q86.0, Q86.1, Q86.8, Q90-Q93, Q95.2, Q95.3, Q97, Q99
	Other	F02.2, F02.3,G00-G09, G10-G12, G13.8, G14, G20-G23, G24.1-G24.9, G25-G30, G31.0-G31.1, G31.8, G31.9, G32-G37, G43-G46, G47.0-G47.2, G47.4-G47.9, G50-G52, G53.0, G53.1, G53.8, G54, G55.8, G56-G58, G59.8, G60, G61, G62.0, G62.2-G62.9, G64, G70, G71,G72.2-G72.9, G73.0, G73.3, G90-G93, G94.2, G94.8, G95, G96, G98, G99.1, G99.2, I60-I67, I68.0, I68.2, I69, I72.0, I72.5, T85.0, T85.1, Y46.7-Y46.8, Z98.2
Cardiovascular	Congenital heart disease	Q20-Q26, Q89.3
	Other	I00*-I28*, I31*-I39*, I41*, I42.0*-I42.5*, I42.7*-I42.9*, I43.0*, I43.1, I43.2*-I43.8*, I44.1*-I44.7*, I45.1*-I45.9*, I46*-I51*, I52.8, I70*-I71*, I72.1*-I72.4*, I72.8*, I72.9*, I73*-I77*, I79.0*, I79.1*, I79.8*, I81*-I82*, I98*-I99*, M03.6, N08.8, Q27, Q28, S26*, T82.0-T82.3, T82.5-T82.9, T86.2, Y60.5, Y61.5, Y62.5, Y84.0, Z45.0, Z50.0, Z94.1, Z95
Codes indicating non-specific chronic condition	-	R62, R63.3, Z43.1, Z51.5, Z75.5, Z93.1, Z99.3

*Codes used with severity criteria: length of stay of hospital admission mentioning code >3 days and the discharge date of the admission where the code is more than 30 days before death.

†Codes used with age criteria: Age at death (if from death certificates) or age at admission (if from hospital records) must be 10 years or older.

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