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CHILD DEATH REVIEW PROGRAMME

Child deaths in Wales:

Patterns and trends report 2016

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Acknowledgements

Your feedback

How did you use the information in this report? Do you have any other comments? Please get in touch using the contact details for the Child Death Review Programme team given above.

About child death review in Wales

Why review child deaths in Wales?

Any death of a child is a tragedy. The loss often has devastating and life changing effects on the parents, siblings, grandparents and the wider family and community. Identifying factors contributing to death may help prevent future child deaths.

What does the Child Death Review Programme do?

The Child Death Review (CDR) Programme routinely collects information on deaths of children who were born alive, who died after 1st October 2009 but before their 18th birthday, and who were normally resident in Wales or died within Wales (including children under local authority care and placed outside of Wales and those temporarily living outside of Wales for healthcare or education reasons). The CDR Programme aims to identify and describe patterns and causes of child deaths and to recommend actions that could prevent future child deaths in Wales.

What have we delivered?

- Thematic reviews that consider the evidence held by CDR, identified in the literature and through panel discussion of circumstances of death. We have published recommendations and key messages on reducing future risk of deaths of teenagers in motor vehicles (2013), children and young people through probable suicide (2014), sudden unexpected death in infancy (2015) and children and young people through drowning (2016).
- Smaller scale reviews have covered deaths from dog bites and from meningitis or meningococcal disease.
- Annual reports published since 2013 contain information on registered deaths and summarise the activity of the CDR Programme during the previous year. For 2016 this has been split into a statistical report on patterns and trends and online information about our activity and impact.
- Stakeholder events to share learning from these reviews and reports and to invite partners to share their ideas on actions that take our recommendations forward.

We also discuss how we can work together to encourage changes to prevent child deaths with partners across Wales and the rest of the UK.

The details of each death are extremely important to those most affected by it, but public health also considers the broad population-level picture. Our role in the Child Death Review Programme is to understand and connect the detail with the wider issues, to learn from what happened and to share advice on preventing further incidents in similar circumstances.

Contents

Summary of key findings

- There are about 210 deaths of children resident in Wales per year (2010–14). Almost two thirds of child deaths in Wales occur below the age of one year.

- The rates of death in Wales are similar to those of the United Kingdom as a whole for children under one year (infants); 1–4 years (pre-school age); 5–11 years (primary school age) and 12–17 years (secondary school age).

- There has been an overall decline in rate of child deaths in Wales since 1996, much of which reflects the decline in infant death rate (which has probably slowed over the last decade).

- Over a third (35%) of deaths among children aged 1–17 years are due to external causes (for example, transport-related accidents account for about a third of these). This represents about 30 fatalities in Wales each year that are potentially avoidable partly through public health preventative interventions. Nearly three quarters of these deaths occur in children aged 12–17 years.

- Over a third (38%) of deaths among children aged 1–17 years are due to various medical causes (for example, diseases of the nervous system such as meningitis account for about a third of these).

- Rates of death from external causes and other medical causes (excluding infants) appear to be declining.

- There is a strong association between deprivation and risk of child death. The rate of child death among the most deprived fifth of the Welsh population is 70% higher than the rate among the least deprived fifth. This inequity highlights the negative health impacts of poverty and disadvantage and is a persisting observation.

List of abbreviations

AWPS	All-Wales Perinatal Survey
CI	confidence interval
GROS	General Registrar Office for Scotland
ICD-10	International Statistical Classification of Diseases and Related Health Problems (10th Revision)
LSOA	Lower layer Super Output Area
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MYE	mid-year estimate (of population)
NISRA	Northern Ireland Statistics and Research Agency
ONS	Office for National Statistics
PHM	Public Health Mortality (File)
WG	Welsh Government
WIMD	Welsh Index of Multiple Deprivation

Glossary

All-Wales Perinatal Survey (AWPS)

All-Wales Perinatal Survey collate data on all babies who die in Wales from 20 weeks of pregnancy to one year of age; see https://awpsonline.uk.

Confidence interval

Confidence intervals are indications of the natural variation that would be expected around a measurement (such as a proportion or a rate) and they should be considered when assessing or interpreting such measures. The size of the confidence interval is dependent on the size of the population from which the events came. Proportions or rates based on small populations are likely to have wider confidence intervals.

Congenital anomaly

A structural, metabolic, endocrine, or genetic defect present in the child/ foetus at the end of pregnancy, even if undetected until later. Only those anomalies featured in chapter XVII (Q codes) of ICD-10 are included in this report.

Infant deaths

Deaths among live born children under one year of age (includes all neonatal deaths and some perinatal deaths).

Neonatal deaths

Deaths among live born children under 28 days of age (includes some perinatal deaths). Expressed as a rate per 1,000 live births.

Perinatal deaths

Stillbirths and deaths among live born children under seven days of age. Expressed as a rate per 1,000 live births.

Statistical significance

A result may be deemed statistically significant if it is considered unlikely to have occurred by chance alone. The basis for such judgements is a predetermined and arbitrary cut-off, usually taken as 5% or 0.05 (the chance/ probability of a difference as extreme being observed, if underlying 'true' values were the same). In this report a difference is considered to be statistically significant when the confidence intervals do not overlap. Statistical significance is not the same as clinical or public health significance.

Stillbirths

Child deaths after 24 completed weeks of pregnancy and showing no signs of life upon delivery.

Introduction

This report describes patterns and causes of death among Welsh residents aged under 18 years, who died following a live birth and where death was registered during the period 1996 to 2014. Within this period, the data are presented using variable time spans.

Data sources

The tables and figures presented in this report use data compiled by the Public Health Wales Observatory from the Public Health Mortality (PHM) File and mid-year population estimates from Office for National Statistics (ONS). Data from ONS are based on official registrations of deaths for children normally resident in Wales, described by area of residence and grouped by age into those under one year (infants); 1–4 years (pre-school age); 5–11 years (primary school age) and 12–17 years (secondary school age). ONS data are compiled based on the year in which death was registered, which can differ from the year in which death occurred. This can lead to some clustering of the counts by year and thus discrepancy in totals compared to reports written using actual year of death.

ONS data on cause of death are coded using the International Statistical Classification of Diseases and Related Health Conditions 10th Edition (ICD-10), since 2001. On 1st January 2014 ONS changed the software that it uses to assign the underlying cause ICD-10 code to a system called Iris, primarily to incorporate changes to ICD-10 codes, but also to improve international comparability of mortality data. As Iris determines underlying cause slightly differently to the previous system, some deaths would be assigned to different underlying causes if run through both systems. As such, caution must be exercised when considering analyses that include pre- and post-2014 data. Comparability ratios have been produced for some codes, which estimate the possible effect of the introduction of Iris on the total number of deaths allocated to certain underlying causes. Comparability ratios have not been used in preparing this report as they have little meaning or value when used at an individual level or with very small counts.

Deprivation refers to a lack of opportunities and resources of all kinds. In Wales the official measure is the Welsh Index of Multiple Deprivation 2014 (WIMD), which has eight domains (income; employment; health; education; access to services; community safety; physical environment and housing). These domains are weighted so that each geographic area (Lower layer Super Output Area, or LSOA) is assigned an overall multi-domain score. In this report WIMD scores are ranked nationally and divided into five equal parts to create bands termed quintiles (each quintile thus equating to 20% of the total). The postcode of usual residence for children who died can be linked to a WIMD score, allowing assumptions to be made about the likely socioeconomic environment in which that child (or their parents) lived. It is important to note that not all children and families living within deprived areas will experience the deprivation their quintile implies; WIMD does not measure individual circumstances. More information

about the WIMD can be found at http://gov.wales/statistics-and-research/welsh-index-multiple-deprivation/.

Causes of death in the first year

Causes of death in the first year are not described in this report. For information on causes of death in the first year of life see AWPS annual reports available from https://awpsonline.uk. In addition, information on causes of neonatal deaths is contained in Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) reports available from https://www.npeu.ox.ac.uk/mbrrace-uk.

Small numbers, uncertainty and combining time periods

When reporting on small numbers of events accidental disclosure is a possibility (a deceased child could be identified). This report has been prepared in accordance with ONS guidance on disclosure control for births and deaths at:

http://www.ons.gov.uk/ons/guide-method/best-practice/disclosure-control-policy-for-birth-and-death-statistics/disclosure-control-guidance-for-birth-and-death-statistics.pdf
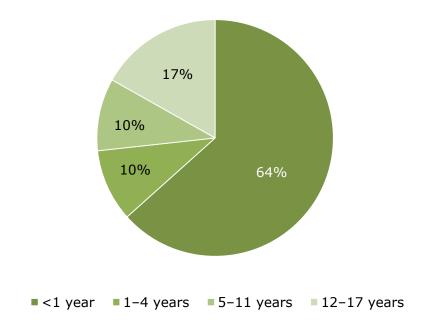
Small numbers also mean greater uncertainty around estimates, as reflected by wider confidence intervals and with resulting inability to detect significant differences (see below). To help offset this, given the relatively small numbers of child deaths registered in any given year in Wales, most data are aggregated (pooled) into groups of three, five or 10 years. These data may be summarised as average annual counts or rolling rates (which help smooth out year-on-year variation). A disadvantage of this is that different figures will be given depending on the time period included. In addition, aggregate figures can disguise subtle differences that may be important. Any calculations based on small numbers (such as a rate of child death by age group) or aggregate data should be interpreted with caution and in conjunction with other relevant information.

Significance of differences and rate comparisons

For comparative purposes rates can be adjusted (standardised) to account for potential differences in population make-up. Crude (unadjusted) rates have been calculated in this report; these are age-specific and thus do permit comparison. Comparing more granular age groups (e.g. 1–4 years) can be preferable to comparing wider age ranges (e.g. 1–17 years). Confidence intervals (95%) have been calculated using a normal approximation to the Poisson distribution and help describe the variation that might be expected around a rate due to the effects of chance. In this report, differences are described as statistically significant if the confidence intervals do not overlap. Where counts are small and confidence intervals wide, any rate comparison should be made with caution due to random variation associated with small numbers. When making multiple comparisons the likelihood increases that a finding reported as significant is in reality due to chance variation.

Deaths by age

During the five-year period 2010–14 there was an average of 210 deaths annually among Welsh residents who were live born, but died before their 18th birthday. The majority (64%, 135 per year) of child deaths in Wales occur during the first year of life, termed infancy (Fig. 1). The remaining deaths are divided almost equally between children aged 1–11 years (20%, 20 per year aged 1–4 and 20 per year aged 5–11 years) and older children aged 12–17 years (17%, 35 per year).

■ <1 year   ■ 1–4 years   ■ 5–11 years   ■ 12–17 years

Fig. 1 Proportion of child deaths by age group, Wales, 2010–2014. Produced by the Public Health Wales Observatory, using PHM & MYE (ONS). Percentages may not add to 100 due to rounding.

The death rate in infancy is much higher than for any other age grouping of child deaths (Table 1), being over 20 times higher than the rate among those aged 12–17 years over a 10-year period. Child death rates are lowest in those aged 5–11 years.

Table 1 All-cause deaths, count and crude rate by age group per 100,000, children aged under 18 years, Wales, 2005–14

Age group (years)	Annual average count*	Rate	95% CI
<1	145	418.0	396.8 – 440.2
1–4	22	16.0	13.9 – 18.2
5–11	21	8.7	7.5 – 9.9
12–17	43	19.2	17.4 – 21.1

Produced by Public Health Wales Observatory, using PHM & MYE (ONS). * rounded; CI = confidence interval for rate.

Deaths by age in Wales and the UK

The infant death rate in Wales during the five-year period 2010–14 is 385 per 100,000 (Table 2). The confidence intervals show the natural variation that might be expected around this rate due chance factors; this may be as low as 356 or as high as 415 per 100,000. There is no statistically significant difference between the Welsh infant death rate and that of the United Kingdom (UK) as a whole (413 per 100,000). Similarly, any differences between the death rates in Wales and the UK for children in other age groups are not statistically significant (Table 2). On the basis of these aggregate figures there is no evidence to indicate that a child is any more or less likely to die in Wales than in the UK as a whole.

Table 2 Child death counts and crude rates per 100,000, children aged under 18 years, United Kingdom, 2010–14
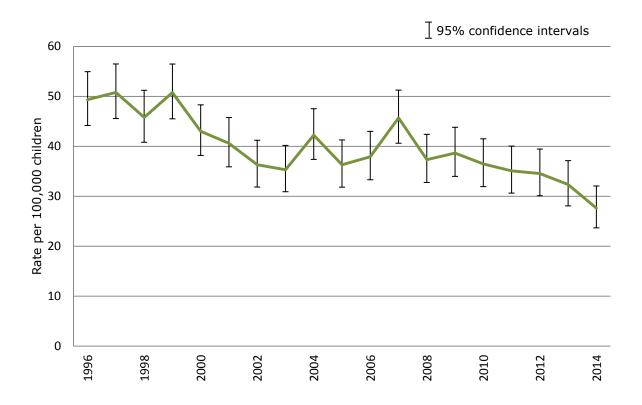
	<1 years			1–4 years		
	Count	Rate	95% CI	Count	Rate	95% CI
England	2,822	416.4	409.5 – 423.3	471	17.5	16.8 – 18.2
Northern Ireland	115	462.6	425.6 – 502.0	16	15.8	12.6 – 19.7
Scotland	213	365.4	343.8 – 388.0	36	15.5	13.3 – 17.9
Wales	135	384.9	356.4 – 415.1	20	14.1	11.5 – 17.2
United Kingdom	3,285	412.7	406.4 – 419.1	543	17.1	16.5 – 17.8

	5–11 years			12–17 years		
	Count	Rate	95% CI	Count	Rate	95% CI
England	358	8.4	8.0 – 8.8	550	14.5	14.0 – 15.1
Northern Ireland	15	9.2	7.2 – 11.6	33	22.6	19.2 – 26.3
Scotland	35	9.0	7.7 – 10.4	63	17.7	15.8 – 19.7
Wales	20	8.4	6.8 – 10.2	35	16.0	13.7 – 18.6
United Kingdom	427	8.4	8.1 – 8.8	681	15.1	14.6 – 15.6

Produced by Public Health Wales Observatory, using PHM & MYE (ONS), NISRA & GROS. CI = confidence interval for rate.
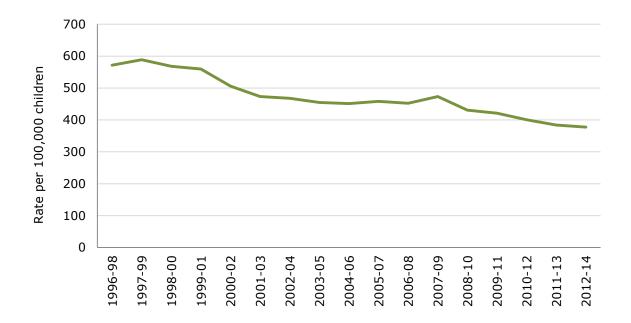
Trend in deaths by age

Figure 2 shows the overall (all-age, all-cause) rate of child death in Wales has fallen over the past 19 years from 49 deaths per 100,000 in 1996 (95% CI: 44–55 per 100,000; 332 deaths) to 28 deaths per 100,000 aged under 18 years in 2014 (95% CI: 24–32 per 100,000; 174 deaths). This difference is statistically significant.
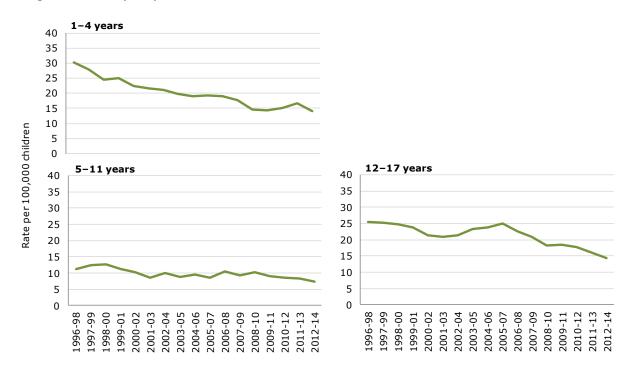

Fig. 2 Time trend in child deaths from all causes, crude rate per 100,000, children aged under 18 years, Wales, 1996–2014. Produced by the Public Health Wales Observatory, using PHM & MYE (ONS).

These trend data are shown by age groups using three year rolling rates to reduce the effects of year-on-year random variation (Figs. 3 and 4). For infant deaths (Fig. 3) there has been a fairly steady decline in rate since 1996–98 (572 per 100,000; 588 deaths), with a less pronounced fall during the latter part of the period to 2012–14 (378 per 100,000; 391 deaths). This reflects the all-age trend, where infant deaths account for the majority of total deaths (see above).

For deaths in other age groups (Fig. 4) there has been a 19-year decline among 1–4 year olds, where the rate has halved from 30 per 100,000 (130 deaths) in 1996–98 to 14 per 100,000 (61 deaths) in 2012–14. Among 5-11 year olds the rate has fallen from 11 per 100,000 (91 deaths) in 1996–98 to seven per 100,000 (52 deaths) in 2012–14. Among 12–17 year olds there has been a decline similar to that among infants, from 26 per 100,000 (172 deaths) in 1996–98 to 14 per 100,000 (92 deaths) in 2012–14.

Fig. 3 Time trend in child deaths from all causes, three-year rolling crude rate per 100,000, children aged under 1 year, Wales, 1996–2014. Produced by the Public Health Wales Observatory, using PHM & MYE (ONS).

Fig. 4 Time trend in child deaths from all causes, three-year rolling crude rate by age group per 100,000, children aged 1–17 years, Wales, 1996–2014. Produced by the Public Health Wales Observatory, using PHM & MYE (ONS).

Deaths by cause (children aged 1–17 years)

Table 3 shows that of 860 deaths among children aged 1–17 years counted over a 10-year period (2005–2014) congenital anomalies accounted for 8% (66 deaths), external causes 35% (304 deaths), ill-defined and unknown causes 5% (41 deaths), neoplasms 14% (121 deaths) and 38% were from other causes (328 deaths).

Table 3 Child death counts and annual averages by cause, children aged 1–17 years, Wales, 2005–14

	1–4		5–11		12–17		Total aged 1–17	
	Count	Annual average	Count	Annual average	Count	Annual average	Count	Annual average
Congenital anomaly (Q00–Q99)	31	3	13	1	22	2	66	7
External (V01-Y98, U509)*	40	4	46	5	218	22	304	30
Ill-defined & unknown causes (R95-R99)	19	2	5	1	17	2	41	4
Neoplasms (C00-D48)	19	2	46	5	56	6	121	12
Other (all other codes)	110	11	97	10	121	12	328	33
All causes	**219**	**22**	**207**	**21**	**434**	**43**	**860**	**86**

Produced by Public Health Wales Observatory, using PHM (ONS). Average annual counts are rounded; * Additional code U509 from 2007 onwards.

Looking at these figures in more detail, almost half of the deaths resulting from congenital anomalies occur among children aged 1–4 years (these are an important cause of death among infants, alongside conditions originating in the perinatal period). Further information on congenital anomalies in Wales can be obtained from http://www.caris.wales.nhs.uk.

The clear majority of deaths from external causes occur among older children, aged 12–17 years (72%; 218 of 304 deaths). External causes include accidents, suicide and assault; these account for half of the deaths in this older age group (50%; 218 of 434 deaths). Among children aged 1–17 years this represents about 30 fatalities each year through external causes. Such causes of death sometimes have modifiable factors which, if changed, may lead to prevention of future deaths. For example, CDR have produced thematic reviews giving

recommendations for preventing deaths of teenagers in motor vehicles (2013), of children and young people through probable suicide (2014) and deaths of children and young people through drowning (2016). These are available on the CDR website at http://www.publichealthwales.org/childdeathreview. An analysis of deaths by type of external cause is given in Table 4.

Neoplasms are abnormal growths that may be either benign or malignant (cancer); some types are called tumours. They account for 14% of deaths among 1–17 year olds (121 of 860 total deaths) or around 12 deaths per year. Further information on cancer in Wales can be obtained from http://www.wcisu.wales.nhs.uk.

In this analysis ill-defined and unknown causes account for the smallest number of deaths among 1–17 year olds (5%; 41 of 860 total) by grouped cause, while deaths from all other causes account for the largest number (38%; 328 of 860 total deaths). An analysis of deaths by other causes is given in Table 5.

During the 10-year period from 2005 to 2014 there were 304 total deaths from external causes in Welsh children aged 1–17 years (Table 4). As noted above, the largest number of these deaths occurred in the 12–17 age group (72%; 218 deaths). Deaths involving transport (37% of total; 112 deaths) and intentional injury through self-harm or assault (29% of total; 89 deaths) together account for two thirds of deaths through external causes.

About 33 deaths per year in Wales are included in the 'other cause' group (Table 5). Of these various medical conditions, about a third of deaths resulted from diseases of the nervous system such as cerebral palsy, epilepsy and meningitis (32%; about 10 child deaths per year across Wales).

Table 4 Child deaths by external cause, by age group, children aged 1–17 years, Wales, 2005–14

	1–4 years	5–11 years	12–17 years	Total 1–17 years
Transport accident				
Pedestrian (V01–V09)	0	6	18	24
Pedal cyclist (V10–V19)	0	2	4	6
Motorcycle (V20–V29)	0	1	7	8
Car passenger & unspecified (V40–V49*)	4	6	37	47
Car driver (V40–V49*)	0	0	14	14
Other & unspecified (V50–V99)	0	6	7	13
Falls (W00–W19)	2	0	4	6
Exposure to inanimate mechanical forces (W20–W49)	4	2	5	11
Accidental drowning and submersion (W65–W74)	5	3	9	17
Other accidental threats to breathing				
Hanging & Strangulation (W75–W76)	2	2	17	21
Other (W77–W84)	0	1	2	3
Exposure to unspecified electric current (W87)	0	0	1	1
Exposure to smoke, fire and flames (X00–X09)	4	3	0	7
Exposure to forces of nature (X30–X39)	0	0	1	1
Accidental poisoning by and exposure to noxious substances (X40–X49)	0	1	13	14
Accidental exposure to other and unspecified factors (X58–X59)	1	0	1	2
Intentional self-harm				
Hanging & Strangulation (X70)	0	0	24	24
Other (X60–X69, X71–X84)	0	0	8	8
Assault (X85–Y09, Y339 before 2007, U509 from 2007 onwards)	15	11	31	57
Event of undetermined intent				
Hanging & Strangulation (Y20)	0	1	10	11
Other (Y10vY19, Y21–Y34 excl. Y339 before 2007)	1	0	4	5
Complications of medical and surgical care (Y40–Y84)	2	1	1	4
All external causes (V01–Y98, U509)**	**40**	**46**	**218**	**304**

Produced by Public Health Wales Observatory, using PHM (ONS). * ICD-10 V40–V48: 4th digit for ICD-10 = 0 or 4 for car driver, 1–3 & 5–9 for car passenger and unspecified; ICD-10 V49: 4th digit for ICD-10 = 0 or 5 for car driver, 1–4 & 6–9 for car passenger and unspecified. ** Additional code U509 from 2007 onwards.
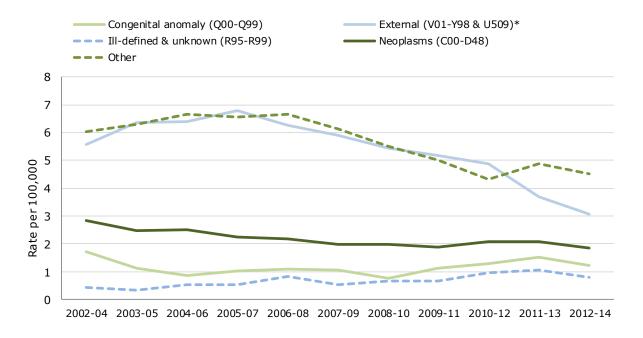
Table 5 Child deaths by other cause, children aged 1–17 years, Wales, 2005–14

	Annual average count	Percentage of other deaths
G00–G99 Diseases of the nervous system	10	32
J00–J99 Diseases of the respiratory system	4	12
A00–B99 Certain infectious and parasitic diseases	4	13
I00–I99 Diseases of the circulatory system	5	14
E00–E90 Endocrine, nutritional and metabolic diseases	4	12
Alternative causes	6	17
Total	**33**	**100**

Produced by Public Health Wales Observatory, using PHM (ONS); average counts are rounded.

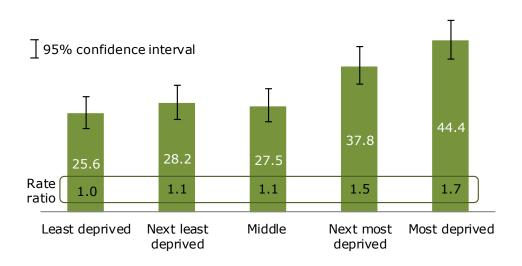## Trend in deaths by cause (children aged 1–17 years)

Examination of the time trend for rate of death by grouped cause shows a decline in deaths from external causes from six per 100,000 in 2002–04 (based on 104 deaths) to three per 100,000 in 2012–14 (55 deaths). Three year rolling crude rates are used in Fig. 5 to smooth out year-on-year variation. Deaths from other causes have fallen from six per 100,000 in 2002–04 (113 deaths) to five per 100,000 in 2012–14 (81 deaths). Rates of death for other groupings appear largely stable, although these are based on smaller numbers of deaths so should be interpreted cautiously.

Fig. 5 Time trend in deaths by cause, three year rolling crude rate per 100,000, children aged 1–17 years, Wales, 2002–2014. Produced by Public Health Wales Observatory, using PHM & MYE (ONS). * Additional code U509 from 2007 onwards.

Deaths by deprivation quintile

There is a significant association between rate of child death and deprivation, based on allocation of 1,049 deaths registered during 2010–14 to a deprivation quintile (Fig. 6). Rates of death among children who lived in the most deprived areas of Wales are 70% higher than deaths among those who lived in the least deprived areas of Wales (rate ratio 1.7; 95% CI: 1.4 – 2.1). Such a pattern can be described as a social gradient in health outcomes, reflecting the slope in rate across quintiles. This pattern of inequity is consistent across the current and previous two CDR annual reports (2015 and 2014), where the difference in rate ratio was also statistically significant.

Fig. 6 Deaths from all causes by deprivation fifth, crude rate per 100,000 and rate ratios (each fifth/ least deprived fifth), children aged under 18 years, Wales, 2010–2014. Produced by Public Health Wales Observatory, using PHM & MYE (ONS), WIMD 2014 (WG).

To examine whether particular causes of death might be contributing to this overall gradient, we repeated the analysis separately by grouped cause (not shown) for all children aged under 18 years. For congenital anomalies (ICD-10 Q00–Q99; 72 deaths); external causes (ICD-10 V01–Y97, U509; 128 deaths) and neoplasms (ICD-10 C00–D48; 60 deaths) there was no obvious gradient. Confidence intervals around death rates for these causes were wide and overlapped. The relatively low numbers of some of these types of death mean we cannot be sure of the role deprivation may or may not play here.

There is an association, however, between deprivation and the ill-defined and unknown cause group (ICD-10 R95–R99; 88 deaths) and for all other causes (all other ICD-10 codes; 701 deaths). While confidence intervals around the rate ratio for the most deprived fifth indicate statistical significance, the 'catch-all' nature of these categories makes meaningful interpretation difficult. These data do however reinforce the overall finding of a strong association between deprivation and risk of child death.

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