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CHILD DEATH REVIEW PROGRAMME

Annual Report

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Foreword

The death of a child is an enormous tragedy and profoundly affects all those who knew and loved them. In such instances, we cannot turn the clocks back, although we may wish to, however it is important that we learn from the circumstance of these deaths to allow us identify what changes can be made to offer protection in the future and prevention of child deaths. It is therefore with great pleasure that I am writing this foreword for the Annual Report of the Child Death Review Programme 2015.

Although child deaths have reduced significantly over the decades, we cannot ignore stark patterns of inequality in the life chances of children in Wales. Yet again, poverty and inequity in the social determinants of health feature highly within the report, confirming the need for further efforts to be made to reach out to all children and provide the support and help needed to allow them to lead full and happy lives.

My aim, as the Children's Commissioner for Wales is to ensure that the '3 Ps' of children and young people's rights are at the top of everyone's agenda in Wales. I believe that children have a right to participate in issues that affect them, provision of essentials to allow them to lead a full and happy life; and last but not least are protected and kept safe from harm. The work of the Child Death Review programme has clearly demonstrated recurring themes and have made recommendations for change in the future. This type of careful analysis is needed in order for us to make evidence-based policies to protect our children and promote their well-being.

I share my predecessor's concerns about child poverty and I note the death rate among children living in the most deprived fifth of Wales remains 70% higher than among children in the least deprived fifth of Wales. In March 2015, Welsh Government released their strategy for child poverty which is based on the fundamental right of a child to have what they need for life, as stated in the United Nations Convention on the Rights of the Child, and aims to eradicate child poverty in Wales by 2020. One important result of reducing poverty would be a reduction in child deaths in Wales.

I commend this Child Death Review annual report 2015, and look forward to working closely with the programme in the future.

Yours

Sally Holland

Abbreviations

ABM	Abertawe Bro Morgannwg [tables, figures]
AB	Aneurin Bevan [tables, figures]
BC	Betsi Cadwaladr [tables, figures]
CDOP	Child Death Overview Panels (England)
CI	Confidence interval [tables, figures]
GROS	General Registrar Office for Scotland [tables, figures]
ICD 10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
LSCB	Local Safeguarding Children Board [tables, figures]
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MYE	Mid year estimates [tables, figures]
NICE	National Institute for Health and Care Excellence
NISRA	Northern Ireland Statistics and Research Agency [tables, figures]
ONS	Office for National Statistics [tables, figures]
PHM	Public Health Mortality
PRUDiC	Procedural Response to Unexpected Death in Childhood
RSCB	Regional Safeguarding Children Board
SCB	Safeguarding Children Board [tables, figures]
SEW	South East Wales [tables, figures]
tHB	Teaching Health Board [tables, figures]
UHB	University Health Board [tables, figures]
uSID	Unexplained Sudden Infant Death
WIMD	Welsh Index of Multiple Deprivation [figure]
WPSU	Welsh Paediatric Surveillance Unit

Glossary

Child death overview panel
Multi-agency panels responsible for reviewing information on all child deaths within a local safeguarding children board area in England and accountable to the local safeguarding children board.

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

Child practice review
Child practice reviews take place after a child dies or is seriously injured, and abuse or neglect is known or suspected.
The purpose of the review is to generate new learning which can support continuous improvement in inter-agency child protection practice.

Conditions originating in the perinatal period
Certain conditions originating in the perinatal period, even if death or morbidity occurs later, as featured in chapter XVI (P codes) of ICD 10.

Congenital anomaly
A structural, metabolic, endocrine, or genetic defect, present in the child / fetus at the end of pregnancy, even if not detected until later. In this report, only those anomalies featured in chapter XVII (Q codes) of ICD 10 are included.

Infant
A child aged less than one year.

Procedural Response to Unexpected Death in Childhood (PRUDiC)
The Procedural Response to Unexpected Death in Childhood sets out a minimum standard for the multi agency response to the unexpected death of a child or young person. The aim of the PRUDiC is to ensure that this response is safe, consistent and sensitive to those concerned, and that there is uniformity in the approach taken across Wales. PRUDiC was first published in 2010 and revised in 2014.

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 (chance of a difference as extreme being observed, if underlying ‘true’ values were the same). In this report a difference is considered statistically significant when the confidence intervals do not overlap.

Statistical significance is not the same as clinical or public health significance.

Unexpected death

i) An unexpected death is one in which the death of a child was not anticipated as a significant possibility 24 hours before the death or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death.

ii) The death of a child where there is no known antecedent condition that might be expected to cause the death at that time, and the child dies either immediately or subsequently from the consequences of the precipitating event or collapse.

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About the Child Death Review programme

The Child Death Review programme aims to identify and describe patterns and causes of child death, including any trends, and to recommend actions to reduce the risk of avoidable factors contributing to child deaths in Wales. The programme covers the deaths of all live born children that occur after 1 October 2009 and before the child's 18th birthday. It includes children who are normally resident in Wales or who die in Wales. It relies on a multidisciplinary approach and seeks to identify, and learn from, common themes across child deaths. Thematic reviews are a key element of the Child Death Review programme. Sharing information between agencies and the Child Death Review programme is essential to this process. The Procedural Response to Unexpected Death in Childhood (PRUDiC)[1] describes how information is shared with the Child Death Review programme in the case of unexpected deaths. Where a death is expected, healthcare professionals are relied on to provide this information.

There is a strong association between deprivation and the risk of death.

External causes of death including accidents, suicide and assault, account for over half of deaths among those aged 12-17 years.

Child deaths in Wales

There were 204 deaths of children resident in Wales registered in 2013. Most child deaths (64%) occur in children under the age of one year. The child death rate in Wales is similar to the rate in the United Kingdom. There is a strong association between deprivation and the risk of death. The death rate among children living in the most deprived fifth of Wales is 70% higher than among children living in the least deprived areas.

There has been a decline in child death rates since 1996, particularly from 1996-2003. This decline relates mostly to the fall in death rates among children under one year of age. There has been a steady decline among 1-4 year olds, but the rate among 5-11 year olds has changed little in the last ten years.

The majority of deaths in children and young people aged 1-17 years (38%) are caused by medical conditions such as diseases of the nervous system for example, cerebral palsy, epilepsy and meningitis. External causes of death,

including accidents, suicide and assault, account for over half of deaths among those aged 12-17 years and around one in five deaths of children between the ages of 1-11 years.

Reviews of child death

In the last year, the Child Death Review programme completed a thematic review on sudden unexpected death in infancy[2] and produced a rapid response on deaths of children from meningitis and meningococcal disease in Wales.[3] A rapid review of deaths of children through dog bites/strikes was published in September 2014[4] and was included in the 2014 Annual Report.

Sudden unexpected death in infancy

The thematic review of sudden unexpected death in infancy was the first collaborative review and was a joint initiative between the Child Death Review programme and the All Wales Perinatal Survey. The review included a brief overview of all sudden deaths under the age of two years, but the main focus was upon those which were unexplained sudden infant deaths. The review was led by Dr Paul Davis of Cardiff & Vale University Health Board (UHB), and the review considered the deaths of 45 infants. A total of 32 key messages and 18 recommendations were made; including nine key recommendations relating to:

- Continuation of the current basis of advice, highlighting the high risk of co-sleeping in association with other risk factors
- Universal provision of advice to all families with new babies
- Effective delivery of existing health promotion messages
- Strengthening of efforts to reduce smoking
- Regular training for front line professionals on prevention of sudden unexpected death in infancy
- Review of policies and provision of social housing
- Encourage research into sudden unexpected death in infancy reduction
- Unimpeded sharing of information with the Child Death Review programme
- Continual monitoring of unexpected deaths in infants.

Rapid response on deaths of children from meningitis and meningococcal disease in Wales

This rapid response was undertaken at the request of Welsh Government. The review sought to describe numbers of cases known to the Child Death Review programme and identify key guidance/ recommendations that are already in existence for the UK that could contribute to reducing child deaths from meningitis. A number of factors that may have potential to reduce the likelihood of deaths of children from meningitis or meningococcal disease were identified, including:

- Universal meningitis B vaccination in early childhood
- Further uptake of pneumococcal polysaccharide vaccine among children over the age of two in clinical risk groups
- Assessing or auditing use of existing guidance among healthcare professionals
- Assessing or auditing training of healthcare professionals both undergraduate and postgraduate, across disciplines and in pre-hospital and hospital settings.

1 Introduction

This is the third annual report of the Child Death Review programme for Wales. It reports on trends in child deaths up to 2013 and activity in the Child Death Review programme during 2014-15. The death of a child is devastating to families and communities, and affects wider society. By systematically reviewing these deaths we hope to gain a greater understanding of why children die and what can be done to prevent these tragedies in future.

Systematic approaches to the evaluation of child deaths are now established in several countries including New Zealand, Australia, Canada, USA and England.[5][6][7] A national child death review system is currently being developed in Scotland.[8] In Wales, the Child Death Review programme was established in 2012 following a successful pilot (2009-2011) and became part of Public Health Wales core activity in 2014. A national thematic approach to child death review has been established. This relies on partnerships with professionals and agencies across Wales and also builds on the multi-agency integrated response to unexpected deaths through the PRUDiC.

A national thematic approach to child death review has been established. This relies on partnerships with professionals and agencies across Wales.

2 Child Death Review Programme

2.1 Aims and objectives of programme

The aim of the programme is to identify and describe patterns and causes of child death, including any trends, and to recommend actions to reduce the risk of avoidable factors contributing to child deaths in Wales.

The objectives of the programme are:

- To ascertain and collate data on child deaths in Wales and deaths of children who are normally resident in Wales
- To undertake thematic reviews and make recommendations
- To produce an annual report that:
  - Describes findings of patterns of child deaths in Wales
  - Highlights where avoidable factors thought to contribute to child deaths have been identified from thematic reviews
- To disseminate findings from the annual report and thematic reports in order to inform action to address avoidable factors contributing to child deaths in Wales.

2.2 Scope of the Child Death Review programme

A child death for the purposes of the Child Death Review programme is:

- Any death of a live born child that occurs after 1 October 2009 and before the child's 18th birthday and where the child is either normally resident in Wales or where the death has occurred in Wales but the child is normally resident elsewhere. This includes children who are under local authority care and placed outside of Wales or those who may temporarily reside outside of Wales for healthcare or education purposes
- For specific thematic reviews, it may be considered necessary to include deaths of young people up to the age of 25 years but these will be identified on an individual themed basis
- In addition, the Child Death Review team will try to identify deaths of children where the event which led to their death took place in Wales, but the child's death occurred elsewhere.

Thematic reviews seek to identify common circumstances which were evident within the child's life and may have contributed to their premature death, and consider if any of these were modifiable and could offer opportunities for future prevention

Child practice reviews, PRUDiC and coroner's inquests continue to have specific functions relating to deaths of individual children. Information gathered during these processes may help to inform the work of the programme; however, making statements on the cause or circumstances of the death of any individual child is beyond the scope of the programme.

2.3 Ways of working

Delivering a programme of child death reviews is a multidisciplinary venture. At its heart is an effort to understand and help prevent deaths of children in Wales by focussing on modifiable factors that may have contributed to those deaths. To achieve this requires an open and enquiring approach to the factors leading to the death of children. The reviews do not seek to blame individuals or agencies but focus on what can be done to prevent deaths in the future.

The programme publishes recommendations which are made by consultation with the panel members selected for each review. The content and publication of these reports and recommendations is the responsibility of Public Health Wales. The Welsh Government receives thematic reports, including their recommendations, six weeks before publication to enable the report to be considered by Welsh Government officials.

The programme relies on information from multiple sources to ensure timely and complete information.

The review programme uses particular mechanisms to gain input from professionals and agencies from across Wales:

- A multi-agency steering group which provides strategic advice and directional guidance to the programme and also facilitates stakeholder ownership and engagement (Appendix A)
- Stakeholder events where findings of the programme are shared in a forum allowing wider engagement and feedback on the work
- Suitable membership of thematic review panels.

2.4 Information sharing

The success of the programme relies heavily on the partnerships between the Child Death Review programme and other organisations and professionals. These partnerships underpin the sharing of information on the circumstances surrounding each child's death, essential to understanding patterns of death and undertaking reviews.

The programme relies on information from multiple sources to ensure timely and complete information. As well as safeguarding children boards (SCBs), health professionals, the police, Welsh Ambulance Service NHS Trust and others, the programme receives data from the Office for National Statistics and other NHS databases such as the Welsh Paediatric Surveillance Unit (WPSU). The programme is currently engaging with the coronial service and with the children's palliative care service in Wales and it is hoped that information may be shared through these routes in future.

For unexpected child deaths, the PRUDiC [1] provides a process for multi-agency communication and information sharing. An unexpected death is defined as:

'The death of a child which was not anticipated as a significant possibility 24 hours before the death or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death'. [1] pg 7

and, especially when there is a significant time delay between the collapse of the child and the eventual death, as:

'The death of a child where there is no known antecedent condition that might be expected to cause the death at that time, and the child dies either immediately or subsequently from the consequences of the precipitating event or collapse' [1] pg 7

The process, which was revised in 2014, aims to ensure that the response is safe, consistent and sensitive to those concerned, and that there is uniformity across Wales in the multi-agency response to unexpected child deaths. It includes informing families about the Child Death Review programme, sharing an early notification of the death and, later, a more detailed record of child death at the end of the PRUDiC process.

The process for expected deaths follows a similar approach, where healthcare professionals are expected to share information with the Child Death Review team. The WPSU has played a significant role in helping to identify child deaths to the programme, allowing follow-up with individual clinicians. This is particularly important where a child's death is expected and so PRUDiC would not be implemented.

All information that is shared with the programme is treated in a confidential manner. Information received electronically that can identify individuals is maintained in a secure, password protected, restricted access database. All hard copies of identifiable information are stored within the programme's office and maintained within a secured cabinet. This information can only be accessed by the Child Death Review team and, for the purposes of preparing information for panels, the professional lead for the review.

All information is anonymised before it is shared with thematic panel members. All thematic panel members sign a data confidentiality statement prior to reviewing anonymised data.

At all times the team works to ensure no new information about individual children is brought into the public domain. In some instances information about children is already in the public domain and media attention about specific deaths may be unavoidable.

All information that is shared with the programme is treated in a confidential manner.

3 Child deaths in Wales

Child deaths have been declining in the UK and globally over many decades.[9][10] However, death rates of those aged 0-4 have been ranked among the highest in Western Europe.[9] A separate analysis across four decades has shown child death rates declining less rapidly in the UK than in other wealthy countries, particularly infant deaths and child deaths from non-communicable diseases.[11]

Sections 3.1, 3.2 and 3.3 use official registrations of child deaths of children normally resident in Wales, derived from Office for National Statistics (ONS) data. Deaths are described by area of residence and are grouped into those aged under one year (infants); 1-4 years (pre-school age); 5-11 years (primary school age) and 12-17 years (secondary school age). Due to the relatively small numbers of child deaths registered in any given year, most data are aggregated into groups of three, five or 10 years. Confidence intervals (95%) are shown to help describe the variation that might be expected around a rate due to the effects of chance. In this report, differences are described as being statistically significant if the confidence intervals do not overlap.

Previous analyses of deaths under one year in the Child Death Review programme annual reports used the first ICD-10 code as the main underlying cause of death, however, for neonatal deaths this may not always represent the underlying cause. The analysis in this year's report does not provide detail on the causes of deaths under the age of one year. Analysis on cause of death up to the first year of life are described within All Wales Perinatal Survey Annual Reports.[12]

3.1 Overall pattern of child deaths in Wales

Although there is some variation in child death rates across the UK nations (Appendix B, Table 6), with Wales and Scotland tending to have slightly lower rates of death in infancy, there was no statistically significant difference between child death rates in Wales and the other UK nations for these age groups.

There were 204 child deaths in Wales registered during 2013, giving a death rate of 32.4 per 100,000 children under 18 years (Appendix B, Table 7). Most deaths (64%, 144 per year) occur in infancy, i.e. aged under one year (Table 1). About half of the remaining child deaths occur among those aged 12-17 years (39 per year). Death rates are lowest in the 5-11 years age group (8.7 per 100,000 children, 20 per year, 2009-2013).

There were 204 child deaths in Wales registered during 2013, giving a death rate of 32.4 per 100,000 children under 18 years.

Table 1 Deaths by age group, children and young people aged under 18 years, Wales, 2009-2013

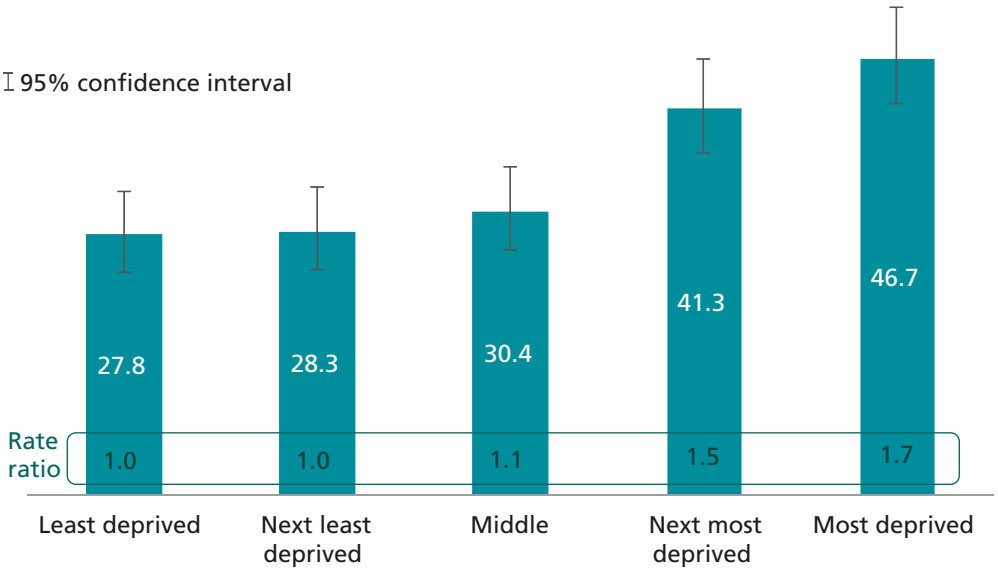
	Annual average count	Percentage of child deaths	Crude rate per 100,000	(95% confidence interval)
<1 year	144	64%	406.2	(377.0 – 437.0)
1-4 years	22	10%	15.2	(12.5 – 18.4)
5-11 years	20	9%	8.7	(7.1 – 10.6)
12-17 years	39	17%	17.4	(15.0 – 20.0)

Produced by the Public Health Wales Observatory, using PHM & MYE (ONS)
Rates should be interpreted with caution where there are a small number of events

There is a strong association between child deaths and deprivation. The death rate among children living in the most deprived fifth of Wales is 70% higher than those living in the least deprived fifth. This difference is statistically significant (Figure 1, rate ratio 1.7, 95% confidence interval: 1.4-2.0, 2009-2013). This rate ratio has not changed since last year's report (1.7, 95% confidence interval 1.4-2.0, 2008-2012).

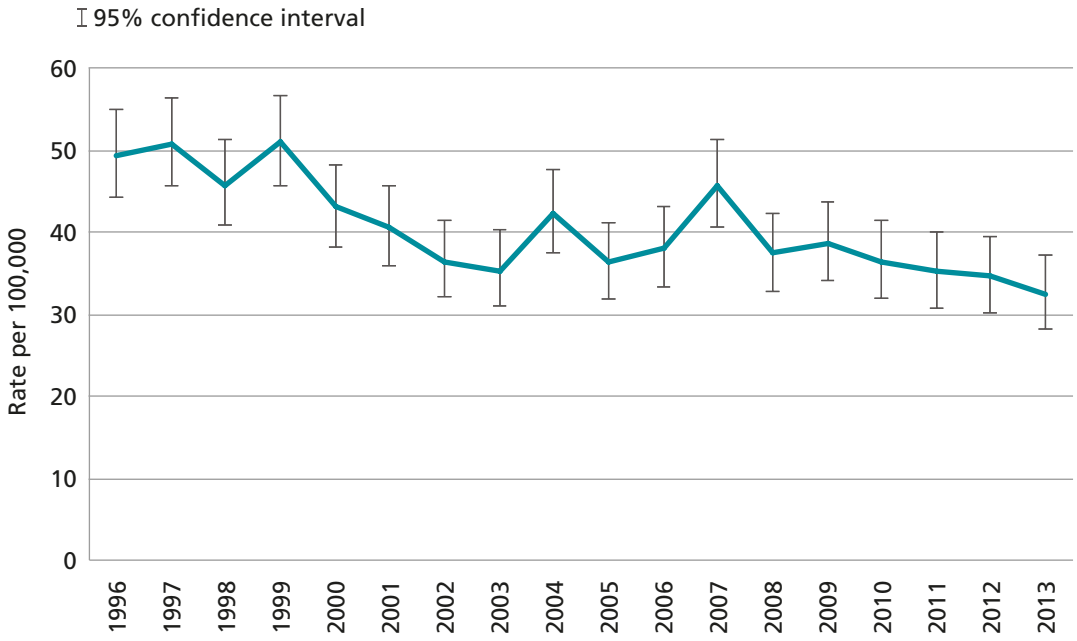
The overall rate of child deaths has declined from 49 deaths per 100,000 (95% confidence interval 44-55 per 100,000) in 1996 to 32 deaths per 100,000 (95% confidence interval 28-37 per 100,000) in 2013 (Figure 2). This is the lowest rate during the 18 years examined, although the confidence intervals for the rates since 2001 overlap (with the exception of 2007; 46 per 100,000, 95% confidence interval 41-51 per 100,000) so the rate is not statistically significantly lower than the previous twelve years.

Figure 1 Deaths from all causes by deprivation fifth, crude rate per 100,000 and rate ratios,* children and young people aged under 18 years, Wales, 2009-2013



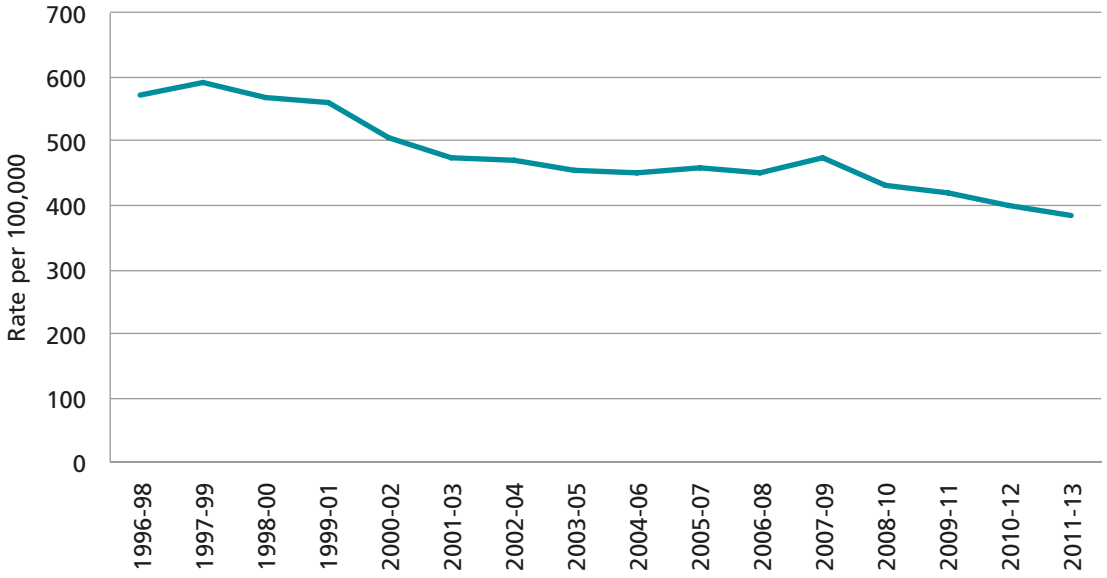
* Rate ratios compared to the least deprived fifth
Produced by Public Health Wales Observatory, using PHM & MYE (ONS), WIMD 2014 (WG)

Figure 2 Trend in deaths, crude rate per 100,000, children and young people aged under 18 years, Wales, 1996-2013



Produced by Public Health Wales Observatory, using PHM & MYE (ONS)

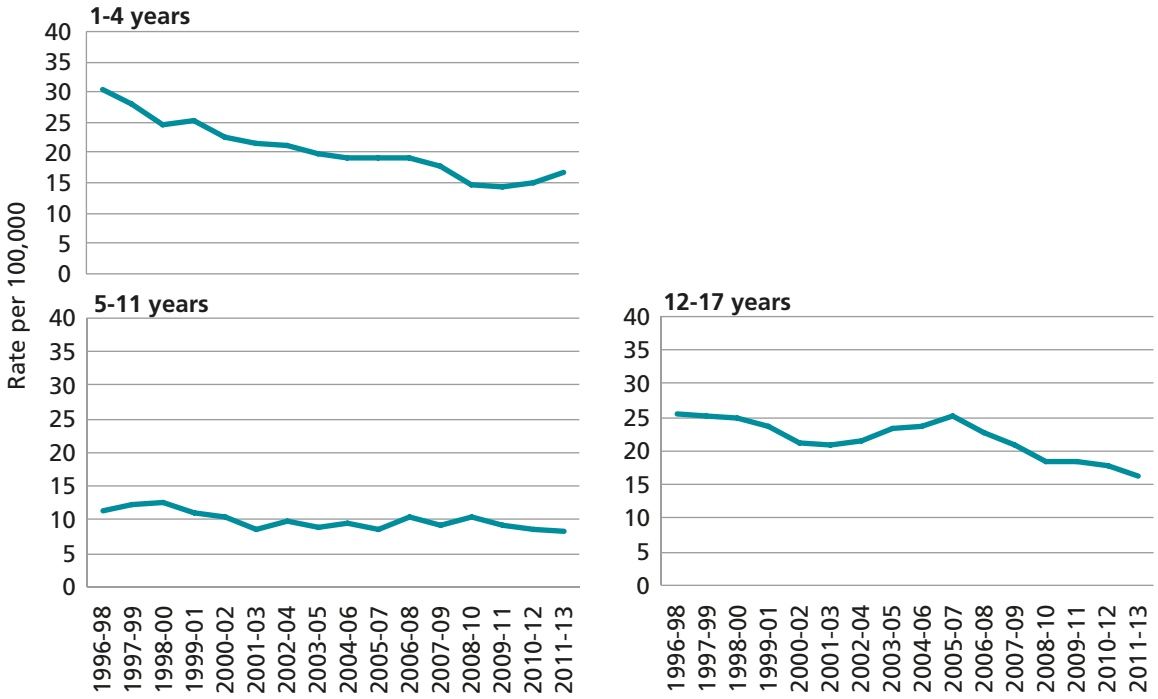
Figure 3 Trend in death rate, three year rolling rate, children under one year of age, Wales, 1996-2013



Produced by Public Health Wales Observatory, using PHM & MYE (ONS)

The decline since 1996 relates to reducing rates of infant death, particularly during the first half of this period (Figure 3). The rates shown in Figure 3 and Figure 4 are rolling rates, which smooth out year on year variation. There has been a steady decline among 1-4 year olds (Figure 4), where the rate in 2011-13 is almost half that in 1996-98. The rate among 5-11 year olds has changed little in the last ten years.

Figure 4 Trend in death rate, three year rolling crude rate, by age group, children and young people aged 1-17 years, Wales, 1996-2013



Produced by Public Health Wales Observatory, using PHM & MYE (ONS)

3.2 Causes of death

Causes of death are described for children and young people aged 1-17 years.

External causes of death, including accidents, suicide and assault, account for 36% of deaths among children aged 1-17 years (33 per year, 2004-13, Table 2) and neoplasms 14% of deaths (13 per year, 2004-13, Table 2).

The majority of deaths in children and young people aged 1-17 years (38%) are caused by 'other' causes which relate to medical conditions shown in Table 3. The most common medical conditions were diseases of the nervous system which accounted for around 11 deaths per year. This includes conditions such as cerebral palsy, epilepsy and meningitis.

Table 2 Deaths by cause, count and annual average, children and young people aged 1-17 years, Wales, 2004-2013

	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)	32	3.2	13	1.3	21	2.1	66	7
External (V01-Y98, U509)*	42	4.2	48	4.8	237	23.7	327	33
Ill-defined and unknown causes (R95-R99)	23	2.3	5	0.5	17	1.7	45	5
Neoplasms (C00-D48)	23	2.3	54	5.4	55	5.5	132	13
Other (all other codes)	112	11.2	103	10.3	134	13.4	349	35
All causes	**232**	**23.3**	**223**	**22.3**	**464**	**46.4**	**919**	**91.9**

Produced by the Public Health Wales Observatory, using PHM (ONS)
* Additional code U509 from 2007 onwards

Table 3 Other causes of death, children and young people aged 1-17 years, Wales, 2004-2013

	Annual average count	Percentage of other deaths
Diseases of the nervous system (G00-G99)	11.4	33%
Diseases of the respiratory system (J00-J99)	3.9	11%
Certain infectious and parasitic diseases (A00-B99)	4.8	14%
Diseases of the circulatory system (I00-I99)	5.0	14%
Endocrine, nutritional and metabolic diseases (E00-E90)	3.8	11%
Alternative causes	6.0	17%
Total	**34.9**	**100%**

Produced by the Public Health Wales Observatory, using PHM (ONS)

Fourteen per cent of deaths in 1-4 year olds are caused by congenital anomaly, 10% of deaths in this age group are ill-defined or have unknown cause, and 10% are caused by neoplasms. Almost half are due to medical conditions listed under 'other' causes.

Around one quarter of deaths in 5-11 year olds are caused by neoplasms and similar to the 1-4 year old age group, almost half are due to 'other' causes.

There were 327 deaths from external causes in children and young people aged 1-17 years in the ten year period from 2004-2013.

In the 12-17 year age group, external causes account for around half of all deaths.

There were 327 deaths from external causes (Table 4) in children and young people aged 1-17 years in the ten year period from 2004-2013. Of the external deaths, 72% (237 deaths) occurred in children and young people aged 12-17 years. The most common external causes were transport accidents, which accounted for 40% of the deaths (131 out of 327 deaths) from external causes in children and young people aged 1-17 years.

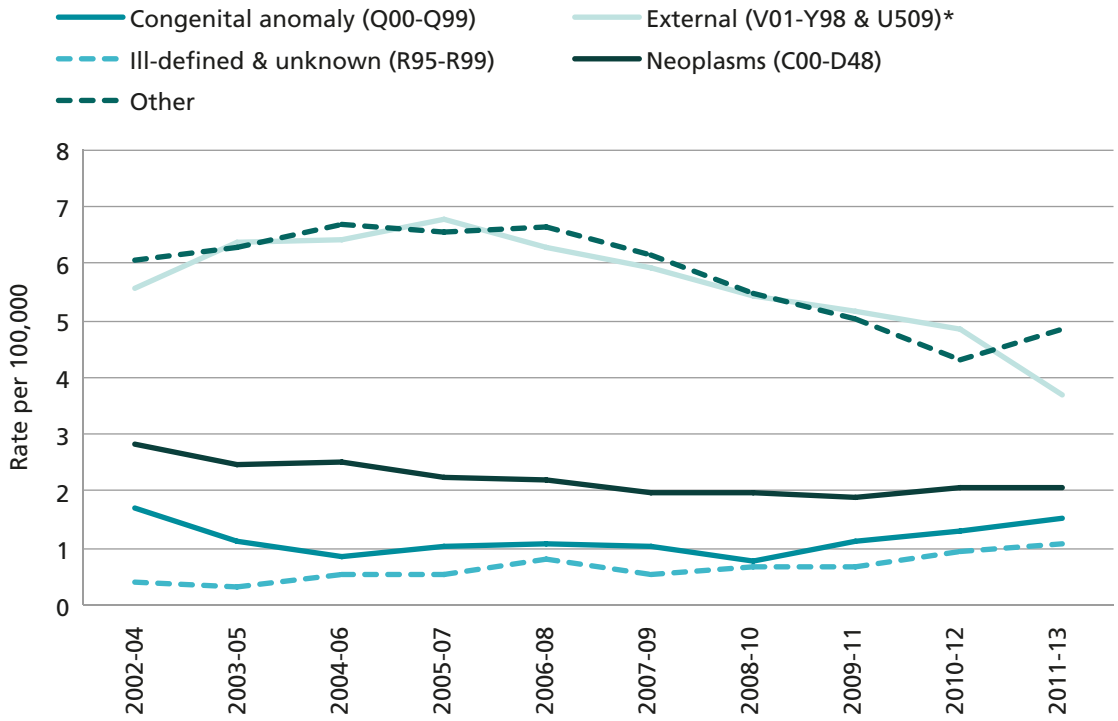
Table 4 Deaths by external cause, by age group, children and young people aged 1-17 years, Wales, 2004-2013

	1-4	5-11	12-17	Total aged 1 - 17
Transport Accident				
Pedestrian (V01-V09)	2	8	23	33
Pedal cyclist (V10-V19)	0	2	6	8
Motorcycle (V20-V29)	0	1	8	9
Car passenger & unspecified (V40-V49*)	4	6	41	51
Car driver (V40-V49*)	0	0	14	14
Other & unspecified (V50-V99)	0	6	10	16
Falls (W00-W19)	3	0	4	7
Exposure to inanimate mechanical forces (W20-W49)	4	2	5	11
Accidental drowning and submersion (W65-W74)	4	3	9	16
Other accidental threats to breathing				
Hanging & Strangulation (W75-W76)	2	1	18	21
Other (W77-W84)	1	1	2	4
Exposure to smoke, fire and flames (X00-X09)	3	3	0	6
Exposure to forces of nature (X30-X39)	0	0	1	1
Accidental poisoning by and exposure to noxious substances (X40-X49)	0	1	11	12
Accidental exposure to other and unspecified factors (X58-X59)	1	1	1	3
Intentional self-harm				
Hanging & Strangulation (X70)	0	0	27	27
Other (X60-X69, X71-X84)	0	0	10	10
Assault (X85-Y09, Y339 before 2007, U509 from 2007 onwards)	15	11	33	59
Event of undetermined intent				
Hanging & Strangulation (Y20)	0	1	10	11
Other (Y10-Y19, Y21-Y34 excl Y339 before 2007)	1	0	3	4
Complications of medical and surgical care (Y40-Y84)	2	1	1	4
All external causes (V01-Y98, U509)**	**42**	**48**	**237**	**327**

Produced by the 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

Figure 5 shows the trend in death rate by cause. Across the ten year period the greatest change is seen in deaths from external causes and deaths from the 'other' cause grouping, both of which have shown a decrease between 2004-06 and 2011-13, although the 'other' category is not maintaining a stable trajectory.

Figure 5 Trend in death rate by cause, three year rolling crude rate, children and young people aged 1-17 years, Wales, 2002-2013



* Additional code U509 from 2007 onwards
Produced by Public Health Wales Observatory, using PHM & MYE (ONS)

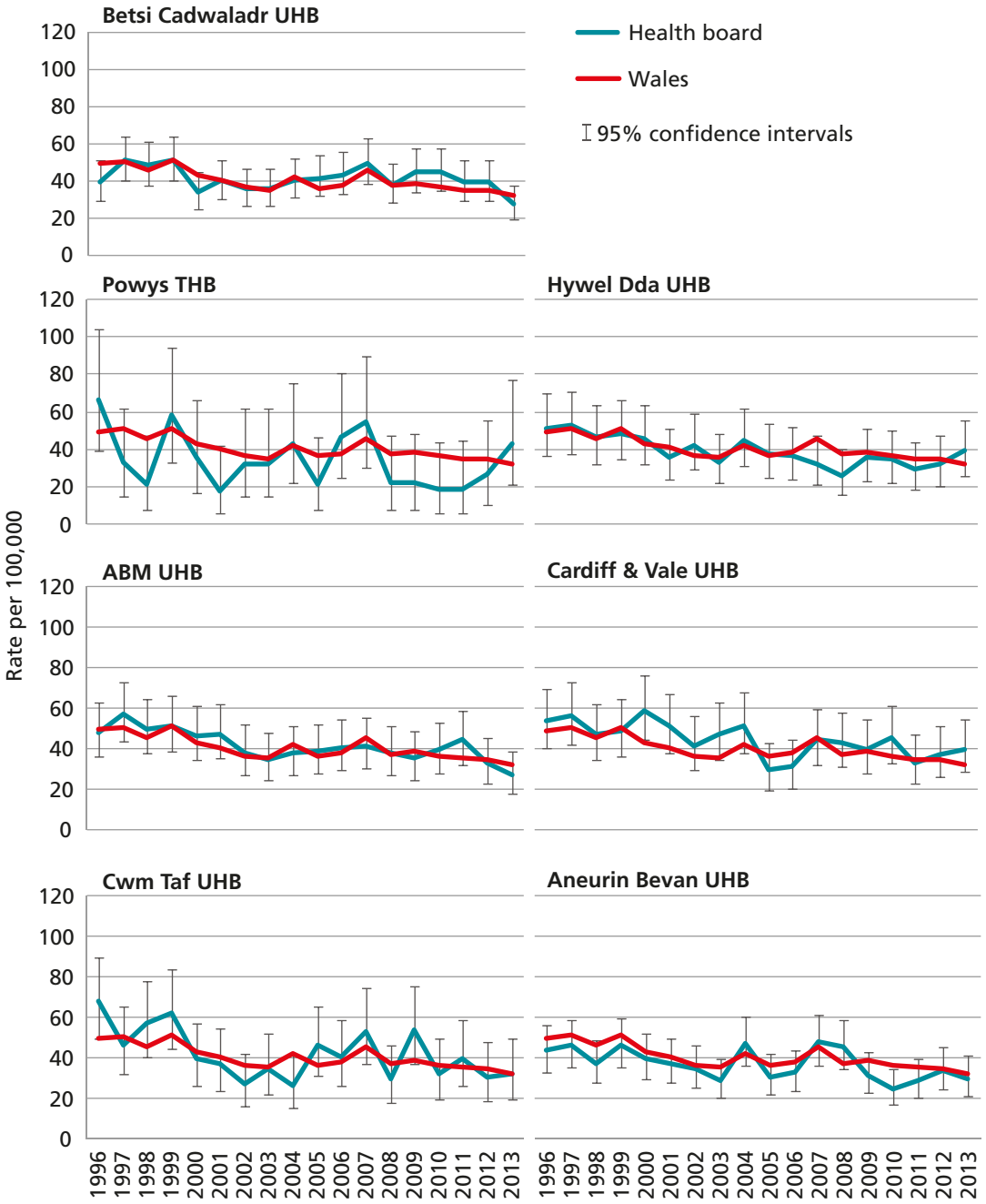
3.3 Geographical pattern of deaths

The death rate across most health board areas in Wales has shown a broadly similar pattern to that of Wales as a whole (Figure 6). Due to the different population sizes, numbers of deaths vary across areas.

Forty (20%) of the 204 deaths in 2013 were among residents of Cardiff & Vale UHB area and 11 (5%) were among residents of the Powys teaching Health Board (tHB) area (Appendix B, Table 8).

Figure 7 shows the proportion of deaths in each age group by area. The proportions of different causes vary but the rates of child death are not statistically significantly different from that of Wales, for almost all age groups across the health board, local authority, police and SCB areas during 2004-13 (Appendix B, Table 9 and Table 10). The exceptions are Flintshire and Wrexham Local Safeguarding Children Board (LSCB) which includes Flintshire local authority where the death rate among 12-17 year olds is statistically significantly lower than that of Wales. In contrast, the Isle of Anglesey and Bridgend local authority areas have statistically significantly higher death rates than that of Wales among 12-17 year olds. The local authority figures are based on a very small number of annual deaths.

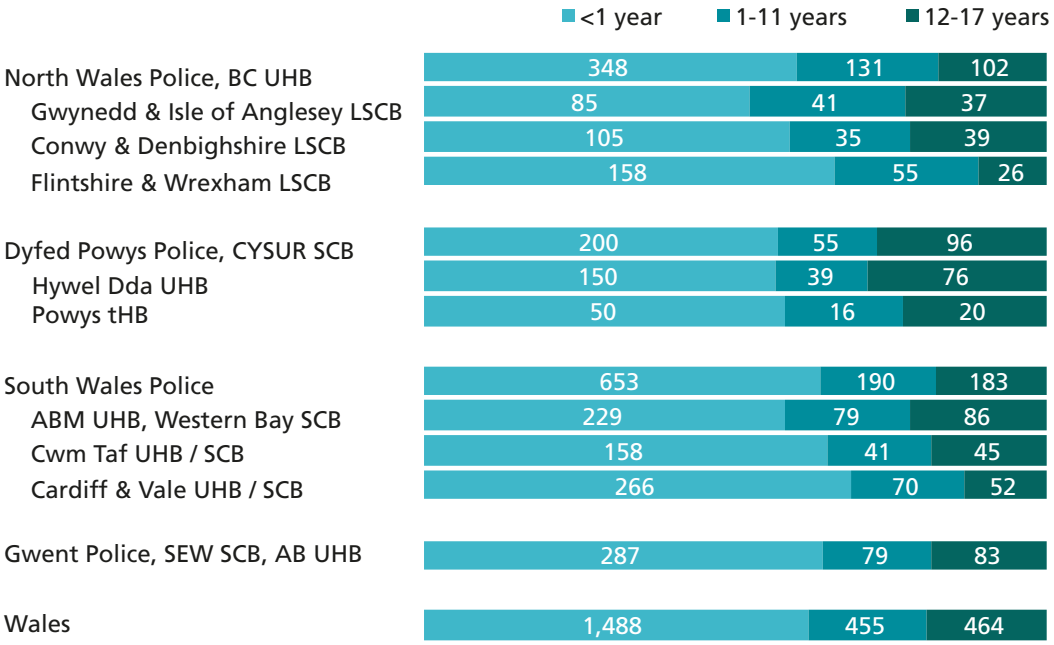
Figure 6 Trends in deaths, crude rate per 100,000, children and young people aged under 18 years, Wales health boards, 1996-2013



Rates should be interpreted with caution where there are a small number of events
Produced by Public Health Wales Observatory, using PHM & MYE (ONS)

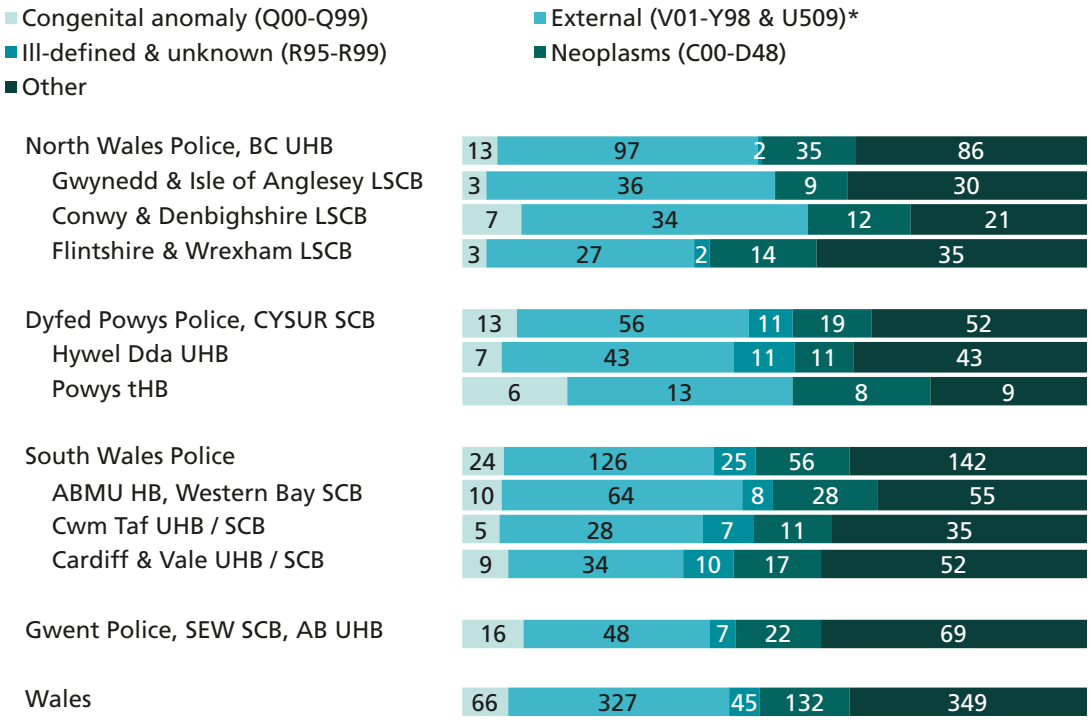
The contributions of different causes of death are broadly similar across areas in Wales (Figure 8). These data should be considered in relation to the death rates by cause across areas (Appendix B, Table 11). During the ten year period from 2004-2013, the area covered by the Gwynedd and Isle of Anglesey LSCB had a statistically significantly higher rate of deaths due to external causes in children and young people aged 1-17 years (Appendix B, Table 11).

Figure 7 Deaths from all causes by age group, count, children and young people aged under 18 years, Wales, police force, safeguarding children board and health boards, 2004-2013



Produced by Public Health Wales Observatory, using PHM (ONS)

Figure 8 Deaths by cause group, count, children and young people aged 1-17 years, Wales, police forces, safeguarding children boards and health boards, 2004-2013



Differences between areas should be interpreted with caution where there are small counts
*Additional code U509 from 2007 onwards
Produced by Public Health Wales Observatory, using PHM (ONS)

3.4 Notification of cases to the Child Death Review programme

The Child Death Review programme relies on information from multiple sources to build a picture of child deaths in Wales and to inform thematic reviews.

Between 2010 and 2014 approximately 48% of deaths were first reported to the programme from a health source (WPSU, NHS databases and other health sources). Other sources are shown in Table 5.

Almost a third of child deaths are not directly reported to the Child Death Review programme.

Table 5 First reporting source to the Child Death Review programme, by age group of child or young person who has died, 2010-2014

	<1	1-4 yrs	5-11 yrs	12-17 yrs	Grand total
ONS	245	25	21	42	333
WPSU	56	14	16	27	113
Other NHS databases	73	8	11	25	117
Other health source	182	36	26	44	288
LSCB	87	18	22	33	160
Coroner/Registrar	8	5	2	3	18
Police	8	2	3	2	15
Notifier ID not provided	28	1	2	3	34
CDOP			1		1
Total	**687**	**109**	**104**	**179**	**1079**

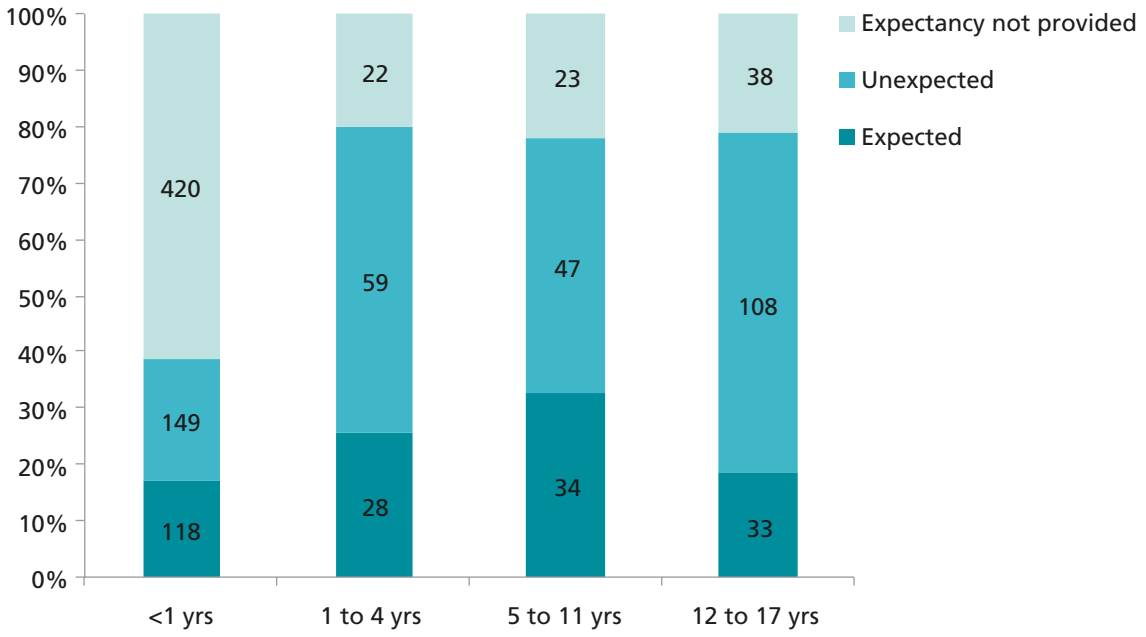
Source: Child Death Review database, Wales

The Child Death Review programme has records of whether or not a child's death was expected for 79% of child deaths occurring after infancy, but for just 39% of deaths occurring during infancy (Figure 9).

Where the death expectancy was reported to the programme, 69% of deaths among those aged 1-17 years were considered unexpected (Figure 9).

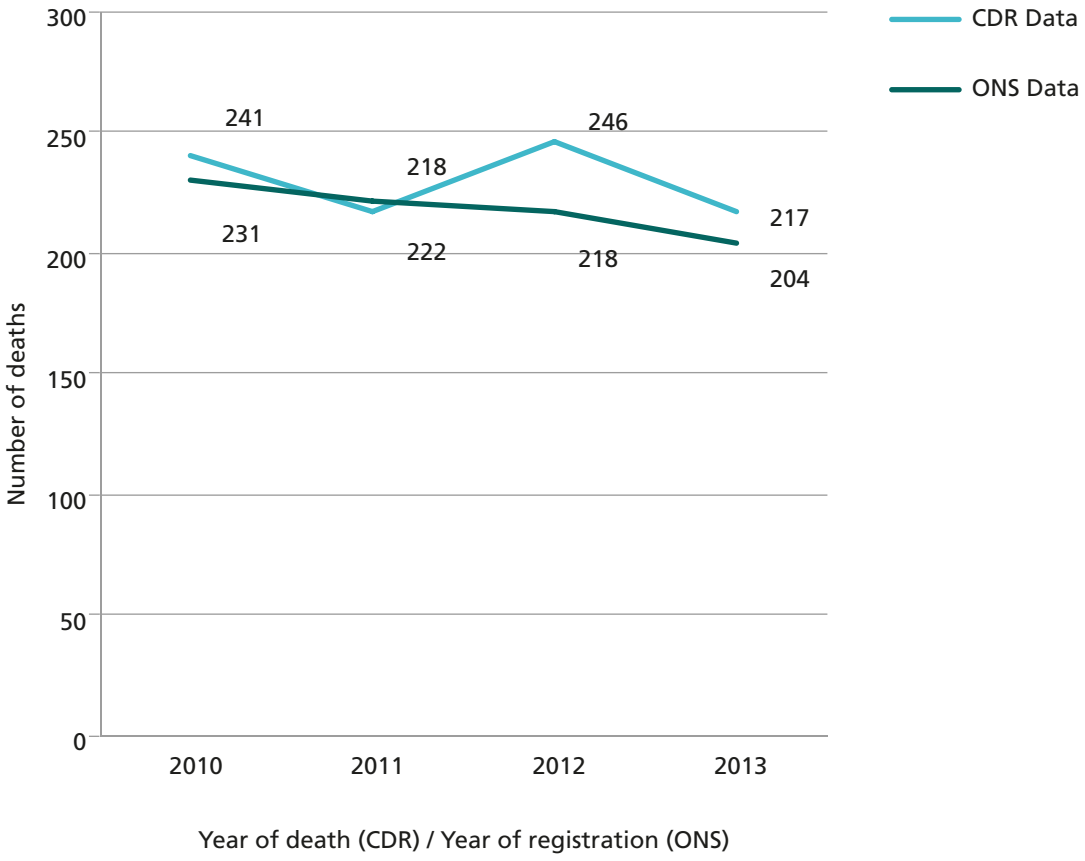
The number of notifications received by the Child Death Review programme is broadly similar to the number of ONS registrations between 2010 and 2013 (Figure 10). The numbers may differ slightly as the Child Death Review database records the date of occurrence of death and ONS records date of death registration, which in some cases could be several months later. The Child Death Review programme also collects information on deaths that occur in Wales, regardless of area of residency, whereas ONS registrations here refer to Welsh residents only.

Figure 9 Deaths reported to the Child Death Review programme by age group and whether or not the death is expected, children and young people aged under 18 years, 2010-2014



Source: Child Death Review database, Wales

Figure 10 Deaths registered by year in Child Death Review programme and Office for National Statistics



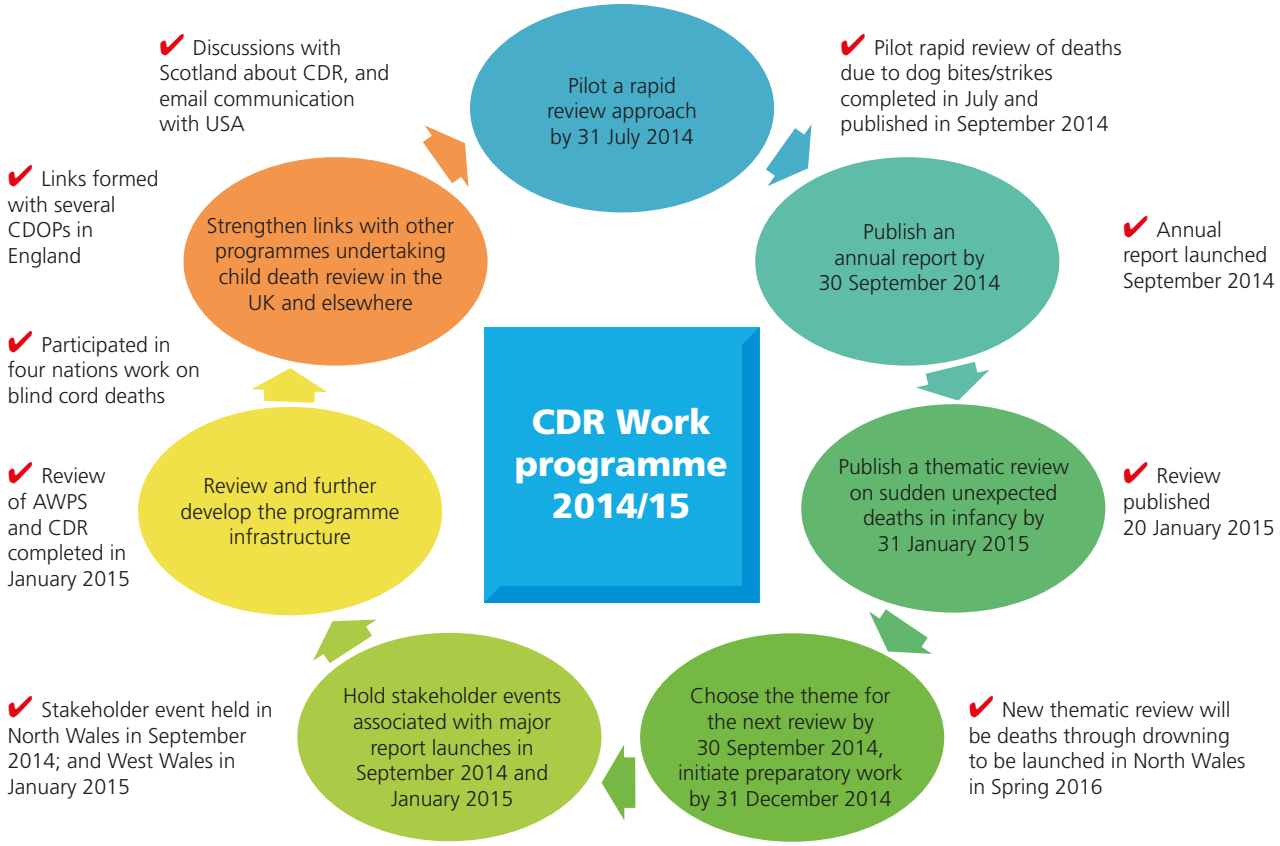
Source: Child Death Review database, Wales and data from PHM and MYE (ONS)

4 Completed work

4.1 Progress against 2014/15 programme objectives

Figure 11 details the Child Death Review programme's work plan with progress made against objectives for 2014/15.

Figure 11 Progress against work programme objectives 2014/15



Source: Child Death Review work programme 2014-15

4.2 Thematic review: Review of sudden unexpected deaths in infancy

The Child Death Review programme collaborated with the All Wales Perinatal Survey for the review of sudden unexpected deaths in infancy.[2] The review was led by Dr Paul Davis, Consultant Paediatrician at Cardiff & Vale UHB. Deaths of children below the age of two years were included in the initial review, however the analysis focussed on children under one year of age.

In the review:

- A total of 75 deaths were considered
- There were 63 deaths in children under one year of age
- There were 12 deaths between the age of one and two years
- The cause of death was identified in 14 children and these were excluded
- Insufficient information was available for four deaths and these could not be included
- A total of 45 deaths were included in the review, all under one year of age.

Twenty four of the deaths reviewed were male infants, 21 female. A higher rate of death occurrence was found between October to March at 64% with the remaining 36% occurring in the warmer months of the year. Death occurred in infants below 12 weeks of age in 54% of the children reviewed, with 33% being between 12 and 24 weeks and 13% being over 24 weeks. This pattern is in keeping with other studies and demonstrates that prevention strategies must focus on very young babies including the neonatal period (first month of life). Other factors identified through the review included younger maternal age with the mean age of 25 years; low birth weight of infants and prematurity; and the period of time that had lapsed since the infant had been checked on since being put to sleep. Socio-demographic factors were clearly identified, with 69% of the deaths occurring in the most deprived areas (WIMD categories 4 and 5).

Information regarding co-sleeping of infants with an adult was evidenced in 26 of the deaths; and in all deaths there was at least one other risk factor present with the majority of infants having three or four additional risk factors present whilst co-sleeping. Parental smoking was high and was evident in 69% of the co-sleeping deaths; and correlates to the 2012 Tobacco and Health report from Public Health Wales which stated that around one in six females living in Wales smoke throughout pregnancy, which is the highest rate in the four UK nations.

The panel made 18 recommendations, of which they felt that nine were strongly recommended including:

- The Welsh Government, Public Health Wales, health boards and primary care providers should continue to provide advice based on "Reduce the risk of cot death"[13] to all families with new babies. The panel agreed that the Welsh Government should not adopt a position of blanket discouragement of co-sleeping, but need to emphasise that co-sleeping in association with other risk factors carries a very high risk of uSID

Socio-demographic factors were clearly identified, with 69% of the deaths occurring in the most deprived areas.

- Welsh Government, Public Health Wales and healthcare providers should continue the universal provision of advice to all families with new babies, recognising the particularly important roles of midwives, health visitors and GPs
- The panel recommends that Welsh Government should consider mechanisms to deliver the existing health promotion messages more effectively. These could include:
  - Facilitating debate about effective prevention strategies
  - Consideration of a national campaign
  - Exploring innovative approaches including modern media
  - Developing mechanisms of reaching the most vulnerable families
  - Evaluating impact
- Health boards, Public Health Wales and Welsh Government should strengthen their efforts to reduce smoking, especially in young women and parents during pregnancy and in the first year after child birth
- Front line professionals should receive regular training so that they understand the key messages on the prevention of uSID, including research evidence on the interaction between co-sleeping and other risk factors such as smoking, low birth weight, very young infants and alcohol consumption, and are able to deliver these messages to parents
- The Welsh Government and local authorities should review their policies and provision of social housing to ensure conditions are appropriate for families with young, vulnerable babies and that urgent action is taken in response to professionals concerns or recommendations
- The Welsh Government should work with partners to promote debate and encourage research into concrete measures to reduce population rates of uSID, and unsafe co-sleeping in particular
- The Welsh Government should inform all safeguarding children board partners of its expectation that there will be unimpeded information sharing with the Child Death Review programme when any child dies
- The Child Death Review programme should continue to monitor trends in unexpected infant death rates as part of its routine activity. This review should be repeated at an appropriate interval if there are concerns about the rate of progress in reducing these deaths.

Nine further recommendations were made relating to other factors including:

- New and imaginative approaches for reducing risk for babies with very young parents
- uSID prevention messages being emphasised when young babies are particularly vulnerable
- Seek to reduce rates of prematurity and low birth weight by promoting pre-conceptual care
- Promoting breast feeding

- Consensus on advice about safest place to feed babies during the night
- Increasing multi-agency ownership of the Child Death Review process
- Refine data collection tool for uSID
- Consider standardised templates for data collection within PRUDiC including paediatric history/first account
- Collaborative working between Child Death Review, All Wales Perinatal Survey and MBRRACE-UK to allow regular monitoring and analysis of infant deaths.

4.3 Rapid response: meningitis and meningococcal disease

The Child Death Review team developed and piloted a rapid response process following a request from the Welsh Government enquiring about deaths of children through meningitis.[3] The rapid response was performed using data from the Child Death Review programme database between 1 October 2009 and 1 July 2014, although individual deaths were not reviewed. A total of 18 deaths with acute meningitis or meningococcal disease as a contributory factor had been recorded within the Child Death Review programme database during this period. The response considered existing recommendations for the UK including immunisation for children; NICE clinical guidance 2010, *Bacterial meningitis and meningococcal septicaemia* [CG102] and the 2013 clinical guidance, *Feverish illness in children* [CG160].

The review identified that a key message for professionals is that a GP working full time in Wales might expect, on average, to see a child with meningitis or meningococcal disease about once every seventeen years*.

A number of factors were highlighted which may have the potential to reduce the likelihood of deaths of children from meningitis or meningococcal disease including:

- Universal meningitis B vaccination in early childhood
- Further uptake of pneumococcal polysaccharide vaccine among children over the age of two in clinical risk groups
- Assessing or auditing use of existing guidance among healthcare professionals
- Assessing or auditing training of healthcare professionals both undergraduate and postgraduate, across disciplines and in pre-hospital and hospital settings, e.g. medical students, general practitioners, and accident and emergency staff.

The programme also plans to develop a specific record of child death template to collect information on deaths from infection; and has proposed to the Child Death Review programme steering group that a thematic review of deaths of children from meningitis and meningococcal disease is scheduled into the work plan for the programme in the future.

The review identified that a key message for professionals is that a GP working full time in Wales might expect, on average, to see a child with meningitis or meningococcal disease about once every seventeen years.

* Based on typically 112 notifications of meningitis or meningococcal disease in people under 18 years per year in Wales, and approximately 1,900 whole time equivalent general practitioners in Wales.

4.4 Stakeholder events

To coincide with the release of the thematic reviews or the annual report, stakeholder events are held on a rotational basis across Wales. The seminar event in September 2014 followed the launch of the annual report 2014 and was held in North Wales. A further event was held following the launch of the thematic review of sudden unexpected deaths in infancy in January 2015 and this event was held in South West Wales. Feedback from these events is shown in Appendix C.

4.5 Implementation of recommendations from the review of deaths of children and young people through probable suicide, 2006-2012

In March 2015, twelve months after the release of the thematic review of deaths of children and young people through probable suicide, 2006-2012 [14] we approached agencies to enquire about progress against the recommendations. We also asked of any barriers identified in implementing the recommendations.

There was generally a good response to the request for information although a few organisations did not respond at all.

In some cases, agencies were unaware of the recommendations. The Child Death Review team will consider how to identify and work with agencies and partnerships in the future to ensure that any recommendations made are communicated appropriately.

The responses to the recommendations include:

- The PRUDiC process is being initiated for probable suicide deaths in most areas however there are still gaps in implementation with some agencies reporting they did not hold key meetings in the process, which may affect information sharing with the Child Death Review programme
- New guidance on firearms licensing law published in October 2014, incorporates the recommendation about safe storage of firearms including inspection by police of storage arrangements.
- Welsh Government have assured us that the recommendations will be considered by officials and fed in to the policy making process. The thematic review has informed the Welsh Government's consultation document of its latest strategy on suicide and self harm prevention, Talk to Me 2. Children and young people from vulnerable backgrounds, particularly those not in education, training and employment have become a priority group for action in Wales and the Child Death Review programme is referenced as a mechanism by which deaths through suicide in young people will be regularly reviewed in Wales.

The responses received from various agencies and organisations highlighted issues which were considered to be preventing full implementation of some of the recommendations including:

- Resource and workforce implications
- Stigma of being referred to a mental health service
- No statutory obligation to respond to recommendations
- Variance across Wales with full PRUDiC process, including compliance with case discussion meetings and review meetings.

The Child Death Review team have noted that LSCBs in Wales have merged to become regional SCBs. Any further recommendations from future thematic reviews will be directed to Chairs of the regional SCBs.

Following the response to the recommendations, the Child Death Review team will meet with the professional lead for the thematic review of deaths of children and young people through probable suicide to discuss further.

Responses received are shown in Appendix D.

4.6 Procedure for the Child Death Review programme Thematic Reviews

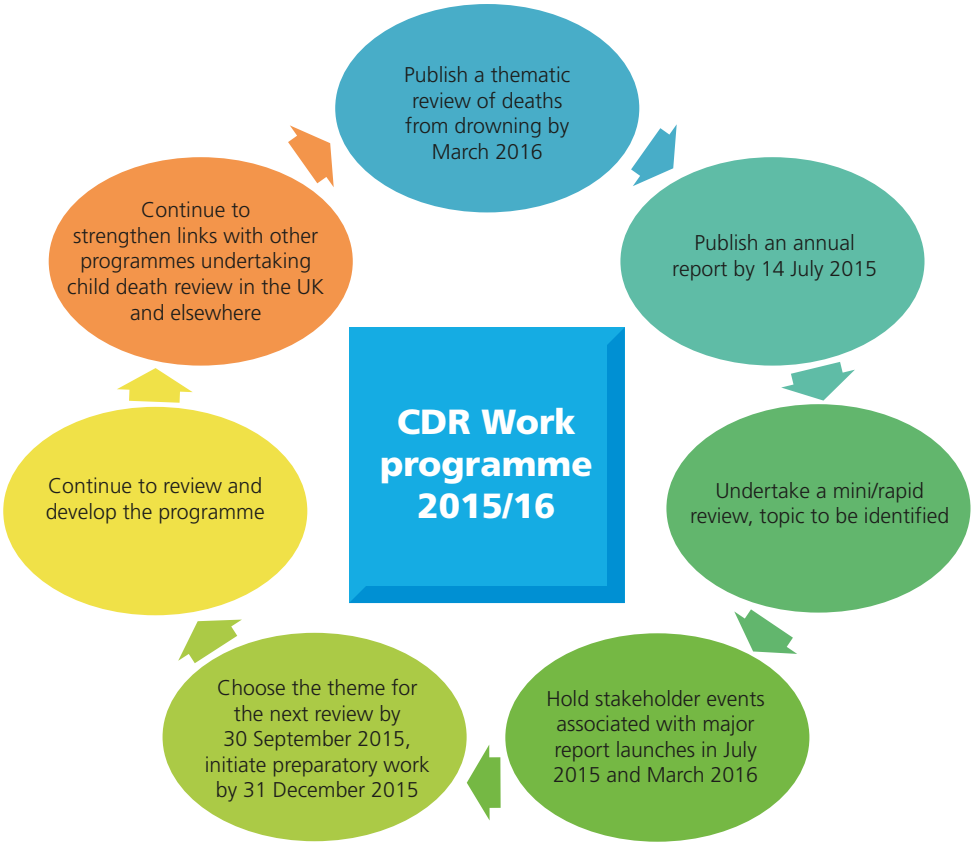
The Child Death Review team have developed the process for thematic reviews. This process will evolve with the learning from each thematic review and the document will be updated accordingly. The first version of this document is shown in Appendix E.

5 Planned work

5.1 Specific programme objectives, 2015/16

The Child Death Review team will undertake a full work programme during 2015/16 including a full thematic review on deaths through drowning. Work will also be undertaken to improve the processes used within the programme and to publish these. Further details of the work programme are shown in Figure 12.

Figure 12 Work programme for 2015/16



Source: Child Death Review programme work plan 2015/16

Thematic review: Deaths from drowning

In July 2014, the Child Death Review team began the process to develop a thematic review of deaths through drowning. This will include all deaths from drowning and where drowning was a factor among children and young people below the age of 25 years:

- Where the death occurred between 1 October 2009 and 30 September 2014 and
- Where the event that led to the death occurred in Wales and/or where the child was normally resident in Wales at the time of the death.

As per the process for thematic review, information has been requested from multiple sources within the public and third sector relating to the deaths identified, and the review is reliant upon these sources to share information to enable the panel to form conclusions and make the necessary recommendations.

The Observatory Evidence Service in Public Health Wales are currently developing an evidence review of risk factors, and will shortly begin to develop the evidence review of effectiveness of interventions in readiness for the panel meetings. The panel meetings are scheduled for October 2015, and the review will be concluded by January 2016 with a report being released in Spring 2016. A stakeholder event is planned to follow the launch and will be held in North Wales.

5.2 Future reviews

The Child Death Review team working with the steering group, will consider topics for further reviews. The Child Death Review team would be happy to receive suggestions for future reviews for consideration by the steering group.

5.3 Stakeholder events

It is intended to continue the rolling programme of events across Wales. The next events planned are 16 July 2015, at the Village Urban Resort, Cardiff, to coincide with the release of this annual report and spring 2016 in North Wales to coincide with the release of the review of deaths from drowning.

6 Opportunities for the future

- Engagement of bereaved families and children and young people; the method of engagement and the purpose need to be considered. The Child Death Review team are discussing this issue with Children in Wales who are the umbrella organization for engaging with children and young people. Further consideration will be given on how best to engage with bereaved families in the future.
- A training/workshop event for the Child Death Review process will allow us to work collaboratively with professionals who report to the programme in order to improve the quality of our data.

7 References

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10. **Wolfe, I, et al.** *Why children die: deaths in infants, children and young people in the UK Part A. RCPCH.* [Online] 2014. [Cited: 5 May 2015.] http://www.rcpch.ac.uk/sites/default/files/page/Death%20in%20infants,%20children%20and%20young%20people%20in%20the%20UK.pdf

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Appendix A

Child Death Review Steering Group 2014/15

Name	Role	Title & Organisation
Dr Judith Greenacre	Chair of Steering Group	Director of Health Intelligence, Public Health Wales
Susan Belfourd	Communications advice	Communications Officer, Public Health Wales
David Clayton	Social care policy advice	Head of Protection & Advocacy, The Welsh Government
Beverley Evans	Health board perspective	Assistant Director of Nursing, Cardiff & Vale University Health Board
Pauline Galluccio	Safeguarding children board perspective	Head of Safeguarding, Powys Teaching Health Board
Nathan Lester	Advice on use of data and information governance	Head of Observatory Analytical Team, Public Health Wales
Karen McFarlane	Voluntary / Third sector perspective	Development Officer, Children in Wales
Dr Shantini Paranjothy	Academic and research perspective	Clinical Senior Lecturer, Institute of Primary Care and Public Health, Cardiff University
Dr Heather Payne	Health policy advice	Snr. Medical Officer Maternal and Child Health, The Welsh Government
Rachel Shaw	Safeguarding Children Service: advice on safeguarding children	Designated Nurse Safeguarding Children Service, Public Health Wales
Andrew Wallsgrove	Children's Commissioner perspective	Operations Manager, Children's Commissioner for Wales
Shane Williams	Police perspective	T/Det, Dyfed Powys Police
Child Death Review in England	To be sought	
Coroners	An open invitation to remain in place	
In attendance		
Dr Ciarán Humphreys	Public Health Lead	Consultant in Public Health, Public Health Wales
Beverley Heatman	Programme manager	Child Death Review Programme Manager, Public Health Wales
Dr Lorna Price	Clinical Lead	Designated Doctor, Safeguarding Children Service, Public Health Wales

Appendix B

Reference tables 6-12

Table 6 Child deaths, count and crude rate per 100,000, children and young people aged under 18 years, United Kingdom, 2009-2013

	England			Northern Ireland			Scotland			Wales			United Kingdom		
	Annual average	**Rate** (95% CI)		**Annual average**	**Rate** (95% CI)		**Annual average**	**Rate** (95% CI)		**Annual average**	**Rate** (95% CI)		**Annual average**	**Rate** (95% CI)	
<1	2,939	433.9	(426.9 - 440.9)	118	468.5	(431.4 - 507.9)	219	370.7	(349.1 - 393.4)	144	406.2	(377.0 - 437.0)	3,419	429.1	(422.7 - 435.5)
1-4	472	17.8	(17.1 - 18.6)	17	17.4	(14.0 - 21.5)	39	16.9	(14.6 - 19.4)	22	15.2	(12.5 - 18.4)	551	17.6	(17.0 - 18.3)
5-11	358	8.5	(8.1 - 8.9)	16	9.8	(7.8 - 12.2)	33	8.7	(7.4 - 10.1)	20	8.7	(7.1 - 10.6)	428	8.6	(8.2 - 9.0)
12-17	584	15.3	(14.7 - 15.8)	35	23.9	(20.5 - 27.8)	72	19.8	(17.8 - 21.9)	39	17.4	(15.0 - 20.0)	730	16.0	(15.5 - 16.5)

Produced by Public Health Wales Observatory, using PHM & MYE (ONS), NISRA & GROS
Rates should be interpreted with caution where there are a small number of events
CI = Confidence Interval

Table 7 Deaths from all causes, count and crude rate per 100,000, children and young people aged under 18 years, Wales, police forces, safeguarding children boards and health boards, 2004-2013

	2004		2005		2006		2007		2008		2009		2010		2011		2012		2013		
	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	(95% CI)
North Wales Police, Betsi Cadwaladr UHB	59	40.8	60	41.8	62	43.4	71	49.9	54	38.1	63	44.8	63	44.9	55	39.2	55	39.2	39	27.9	(19.8 - 38.1)
Gwynedd & Isle of Anglesey LSCB	15	38.4	16	41.5	17	44.5	30	79.2	16	42.5	14	37.4	18	48.2	16	43.0	13	34.8	8	21.5	(9.3 - 42.3)
Conwy & Denbighshire LSCB	19	43.6	18	41.7	20	46.6	21	49.2	17	40.1	28	66.7	12	28.8	17	41.0	17	41.3	10	24.3	(11.7 - 44.7)
Flintshire & Wrexham LSCB	25	40.2	26	42.0	25	40.6	20	32.5	21	34.1	21	34.2	33	53.9	22	35.7	25	40.5	21	34.1	(21.1 - 52.1)
Dyfed Powys Police, CYSUR (Mid and West Wales SCB)	47	44.2	35	33.1	41	39.0	40	38.2	26	24.9	33	32.0	31	30.4	27	26.6	31	30.7	40	39.9	(28.5 - 54.3)
Hywel Dda UHB	35	44.6	29	37.2	28	36.1	25	32.3	20	25.9	27	35.3	26	34.4	22	29.1	24	31.9	29	38.8	(26.0 - 55.7)
Powys tHB	12	43.1	6	21.6	13	47.0	15	54.7	6	22.0	6	22.4	5	18.9	5	19.1	7	27.2	11	43.2	(21.6 - 77.3)
South Wales Police	107	39.8	100	37.4	99	37.2	121	45.5	101	38.0	110	41.4	106	40.1	104	39.3	90	34.0	88	33.1	(26.5 - 40.8)
Abertawe Bro Morgannwg UHB, Western Bay SCB	40	37.6	41	38.7	43	40.7	44	41.6	40	37.9	37	35.3	41	39.4	46	44.3	34	32.8	28	27.0	(17.9 - 39.0)
Cwm Taf UHB / SCB	17	25.9	30	46.0	26	40.3	34	53.2	19	29.9	34	53.8	20	31.9	25	39.9	19	30.4	20	32.0	(19.5 - 49.4)
Cardiff & Vale UHB/ SCB	50	51.6	29	30.1	30	31.3	43	44.7	42	43.3	39	40.1	45	46.1	33	33.6	37	37.5	40	40.2	(28.7 - 54.7)
Gwent Police, South East Wales SCB, Aneurin Bevan UHB	62	47.3	40	30.8	42	32.5	61	47.6	58	45.4	40	31.6	31	24.6	36	28.6	42	33.7	37	29.8	(21.0 - 41.1)
Wales	**275**	**42.2**	**235**	**36.3**	**244**	**37.9**	**293**	**45.7**	**239**	**37.3**	**246**	**38.7**	**231**	**36.5**	**222**	**35.1**	**218**	**34.6**	**204**	**32.4**	**(28.1 - 37.1)**

Produced by the Public Health Wales Observatory, using PHM & MYE (ONS)
Rates should be interpreted with caution where there are a small number of events
N = number of deaths
CI = Confidence Interval

Table 8 Deaths from all causes, count and crude rate 100,000, children and young people aged under 18 years, Wales, health boards and local authorities, 2004-2013

	2004		2005		2006		2007		2008		2009		2010		2011		2012		2013		
	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate	(95% CI)
Isle of Anglesey	4	27.3	5	34.4	6	41.7	14	99.0	7	50.3	8	58.2	9	66.1	7	51.8	6	44.1	4	29.4	(8.0 - 75.2)
Gwynedd	11	45.1	11	45.8	11	46.1	16	67.4	9	38.0	6	25.3	9	37.9	9	38.0	7	29.5	4	17.0	(4.6 - 43.4)
Conwy	11	47.7	8	35.0	13	57.1	10	44.2	11	49.1	14	63.1	5	22.7	12	54.7	7	32.0	3	13.8	(2.8 - 40.2)
Denbighshire	8	39.0	10	49.2	7	34.7	11	54.8	6	30.0	14	70.8	7	35.6	5	25.6	10	51.8	7	36.1	(14.5 - 74.5)
Flintshire	14	41.2	12	35.6	17	51.0	10	30.1	12	36.3	12	36.6	16	49.1	9	27.6	11	34.0	12	37.2	(19.2 - 65.1)
Wrexham	11	39.0	14	49.7	8	28.3	10	35.3	9	31.6	9	31.5	17	59.4	13	44.7	14	47.8	9	30.6	(14.0 - 58.2)
Powys	12	43.1	6	21.6	13	47.0	15	54.7	6	22.0	6	22.4	5	18.9	5	19.1	7	27.2	11	43.2	(21.6 - 77.3)
Ceredigion	12	87.5	5	36.9	2	14.9	2	15.0	2	15.1	2	15.2	5	38.7	7	54.8	4	31.7	4	31.9	(8.7 - 81.6)
Pembrokeshire	13	49.4	9	34.3	10	38.2	9	34.6	6	23.1	9	35.2	9	35.6	7	27.9	8	32.0	9	36.2	(16.5 - 68.7)
Carmarthenshire	10	26.0	15	39.2	16	42.2	14	36.8	12	31.5	16	42.4	12	32.0	8	21.3	12	32.0	16	42.8	(24.5 - 69.5)
Swansea	14	29.8	21	44.9	21	44.9	16	34.2	17	36.3	15	32.0	14	30.0	21	44.9	15	32.1	9	19.1	(8.8 - 36.3)
Neath Port Talbot	18	60.7	10	33.8	13	44.3	11	37.7	14	48.3	11	38.2	11	38.7	10	35.4	11	39.2	14	50.3	(27.5 - 84.4)
Bridgend	8	26.9	10	33.6	9	30.3	17	57.2	9	30.4	11	37.6	16	55.2	15	51.9	8	27.7	5	17.2	(5.6 - 40.2)
Vale of Glamorgan	19	66.4	7	24.7	8	28.4	13	46.3	13	46.3	5	18.0	9	32.6	3	11.0	9	33.2	6	22.2	(8.1 - 48.3)
Cardiff	31	45.4	22	32.4	22	32.5	30	44.0	29	42.1	34	48.8	36	51.4	30	42.3	28	39.1	34	46.9	(32.5 - 65.6)
Rhondda Cynon Taf	14	26.6	29	55.6	21	40.7	29	56.8	13	25.6	25	49.5	17	33.9	20	39.9	16	32.0	18	36.0	(21.3 - 56.9)
Merthyr Tydfil	3	22.9	1	7.7	5	38.5	5	38.7	6	46.8	9	70.6	3	23.8	5	39.8	3	24.1	2	16.0	(1.9 - 57.8)
Caerphilly	20	49.0	12	29.7	19	47.4	22	55.2	18	45.3	16	40.3	14	35.3	10	25.3	15	38.2	9	23.1	(10.6 - 43.8)
Blaenau Gwent	8	50.4	4	25.6	4	25.8	9	58.8	8	53.0	7	47.3	2	13.8	8	55.8	7	49.4	5	35.5	(11.5 - 82.9)
Torfaen	7	33.3	5	23.9	6	28.9	9	43.8	11	54.1	5	24.9	1	5.0	7	35.3	7	35.7	10	51.5	(24.7 - 94.7)
Monmouthshire	9	45.8	1	5.1	4	20.5	9	46.4	3	15.6	2	10.5	1	5.3	4	21.2	6	32.4	4	21.8	(5.9 - 55.8)
Newport	18	53.4	18	53.8	9	27.0	12	36.2	18	54.1	10	30.2	13	39.2	7	21.1	7	21.1	9	27.1	(12.4 - 51.4)
Betsi Cadwaladr UHB	59	40.8	60	41.8	62	43.4	71	49.9	54	38.1	63	44.8	63	44.9	55	39.2	55	39.2	39	27.9	(19.8 - 38.1)
Powys tHB	12	43.1	6	21.6	13	47.0	15	54.7	6	22.0	6	22.4	5	18.9	5	19.1	7	27.2	11	43.2	(21.6 - 77.3)
Hywel Dda UHB	35	44.6	29	37.2	28	36.1	25	32.3	20	25.9	27	35.3	26	34.4	22	29.1	24	31.9	29	38.8	(26.0 - 55.7)
Abertawe Bro Morgannwg UHB	40	37.6	41	38.7	43	40.7	44	41.6	40	37.9	37	35.3	41	39.4	46	44.3	34	32.8	28	27.0	(17.9 - 39.0)
Cardiff & Vale UHB	50	51.6	29	30.1	30	31.3	43	44.7	42	43.3	39	40.1	45	46.1	33	33.6	37	37.5	40	40.2	(28.7 - 54.7)
Cwm Taf UHB	17	25.9	30	46.0	26	40.3	34	53.2	19	29.9	34	53.8	20	31.9	25	39.9	19	30.4	20	32.0	(19.5 - 49.4)
Aneurin Bevan UHB	62	47.3	40	30.8	42	32.5	61	47.6	58	45.4	40	31.6	31	24.6	36	28.6	42	33.7	37	29.8	(21.0 - 41.1)
Wales	**275**	**42.2**	**235**	**36.3**	**244**	**37.9**	**293**	**45.7**	**239**	**37.3**	**246**	**38.7**	**231**	**36.5**	**222**	**35.1**	**218**	**34.6**	**204**	**32.4**	**(28.1 - 37.1)**

Produced by the Public Health Wales Observatory, using PHM & MYE (ONS) Rates should be interpreted with caution where there are a small number of events
N = number of deaths CI = Confidence Interval

Table 9 Deaths from all causes, annual average number and crude rate per 100,000, children and young people aged under 18 years, Wales, police forces, safeguarding children boards and health boards, 2004-2013

	<1 year			1-4 years			5-11 years			12-17 years		
	Annual average	Rate (95% CI)		Annual average	Rate (95% CI)		Annual average	Rate (95% CI)		Annual average	Rate (95% CI)	
North Wales Police, Betsi Cadwaladr UHB	34.8	457.1	(410.3 - 507.7)	7.2	23.9	(18.7 - 30.0)	5.9	11.1	(8.4 - 14.3)	10.2	20.2	(16.4 - 24.5)
Gwynedd & Isle of Anglesey LSCB	8.5	415.9	(332.2 - 514.3)	2.4	29.6	(18.9 - 44.0)	1.7	11.8	(6.9 - 18.9)	3.7	27.9	(19.7 - 38.5)
Conwy & Denbighshire LSCB	10.5	485.9	(397.4 - 588.3)	2.1	24.5	(15.2 - 37.5)	1.4	8.9	(4.9 - 15.0)	3.9	24.7	(17.5 - 33.7)
Flintshire & Wrexham LSCB	15.8	463.5	(394.0 - 541.8)	2.7	20.0	(13.2 - 29.1)	2.8	12.1	(8.0 - 17.5)	2.6	12.1	(7.9 - 17.7)
Dyfed Powys Police, CYSUR (Mid and West Wales SCB)	20.0	392.9	(340.3 - 451.3)	2.4	11.5	(7.4 - 17.2)	3.1	7.9	(5.4 - 11.2)	9.6	25.0	(20.2 - 30.5)
Hywel Dda UHB	15.0	391.0	(330.9 - 458.9)	1.6	10.2	(5.9 - 16.6)	2.3	7.9	(5.0 - 11.9)	7.6	26.9	(21.2 - 33.7)
Powys tHB	5.0	398.6	(295.8 - 525.5)	0.8	15.4	(6.7 - 30.4)	0.8	7.9	(3.4 - 15.5)	2.0	19.5	(11.9 - 30.2)
South Wales Police	65.3	435.4	(402.6 - 470.1)	9.4	16.3	(13.1 - 19.9)	9.6	9.6	(7.8 - 11.7)	18.3	19.6	(16.9 - 22.7)
Abertawe Bro Morgannwg UHB, Western Bay SCB	22.9	402.3	(351.9 - 458.0)	4.1	18.4	(13.2 - 24.9)	3.8	9.6	(6.8 - 13.2)	8.6	23.0	(18.4 - 28.5)
Cwm Taf UHB / SCB	15.8	443.4	(376.9 - 518.2)	1.6	11.6	(6.6 - 18.8)	2.5	10.5	(6.8 - 15.5)	4.5	20.0	(14.6 - 26.8)
Cardiff & Vale UHB / SCB	26.6	463.2	(409.2 - 522.4)	3.7	17.1	(12.0 - 23.5)	3.3	9.1	(6.2 - 12.7)	5.2	15.5	(11.6 - 20.3)
Gwent Police, South East Wales SCB, Aneurin Bevan UHB	28.7	428.1	(380.0 - 480.7)	4.2	15.8	(11.4 - 21.3)	3.7	7.7	(5.5 - 10.7)	8.3	18.0	(14.3 - 22.3)
Wales	**148.8**	**432.5**	**(410.8 - 455.0)**	**23.2**	**17.1**	**(15.0 - 19.5)**	**22.3**	**9.3**	**(8.1 - 10.6)**	**46.4**	**20.3**	**(18.5 - 22.2)**

Produced by the Public Health Wales Observatory, using PHM & MYE (ONS)
Rates should be interpreted with caution where there are a small number of events
CI = Confidence Interval

Table 10 Deaths from all causes, annual average count and crude rate per 100,000, children and young people aged under 18 years, Wales, health boards and local authorities, 2004-2013

	<1 year			1-4 years			5-11 years			12-17 years		
	Annual average	Rate (95% CI)		Annual average	Rate (95% CI)		Annual average	Rate (95% CI)		Annual average	Rate (95% CI)	
Isle of Anglesey	3.7	487.9	(343.5 - 672.5)	0.9	30.6	(14.0 - 58.1)	0.5	9.6	(3.1 - 22.5)	1.9	37.4	(22.5 - 58.4)
Gwynedd	4.8	373.4	(275.3 - 495.1)	1.5	29.0	(16.2 - 47.8)	1.2	13.1	(6.7 - 22.8)	1.8	22.0	(13.1 - 34.8)
Conwy	5.4	478.1	(359.2 - 623.9)	0.9	20.1	(9.2 - 38.2)	0.7	8.4	(3.4 - 17.4)	2.4	28.4	(18.2 - 42.2)
Denbighshire	5.1	494.4	(368.1 - 650.0)	1.2	29.4	(15.2 - 51.3)	0.7	9.4	(3.8 - 19.5)	1.5	20.4	(11.4 - 33.7)
Flintshire	8.1	466.0	(370.1 - 579.2)	1.8	25.7	(15.2 - 40.7)	1.4	11.3	(6.2 - 18.9)	1.2	10.1	(5.2 - 17.7)
Wrexham	7.7	460.9	(363.7 - 576.1)	0.9	13.8	(6.3 - 26.3)	1.4	13.0	(7.1 - 21.8)	1.4	14.4	(7.9 - 24.2)
Powys	5.0	398.6	(295.8 - 525.5)	0.8	15.4	(6.7 - 30.4)	0.8	7.9	(3.4 - 15.5)	2.0	19.5	(11.9 - 30.2)
Ceredigion	2.2	341.8	(214.2 - 517.5)	0.2	7.6	(0.9 - 27.6)	0.5	10.0	(3.3 - 23.4)	1.6	32.8	(18.8 - 53.3)
Pembrokeshire	5.4	425.5	(319.6 - 555.2)	0.5	9.7	(3.1 - 22.6)	0.5	5.2	(1.7 - 12.0)	2.5	26.2	(17.0 - 38.7)
Carmarthenshire	7.4	384.6	(302.0 - 482.9)	0.9	11.5	(5.2 - 21.8)	1.3	9.1	(4.8 - 15.5)	3.5	25.4	(17.7 - 35.3)
Swansea	9.8	377.0	(306.1 - 459.5)	2.1	20.7	(12.8 - 31.7)	1.7	9.5	(5.6 - 15.3)	2.7	16.6	(10.9 - 24.1)
Neath Port Talbot	7.2	472.3	(369.6 - 594.8)	1.2	20.0	(10.3 - 34.9)	1.4	13.0	(7.1 - 21.8)	2.5	23.8	(15.4 - 35.1)
Bridgend	5.9	376.1	(286.3 - 485.2)	0.8	13.0	(5.6 - 25.5)	0.7	6.3	(2.5 - 13.0)	3.4	32.3	(22.3 - 45.1)
Vale of Glamorgan	5.8	417.3	(316.8 - 539.4)	0.7	12.4	(5.0 - 25.5)	0.8	7.6	(3.3 - 15.0)	1.9	18.5	(11.2 - 29.0)
Cardiff	20.8	477.9	(415.2 - 547.5)	3.0	18.7	(12.6 - 26.7)	2.5	9.7	(6.3 - 14.3)	3.3	14.2	(9.7 - 19.8)
Rhondda Cynon Taf	12.8	448.3	(374.0 - 533.1)	1.2	10.8	(5.6 - 18.9)	2.4	12.6	(8.1 - 18.7)	3.8	21.3	(15.1 - 29.2)
Merthyr Tydfil	3.0	423.6	(285.8 - 604.7)	0.4	14.7	(4.0 - 37.6)	0.1	2.1	(0.1 - 11.9)	0.7	15.1	(6.1 - 31.0)
Caerphilly	9.0	421.4	(338.8 - 517.9)	2.3	26.8	(17.0 - 40.3)	1.4	9.3	(5.1 - 15.6)	2.8	19.9	(13.2 - 28.8)
Blaenau Gwent	4.0	509.8	(364.2 - 694.2)	0.4	13.2	(3.6 - 33.7)	0.6	11.0	(4.0 - 24.0)	1.2	21.2	(11.0 - 37.0)
Torfaen	4.9	461.9	(341.7 - 610.6)	0.3	7.2	(1.5 - 21.0)	0.5	6.7	(2.2 - 15.5)	1.1	14.7	(7.3 - 26.2)
Monmouthshire	3.1	355.6	(241.6 - 504.7)	0.0	0.0	(0.0 - 10.0)	0.2	2.8	(0.3 - 10.0)	1.0	13.6	(6.5 - 25.0)
Newport	7.7	416.1	(328.4 - 520.1)	1.2	16.7	(8.6 - 29.2)	1.0	7.9	(3.8 - 14.6)	2.2	18.9	(11.8 - 28.6)
Betsi Cadwaladr UHB	34.8	457.1	(410.3 - 507.7)	7.2	23.9	(18.7 - 30.0)	5.9	11.1	(8.4 - 14.3)	10.2	20.2	(16.4 - 24.5)
Powys tHB	5.0	398.6	(295.8 - 525.5)	0.8	15.4	(6.7 - 30.4)	0.8	7.9	(3.4 - 15.5)	2.0	19.5	(11.9 - 30.2)
Hywel Dda UHB	15.0	391.0	(330.9 - 458.9)	1.6	10.2	(5.9 - 16.6)	2.3	7.9	(5.0 - 11.9)	7.6	26.9	(21.2 - 33.7)
Abertawe Bro Morgannwg UHB	22.9	402.3	(351.9 - 458.0)	4.1	18.4	(13.2 - 24.9)	3.8	9.6	(6.8 - 13.2)	8.6	23.0	(18.4 - 28.5)
Cardiff & Vale UHB	26.6	463.2	(409.2 - 522.4)	3.7	17.1	(12.0 - 23.5)	3.3	9.1	(6.2 - 12.7)	5.2	15.5	(11.6 - 20.3)
Cwm Taf UHB	15.8	443.4	(376.9 - 518.2)	1.6	11.6	(6.6 - 18.8)	2.5	10.5	(6.8 - 15.5)	4.5	20.0	(14.6 - 26.8)
Aneurin Bevan UHB	28.7	428.1	(380.0 - 480.7)	4.2	15.8	(11.4 - 21.3)	3.7	7.7	(5.5 - 10.7)	8.3	18.0	(14.3 - 22.3)
Wales	**148.8**	**432.5**	**(410.8 - 455.0)**	**23.2**	**17.1**	**(15.0 - 19.5)**	**22.3**	**9.3**	**(8.1 - 10.6)**	**46.4**	**20.3**	**(18.5 - 22.2)**

Produced by the Public Health Wales Observatory, using PHM & MYE (ONS) Rates should be interpreted with caution where there are a small number of events
CI = Confidence Interval

Table 11 Deaths by cause (ICD-10), count and crude rates per 100,000, children and young people aged 1-17 years, Wales, police forces, safeguarding children boards and health boards, 2004-2013

	Congenital anomaly (Q00-Q99)			External (V01-Y98, U509)*			Ill-defined and unknown causes (R95-R99)			Neoplasms (C00-D48)			Other (all other codes)			Total		
	Count	Rate (95% CI)		Count	Rate (95% CI)		Count	Rate (95% CI)		Count	Rate (95% CI)		Count	Rate (95% CI)		Count	Rate (95% CI)	
North Wales Police, Betsi Cadwaladr UHB	13	1.0	(0.5 - 1.7)	97	7.2	(5.9 - 8.8)	2	0.1	(0.0 - 0.5)	35	2.6	(1.8 - 3.6)	86	6.4	(5.1 - 7.9)	233	17.4	(15.2 - 19.8)
Gwynedd & Isle of Anglesey LSCB	3	0.8	(0.2 - 2.5)	36	10.1	(7.1 - 13.9)	0	0.0	(0.0 - 1.0)	9	2.5	(1.2 - 4.8)	30	8.4	(5.7 - 12.0)	78	21.8	(17.2 - 27.2)
Conwy & Denbighshire LSCB	7	1.7	(0.7 - 3.6)	34	8.5	(5.9 - 11.9)	0	0.0	(0.0 - 0.9)	12	3.0	(1.5 - 5.2)	21	5.2	(3.2 - 8.0)	74	18.5	(14.5 - 23.2)
Flintshire & Wrexham LSCB	3	0.5	(0.1 - 1.5)	27	4.6	(3.1 - 6.7)	2	0.3	(0.0 - 1.2)	14	2.4	(1.3 - 4.0)	35	6.0	(4.2 - 8.4)	81	13.9	(11.0 - 17.3)
Dyfed Powys Police, CYSUR (Mid and West Wales SCB)	13	1.3	(0.7 - 2.3)	56	5.7	(4.3 - 7.4)	11	1.1	(0.6 - 2.0)	19	1.9	(1.2 - 3.0)	52	5.3	(3.9 - 6.9)	151	15.3	(13.0 - 18.0)
Hywel Dda UHB	7	1.0	(0.4 - 2.0)	43	5.9	(4.3 - 8.0)	11	1.5	(0.8 - 2.7)	11	1.5	(0.8 - 2.7)	43	5.9	(4.3 - 8.0)	115	15.8	(13.0 - 19.0)
Powys tHB	6	2.3	(0.9 - 5.1)	13	5.1	(2.7 - 8.7)	0	0.0	(0.0 - 1.4)	8	3.1	(1.3 - 6.2)	9	3.5	(1.6 - 6.7)	36	14.1	(9.8 - 19.5)
South Wales Police	24	1.0	(0.6 - 1.4)	126	5.0	(4.2 - 6.0)	25	1.0	(0.6 - 1.5)	56	2.2	(1.7 - 2.9)	142	5.7	(4.8 - 6.7)	373	14.9	(13.4 - 16.4)
Abertawe Bro Morgannwg UHB, Western Bay SCB	10	1.0	(0.5 - 1.9)	64	6.4	(5.0 - 8.2)	8	0.8	(0.3 - 1.6)	28	2.8	(1.9 - 4.1)	55	5.5	(4.2 - 7.2)	165	16.6	(14.2 - 19.4)
Cwm Taf UHB / SCB	5	0.8	(0.3 - 1.9)	28	4.7	(3.1 - 6.7)	7	1.2	(0.5 - 2.4)	11	1.8	(0.9 - 3.3)	35	5.8	(4.1 - 8.1)	86	14.3	(11.4 - 17.7)
Cardiff & Vale UHB / SCB	9	1.0	(0.4 - 1.9)	34	3.7	(2.6 - 5.2)	10	1.1	(0.5 - 2.0)	17	1.9	(1.1 - 3.0)	52	5.7	(4.2 - 7.4)	122	13.3	(11.1 - 15.9)
Gwent Police, South East Wales SCB, Aneurin Bevan UHB	16	1.3	(0.8 - 2.2)	48	4.0	(2.9 - 5.3)	7	0.6	(0.2 - 1.2)	22	1.8	(1.1 - 2.8)	69	5.7	(4.4 - 7.2)	162	13.4	(11.4 - 15.7)
Wales	**66**	**1.1**	**(0.8 - 1.4)**	**327**	**5.4**	**(4.8 - 6.0)**	**45**	**0.7**	**(0.5 - 1.0)**	**132**	**2.2**	**(1.8 - 2.6)**	**349**	**5.8**	**(5.2 - 6.4)**	**919**	**15.2**	**(14.2 - 16.2)**

Produced by the Public Health Wales Observatory, using PHM & MYE (ONS)
Rates should be interpreted with caution where there are a small number of events.
* Additional code U509 from 2007 onwards
CI = Confidence Interval

Table 12 Deaths by external cause, count, children and young people aged 1-17 years, Wales, police forces, safeguarding children boards and health boards, 2004-2013

	Accidental			Intentional Self Harm		Assault (X85-Y09, Y339, U509)*	Undetermined Intent		Other External Causes (Y35-Y36 & Y40-Y84)	Total External Causes (V01-Y98, U509)†
	Transport accidents (V01-V99)	Hanging & Strangulation (W75-W76)	Other (W00-X59 excl. W75-W76)	Hanging & Strangulation (X70) Other (X60-X84 excl. X70)	Other (X60-X84 excl. X70)		Hanging & Strangulation (Y20)	Other (Y10-Y34 excl. Y20)**		
North Wales Police, Betsi Cadwaladr UHB	40	4	22	8	3	17	1	1	1	97
Gwynedd & Isle of Anglesey LSCB	16	3	9	2	1	4	0	0	1	36
Conwy & Denbighshire LSCB	14	1	5	4	1	8	0	1	0	34
Flintshire & Wrexham LSCB	10	0	8	2	1	5	1	0	0	27
Dyfed Powys Police, CYSUR (Mid and West Wales SCB)	32	1	8	5	1	7	1	1	0	56
Hywel Dda UHB	23	1	7	5	1	4	1	1	0	43
Powys tHB	9	0	1	0	0	3	0	0	0	13
South Wales Police	43	11	25	8	6	20	9	2	2	126
Abertawe Bro Morgannwg UHB, Western Bay SCB	21	8	14	6	2	8	3	1	1	64
Cwm Taf UHB / SCB	12	2	5	0	2	3	3	0	1	28
Cardiff & Vale UHB / SCB	10	1	6	2	2	9	3	1	0	34
Gwent Police, South East Wales SCB, Aneurin Bevan UHB	16	5	5	6	0	15	0	0	1	48
Wales	**131**	**21**	**60**	**27**	**10**	**59**	**11**	**4**	**4**	**327**

Produced by the Public Health Wales Observatory, using PHM (ONS)
* ICD-10 code Y339 before 2007, U509 from 2007 onwards
** Excludes ICD-10 code Y339 before 2007
† Additional code U509 from 2007 onwards

Appendix C

Feedback from Stakeholder events

16 September 2014 — Catrin Finch Centre, Mold

CHILD DEATH REVIEW STAKEHOLDER EVENT EVALUATION September 2014

A stakeholder seminar event was held in North Wales to follow the launch of the Annual report 2014, and the rapid review of deaths through dog bites/strikes.

The Children's Commissioner for Wales highlighted in the foreword the correlation between child death and poverty; and raised concerns about the levels of child poverty in Wales which have now increased to 1:3 children in Wales.

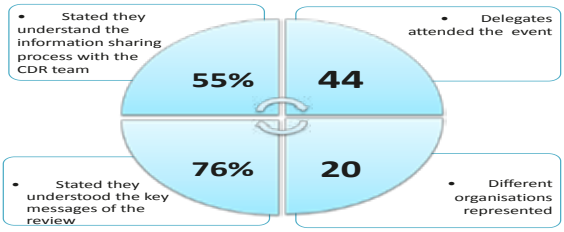
Figures from the Annual report reveal that 218 deaths were recorded in Wales during 2013, and most of these deaths occur during infancy (first year of life). A major issue is the link between poverty and risk of child death, and the report identifies that the risk of child death in those living in the most deprived fifth of Wales is 70% higher than those living in the least deprived fifth.

On a positive note, there has been a decline in child deaths over the last 15 years, mostly relating to a reduction in deaths of infants, however 13% of these deaths remained unexplained after full investigation. The CDR programme is currently working on a thematic review of sudden unexpected deaths in infancy which will be published in 2015.

The delegates also learned about the recent rapid review of deaths through dog bites/strikes. The key message from this review was:

- **NEVER** leave a baby or young child unsupervised with a dog, even for a moment, no matter how well you know that dog.

Stakeholder Event, North Wales September, 2014



Comments from Event

The event was well attended with representation from within the public and third sectors including education, fire and rescue, health, police and social care.

Comments received from delegates included:

- Health Visitors are not routinely involved in child deaths
- Wrexham is not an ideal central location for North Wales
- More involvement from Emergency Services
- The role of social media/ technology and mobile phones should be explored
- Comparative trends from young adults up to 25 years would be good
- Engage and involve school nurses, and head teachers
- Identification of child deaths in flying start areas would be interesting
- Message of event not being disseminated fully
- Line managers need to attend events
- Email alert that reports are published to one person in HB for dissemination
- Identify a link officer for each organisation
- More advertising to spread the word
- Good networking opportunity
- Information regarding work being completed—factual and explained well
- Would like to know more about selection of reviews
- Focus groups for work group session
- Bilingual support

CHILD DEATH REVIEW PROGRAMME

Highlights

Following the launch of the report, Dr Ciaran Humphreys provided a number of media interviews which were broadcast throughout the day.

SOME KEY MESSAGES

- **NEVER leave a baby or young child unsupervised with a dog, even for a moment, no matter how well you know that dog**
- **DOG owners to be aware of the risks to children, and to share advice with others who may be caring for the dog when the owner is not present**
- **FURTHER research into dog bites/strikes**
- **DEATH rates in 0-4 years age group are ranked amongst the highest in Western Europe**
- **CHILD death rates are declining less rapidly in the UK than in other wealthy countries**

22 January 2015

Stakeholder Event, Parc y Scarlets, Llanelli

CHILD DEATH REVIEW STAKEHOLDER EVENT EVALUATION JANUARY 2015

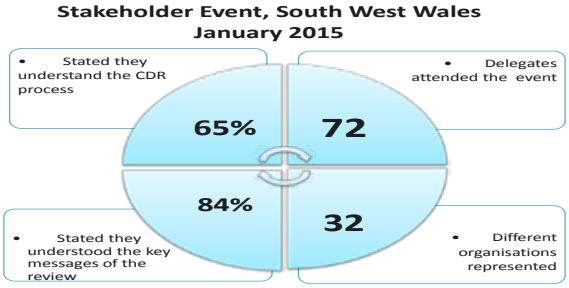
A stakeholder event was held at Parc y Scarlets, Llanelli in January 2015. following the launch of the Thematic Review of Sudden Unexpected Deaths in Infants. This was the first collaborative piece of work completed between the Child Death Review programme and the All Wales Perinatal Survey . The review was led by Dr Paul Davis, Consultant Paediatrician of Cardiff & Vale University Health Board who has a keen interest in sudden unexpected infant death.

The report which was released two days prior to the event received high media coverage with both radio and television interviews being recorded.

Eighteen recommendations were made by the thematic panel members to prevent deaths in the future including: nine related to:

- Co-sleeping
- Universal provision of advice to all families with new babies
- Effective delivery of existing health promotion messages
- Strengthening of efforts to reduce smoking
- Regular training for front line professionals on prevention of uSID
- Review of policies and provision of social housing
- Encourage research into uSID reduction
- Unimpeded sharing of information with the CDR programme
- Continual monitoring of unexpected deaths in infants

Thirty two key messages were also reported highlighting the risk factors that had been identified within the review of the



Comments from Event

56 Evaluation questionnaires were returned; 25% were incomplete for the afternoon session. Delegates were asked for comments regarding the event; and the learning. This enables the CDR team to try and provide the environment to encourage the learning and to develop the programme further. Comments received from the most recent event included:

- Useful to share best practice with a range of professionals
- Identifying risk factors for Sudden unexpected death
- Asking parents about lifestyle choices
- Increased effect when >1 risk factor present
- Identifying opportunities to share information with parents about safe sleeping
- Importance of preparation for pregnancy
- Information on dog bites/ strikes very useful
- Would fully recommend this to other practitioners and will disseminate findings within my own remit
- We will do some educational boards for use in the Emergency Departments and will deliver some training for nursing staff
- Would like presentations to be made available
- More education needed for families

CHILD DEATH REVIEW PROGRAMME

Highlights

Following the launch of the report, Dr Paul Davis provided a number of television and radio interviews which were broadcast throughout the day.

SOME KEY RECOMMENDATIONS

- **PARENTAL advice , co-sleeping with other risk factors increases risk of uSID**
- **STRENGTHEN efforts to reduce smoking iny9oung women**
- **TRAINING for front line professionals**
- **REVIEW of policies and provision of social housing**
- **RESEARCH into concrete measures to reduce population rates of uSID**
- **UNIMPEDED information sharing with CDR programme**
- **CONTINUED monitoring of trends in unexpected infant death rates**

Suggestions from delegates for future:

- Head injury deaths
- Provide some feedback to agencies about expectations of recommendations
- Would like to have list of attendees in future
- Very keen to work with the programme
- Roll out to practitioners

Appendix D

Progress with recommendations from the thematic review of deaths of children and young people through probable suicide, 2006-2012, summary of agency responses

Each organisation identified within the recommendations was contacted in March 2015 and invited to share their progress against the recommendations of the review of deaths of children and young people through probable suicide, 2006-2012[14]. The table below details the responses received.

Recommendations for Welsh Government	
7.1.1 Welsh Government should pursue mechanisms to restrict the access of children and young people to alcohol. This includes a minimum price per unit, regulation of marketing and availability and action on under-age sales. This may be through working within existing powers, seeking further or additional powers, or lobbying the UK government for changes. **7.1.2** Welsh Government should explore mechanisms to ensure children and young people between the ages of 16 and 18 years are supported in education or training, which includes work based training. This could be enabled by raising the school leaving age to 18 years. **7.1.3** Welsh Government should develop mechanisms for an all-Wales child protection register to which all local authorities contribute which is accessible by relevant services as needed, and emergency departments in particular. **7.1.4** Welsh Government should explore and support mechanisms to co-ordinate this all-Wales child protection register with child protection plans of other nations. **7.1.5** Welsh Government should issue explicit guidance to ensure that across Wales, repeat attendances of children and young people at emergency departments following episodes of self harm, mental health concerns or with alcohol or drug misuse, result in a referral and assessment by children's social care with lower thresholds for holding strategy meetings and earlier multiagency planning. **7.1.6** Welsh Government should support and develop mechanisms to ensure that NICE guidance on the short and longer term management of self harm in children and young people is implemented in Wales particularly with regard to admission, psychosocial assessment, evidence based interventions and staff training. Consideration should be given to including healthcare improvement approaches and to formally requesting health boards give assurances that the guidance is fully implemented. **7.1.7** Welsh Government should support greater awareness of the risk factors for probable suicide amongst the public to tackle stigma and enable personal responses to children and young people in distress. This could include suicide awareness training, mental health literacy, an awareness raising campaign and a national suicide and self harm prevention website. **7.1.8** Welsh Government should support the training of key gatekeepers in suicide awareness, mental health literacy and sign posting to suitable services. Any such training programmes should be evaluated appropriately. **7.1.9** Welsh Government should continue to support new research in the epidemiology and prevention of suicide and self harm in children and young people. **7.5.15** Welsh Government should develop explicit statutory mechanisms to support information sharing for the Child Death Review programme **7.5.17** Welsh Government and the Child Death Review programme should ensure deaths of children and young people through probable suicide remain a regular focus for child death thematic review on a 3 yearly basis, including examination of specific types of death and collaboration with National Confidential Inquiry into Suicide and Homicide and Suicide Information Database-Cymru. Such forward planning will allow for the timely collection and collation of information relating to children and young people included in the review. A future review of possible suicides i.e. accidental hangings and poisonings **7.5.18** Welsh Government should sponsor mechanisms to review deaths through suicide in all those under the age of 25 years (known and unknown to mental health services) to identify opportunities for prevention. Commissioning the Child Death Review programme to do this work may be an appropriate mechanism.	
Welsh Government	• Welsh Government have assured us that the recommendations will be considered by officials and fed in to the policy making process. The thematic review has informed the Welsh Government's consultation document of its latest strategy on suicide and self harm prevention, Talk to Me 2.

Recommendations for Police

7.2.10 Police forces in Wales should ensure that licensed fire arms are stored at home in a safe and secure manner, paying particular attention to the potential for children or young people acting impulsively to easily access them.

Police

- The Home Office published in October 2014 a Guide on Firearms Licensing Law, which is available on the following link https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/363016/Guidance_on_Firearms_Licensing_Law_v10_-_Oct_2014.pdf
- Chapter 19 deals with the Security of Firearms and Ammunition Paragraph 19.17 refers to security and limited access to weapons, especially where children are present
- Effective and appropriate governance is a critical element of firearms licensing
- The Authorised Professional Practice states "A chief officer is ultimately responsible and accountable to the public for decisions made concerning firearms licensing. They must audit and justify decisions concerning refusals, revocations and grants. They must also ensure that the highest level of scrutiny and investigation is applied should any risks to public safety and/or any breaches of the Firearms Act 1968 be identified, especially those that are avoidable or foreseeable." (This would include security matters)
- HMIC are currently conducting an inspection process with forces and are currently in with Dyfed-Powys.

Other comments

Police

- The action based on national guidance which is quite clear has been updated since the review, and all forces work to the same set of guidance.

Recommendations for healthcare commissioners and providers, including clinicians

7.3.11 Healthcare Commissioners and providers should ensure that evidence based cognitive behavioural therapy services are available for all children who have suffered sexual abuse, including the non-offending parent. They should also ensure pathways are in place to encourage access to these services.

Responses	
Hywel Dda UHB	• HDUHB provide evidence based cognitive behavioural and psychotherapy services for those children and young people who have suffered sexual abuse • These therapeutic resources are limited and therefore they are targeted at those children and young people in most distress, presenting with an associated mental disorder • There is however a need to further enhance the availability of therapeutic interventions across all agencies and stakeholders providing assessment and intervention services to these and other vulnerable groups of children and young people • HDUHB developed Therapeutic Day Service (TDS) provision across the Health Board footprint for those 18 and older. This service is available via Primary and Secondary Care pathways • Further clarification is required because CBT interventions and / or post abuse interventions can be delivered within Non-Health settings and therefore it is not only just a healthcare issue.
Velindre NHS Trust	• Velindre Trust is a specialist non surgical treatment and diagnosis centre for adults across south east wales and operates in a different way to the local Health Boards and other NHS Trusts across Wales. Consequently it is difficult to apply the recommendations directly to our work • Our clinicians may come into contact with children and young people in the paediatric haematology and oncology service, or the Teenager Cancer trust. Both of these services have access to dedicated psychology services and established links with child and adolescent mental health services. In addition young people who are under the care of the Teenage Cancer Centre may on occasion, and for short periods of time only, be cared for in Velindre Cancer Centre. For young people aged 18 and over the Velindre NHS Trust clinical guidelines for assessing and managing suicide risk are applied.
Cwm Taf UHB	• Children and young people who have suffered sexual abuse and their families are referred to New Pathways, a service specifically providing specialist counselling for those affected by rape or sexual abuse • Children and young people with mental health needs identified as a result of sexual abuse are supported by CAMHS.
Cardiff & Vale UHB	• The CAMHS network who would provide this service is managed by Cwm Taf UHB.
Public Health Wales – Safeguarding	• Public Health Wales does not provide or commission any therapeutic services to children or families.

Other comments	
Hywel Dda UHB	• Appropriateness of this recommendation needs further consideration as the responsibility cannot solely be on mental health services. There are a variety of agencies delivering post abuse interventions that are not healthcare commissioned and/or provided • Responsibility for LA, HB and third sector to work collaboratively to develop services • Consider the third sector provision of services such as Seren and SARC.
Cardiff & Vale UHB	• Cardiff & Vale SARC also offers counselling to any child / young person or non-offending parent/carer; the waiting list is approximately one month • This recommendation is specific to prescriptive CBT therapy, however, since each child needs to be treated individually, use of a specific therapy does not always allow for this difference • Interventions need to be as varied as children themselves so play therapy, sand therapy, art, and music therapy should not be dismissed.
Public Health Wales - Safeguarding	• Information on suicide in young people has been included in Level 2 safeguarding training for staff.

7.3.12 Clinicians caring for children or young people at risk of suicide should consider the capacity of adults within the household to safely store potentially toxic medication or drugs and liaise with other services as required. Relevant bodies, such as The Royal College of Psychiatrists and the medicines management programme, should consider developing guidance of this issue.

Responses	
Hywel Dda UHB	• Consideration will be given to further enhance training programmes and clinicians guidance with regards to this point. This will need to be done in accordance with any national issued guidance and / or guidance from the Royal College of Psychiatrists.
Cwm Taf UHB	• Parents / carers of children and young people at risk are routinely advised about the need to safely store all forms of medication. • Work has been undertaken in the Cwm Taf area around the safe storage of controlled substances • Work has also been undertaken with CAMH, AMH and Primary Care Services to consider the types and amounts of medication prescribed to households (including potentially toxic medication), particularly where there are individuals with a history of depression and / or suicide / self harm.

Cardiff & Vale UHB	• The substance misuse service uses wooden, lockable storage boxes (primarily for Methadone/Subutex storage) for clients with children or who may have regular contact with children at their address. This is for accidental ingestion and not necessarily for suicidal ideation however it serves the same purpose • In response to the Adfam report published in April 2014, Medications in drug treatment: tackling the risks to children, a Task & Finish Group was set up within Cardiff & Vale UHB to address issues identified. This included drawing up a safety plan with each service user whereby they sign and agree to safe storage of potentially toxic medication and they acknowledge that they have fully understood all of the dangers. This plan is then shared with other professionals involved i.e. the Health visitor, Midwife, MH staff and GP, and reviewed if there are any changes identified within the family e.g. additional children moving into the family home. This again is for addressing accidental ingestion; however, it does re-iterate to carers of children the necessity of safe storage of toxic medication.
Public Health Wales - Safeguarding	• Public Health Wales does not provide or commission any therapeutic services to children or families.
Other comments	
Hywel Dda UHB	• HDUHB acknowledge this important issue • Risk assessment undertaken on all children and young people who self harm include consideration of parenting capacity and risk under safeguarding • Further work is progressing on the development of a leaflet to support the clinicians and carers to further enhance the clinical discussions and guidance to parents / carers in these situations.
Public Health Wales - Safeguarding	• Information on suicide in young people has been included in Level 2 safeguarding training for staff.

N.B. Following the launch of the report, we were advised that medicines management programmes are no longer in existence.

Recommendations for partnerships and agencies

7.4.13 Communication between professionals for the prevention of suicide should be strengthened, in particular:

- Suicide prevention partnerships should ensure representation is truly cross governmental and cross sectoral, including health, local government and the third sector
- Services should work together to consider mechanisms for improving communication about children and young people at risk of suicide; in particular, they should consider lowering the threshold for multi-agency meetings for such individuals.

Responses	
Aneurin Bevan UHB Local Public Health Team	• A Gwent suicide and self harm prevention group has been established. This is chaired by Dr Sarah Aitken (Public Health Wales) and reports to the Gwent Mental Health and Learning Disabilities Partnership Board. Health, local government and the third sector are represented. • CAMHS is currently exploring how it improves the availability of consultation, liaison and joint training to children social services and education services in the five local authorities across Gwent to ensure children and young people with the highest need and risk get timely access to correct services whilst maximising the capabilities and competencies of community generic services. We would hope that the specific structures around this are in place by Autumn 2015 • Recommendations from the review are incorporated into the Gwent suicide and self harm prevention action plan (draft).
Cwm Taf UHB	• The multi-agency Reduction of Suicide and Self Harm by Children and Young People Steering Group was established in the Cwm Taf area in 2007 and includes representation from the health board, local authority (including education, social services and youth offending services), police, probation and third sector. Task and Finish groups established as sub-groups to undertake specific work-streams as directed by the steering group are also multi-disciplinary • Extensive work is being progressed locally to consider children and young people at risk and how services can work together to improve outcomes. This is being undertaken in conjunction with the multi-agency risky behaviour strategy group in Cwm Taf to ensure the inclusion of the most vulnerable, high risk children and young people.

Other comments

7.4.14 Agencies delivering interventions and programmes which may prevent suicide or promote mental health and wellbeing should ensure that these are in line with the current evidence base for effectiveness and are evaluated. Where that evidence base is not yet available or the programme is developed locally, an evaluative framework should be developed from the onset to identify what works. Those that are not effective should be stopped and resources deployed to more effective interventions. Particular consideration in respect to this recommendation should be given to programmes in school based settings including those delivered to address and prevent bullying.

Responses	
Aneurin Bevan UHB Local Public Health Team	• Two workshops have been held to which group members and key stakeholders were invited. The purpose of these was to identify areas of good practice in Gwent, to highlight gaps in service provision and to develop an interim suicide and self harm prevention plan (2015/16, prior to guidance for local plans being issued by Welsh Government). Evidence based actions included in the plan are those detailed in Talk To Me 2 (consultation document). The plan covers all age groups including children and young people. It is anticipated that the plan will be approved by the MH&LD Partnership Board this month.
Hywel Dda UHB	• SPAT (Suicide Prevention Assessment Team) in Pembrokeshire. Provision now available throughout the HB • Information is relayed to other local authorities on good practice developed in other areas. Training is available to progress this • HDUHB have developed a DVD on bullying and self-harm. The DVD developed by the S-CAMHS service has been purchased in Pembrokeshire for every school and will form a regular part of the PSE Curriculum. Carmarthenshire has purchased some copies for all the secondary schools. Ceredigion has declined the offer • Training on self harm is available to all agencies. our primary mental health service provides an essential psycho-educational programme and role both within primary care and educational settings to further promote mental health & wellbeing and suicide prevention.
Cwm Taf UHB	• Multi-agency services have worked together in Cwm Taf to develop a comprehensive training package to raise awareness of suicide and self harm; how to recognise signs, manage suspicions and disclosures and signpost for further appropriate support • The training is provided free of charge to multi-agency staff across the Cwm Taf area and is routinely evaluated. This evaluation is fed into the training delivery group on an annual basis to support review of the training pack to ensure that it remains up-to-date and fit for purpose • Over 800 multi-agency staff have been trained over the past three years and feedback from 2014/15 (436 staff) shows that 97% were 'satisfied' or 'highly satisfied' with the training and 94% indicated that they had increased / improved knowledge and skills after completing the course • In order to support the delivery of training in schools, the one-day course is offered as two twilight sessions to enable staff to attend without encroaching on teaching time within the school day.

Other comments	

Cwm Taf UHB	• This work has a high profile within Cwm Taf with regular reporting to:
	  ◦ Safeguarding Board
	  ◦ Together for Mental Health Partnership Board
	  ◦ Regional Collaborative Board

Hywel Dda UHB	• Although there are numerous opportunities to access appropriate training there remain operational challenges to release staff from across the HDUHB service areas to access these training events. This is also the case for other agencies to whom these training events are made available

Recommendations to support future reviews
7.5.16 Local safeguarding children boards should ensure that the PRUDiC process is initiated, progressed through further meetings and completed for every probable suicide involving a child or young person and that the required information for the Child Death Review programme is completed and returned to the programme

Responses	
Aneurin Bevan UHB	• Within Gwent the PRUDiC has been fully implemented and includes all probable suicides involving children and young people. All cases managed under PRUDiC process are reported to the South East Wales Children Safeguarding Board by the Aneurin Bevan University Health Board member who also completes the paper work for the Child Death Review programme.
Hywel Dda UHB	• HDUHB fully cooperates with the PRUDIC process and has formally adopted the use of Procedural Response to Unexpected Deaths in Childhood (PRUDIC) 2014 protocol. HDUHB has developed and implemented a supporting PRUDiC–Health Action Flowchart to ensure compliance with the protocol and that the required health information for the CDRP is provided and sent via the RSCB nominated person along with other agencies data. HDUHB completes an annual audit on all PRUDiC cases.
Abertawe Bro Morgannwg UHB	• The PRUDiC process is implemented in all cases of probable suicide, and the revised PRUDiC guidance is followed.
Betsi Cadwaladr UHB	• The PRUDiC process was implemented in North Wales in May 2013. All suicides or probable suicides are discussed via the PRUDiC process • The National Child Death Review programme is informed of all child deaths and the relevant paperwork is completed and provided.

Other comments	
Aneurin Bevan UHB	• Annual audit on the implementation of the PRUDiC audit process undertaken
Abertawe Bro Morgannwg	• The Coroner may not report a verdict of suicide – this can cause difficulties completing CDR notification.
Betsi Cadwaladr UHB	• North Wales is taking part in an all-Wales Audit on the PRUDiCs as arranged through the All-Wales NHS Safeguarding Clinical Network. This will be running from April 2014 to March 2015
Hywel Dda UHB	• Talk to me 2: Self harm and Suicide prevention Strategy for Wales has recently been out for consultation and we are awaiting the outcome of this. On publication we will then develop an action plan to ensure that the recommendations and best practice are in place.

7.5.17 Welsh Government and the Child Death Review programme should ensure deaths of children and young people through probable suicide remain a regular focus for child death thematic review on a 3 yearly basis, including examination of specific types of death and collaboration with National Confidential Inquiry into Suicide and Homicide and Suicide Information Database-Cymru. Such forward planning will allow for the timely collection and collation of information relating to children and young people included in the review. A future review of possible suicides i.e. accidental hangings and poisonings excluding narcotics is particularly relevant.

Responses	
CDR Programme	• A repeat review process will be developed to enable the CDR team to consider deaths of children where thematic reviews have already been completed.

7.5.19 The Child Death Review programme should follow up progress made against the recommendations in this review and publish them in its annual report after one year

Responses	
CDR programme	• Process in place to request progress against recommendations made and are reported in this annual report.

7.5.20 The Child Death Review programme should develop mechanisms to engage families and children or young people in the delivery of the programme, which may include involvement in specific aspects of thematic reviews

Responses	
CDR programme	• The CDR team are considering how to engage with families and children/young people. Children in Wales are now the umbrella organisation for this function and the CDR team will be liaising with Children in Wales in the future to progress this.

Appendix E

Procedure for the Child Death Review programme Thematic Reviews

Child Death Review programme	
Procedure for the Child Death Review programme Thematic Reviews	
Author: Beverley Heatman, Child Death Review Manager & Dr Rosalind Reilly, Consultant in Public Health	
Date: 5 May 2015	**Version:** 1
Publication/ Distribution: CDR website	
Review Date: May 2016	
Purpose and Summary of Document:	
This document provides the guidance for Child Death Review programme thematic review process.	

Introduction

The Child Death Review programme has been established and aims to identify and describe patterns and causes of child death, including any trends, and to recommend actions to reduce the risk of avoidable factors contributing to child deaths in Wales. A key objective of the programme is to undertake thematic reviews and make recommendations, and to disseminate findings from the thematic reports in order to inform action to address avoidable factors contributing to child deaths in Wales.

Purpose

The purpose of this document is to provide guidance for the undertaking of thematic reviews of children's deaths.

Choice of Theme for Review

The Child Death Review (CDR) team will present data on child deaths in Wales to the steering group, highlighting areas which could be progressed to a thematic review. This information is used along with current emerging themes identified through the child death review database, topical issues, issues of concern raised by stakeholders and potential for prevention; and any suggestions from the steering group members or from stakeholders are discussed. Agreement on the topic for review is reached through the steering group.

Roles and Responsibilities

The CDR team will identify an appropriate professional lead, chairperson and multidisciplinary panel members for each thematic review, with advice and guidance from the steering group in suggesting expert advisors where necessary.

Core Team membership

The CDR team (Designated paediatrician for safeguarding, public health consultant, Child Death Review programme manager) and professional lead will form the core membership of the thematic review panel which will ensure the panel will have consistency with each review.

Professional Lead

The role of the professional lead will usually be to:

- Provide a professional lead in the direction and development of the review
- Comment on, and agree, the protocol for the review
- Engage in early discussions and work closely with the core team and the Observatory Evidence Service at Public Health Wales to advise on the literature search for risk and evidence of effectiveness of interventions, and agree the literature protocol
- Attend core team meetings throughout the process of the review to support the data collection and development of information for the panel meetings
- Review the data along with the core team to develop the qualitative and quantitative presentations of the deaths under review
- Attend all panel meetings and present data at each of the meetings
- Prepare information about existing policy and epidemiology on the theme being reviewed, and present this at the first panel meeting
- With other members of the core team, develop and finalise the report, acting as named author

- Present the findings of the review to the CDR steering group, and if agreed, to specific other fora such as Welsh Government
- Attend the stakeholder event following the launch of the report, and present the findings of the review at this event
- Respond to any media queries, providing interviews on a pre-recorded, or live basis as necessary
- Act as a conduit for driving forward the recommendations made through the review
- Attend the reflections meeting at the end of the process to feed back on areas for improvement or change
- Attend a final review meeting approximately one year following the completion of the review to consider the progress made against recommendations and next steps.

Chair Person

The chair person will be chosen for their skills and ability to chair the panel meetings and is not necessarily required to have experience or knowledge in the theme being reviewed.

The chair person will:

- Attend each thematic review panel meeting
- Liaise with the Programme Manager to establish the plan for the thematic review panel meetings
- Chair each panel meeting, ensuring that all panel members are provided with opportunity to speak; seek clarity on issues that may be arising; provide controls within the panel meetings to ensure fair representation across panel members and that the plan is executed to timescale
- Attend the stakeholder event (if possible) where the findings of the thematic review are presented, this may also include addressing the audience to introduce the thematic review.

Thematic Review Panel

The panel meet to review relevant information including background data and epidemiology and summaries of cases brought to the panel. The panel consider the causes and mechanisms by which the deaths occurred and if appropriate events that occurred in the life of the child or young person. The panel consider opportunities for prevention or further learning. The panel contributes to the development of the conclusions, key messages and recommendations and approves the final recommendations.

There is no fixed number of persons to form a thematic review panel. The panel will include the chair, core team and will require the identification of professionals from within the field to be co-opted as and when appropriate. This will ensure that the membership of the thematic review panel is better equipped to provide a perspective on certain aspects of child death or to contribute to the discussion of certain types of death and may include professionals from:

- Fire and Rescue Service
- Healthcare/CAMHS
- Education/early years etc
- Local Authority/Social Services
- Police
- Third Sector organisations.

Other professional bodies, organisations or agencies may be identified as appropriate depending on the theme being reviewed.

Thematic Reviews

Notification of review to be performed

On identifying the theme to be reviewed, the CDR team will advise the relevant key organisations of the theme to be reviewed (Health, Social Care, Police and Coroners).

Identifying deaths to be reviewed and data collection

The CDR team will develop a specific protocol for each thematic review which will include a case definition. The team will identify the deaths of children which meet the criteria set for the thematic review; and will seek to obtain further information on the identified deaths. On receipt of this information the CDR team will aggregate the data and will work closely with the professional lead to prepare the data into an anonymised format for presenting to the panel.

Governance

The data used within the thematic review will be subject to quality checking and controls. The process used for the thematic review will be subject to a quality assurance check.

All information shared within the thematic panel meetings will be anonymised to protect the identification of individuals. Each panel member will be required to sign a data confidentiality statement prior to receiving any information about the deaths either verbally or through presentations.

Evidence Review

The core team will liaise with the Observatory Evidence Service to develop a protocol for the literature search for risk factors and evidence of effectiveness of interventions.

Panel meetings

A schedule of panel meetings will be established and shared with the panel members a minimum of three months in advance of the date of the first meeting.

Information will be provided by email regarding the review being undertaken. A panel member information pack will be shared with panel members at least four weeks prior to the first meeting; and will consist of:

- Protocol for the thematic review
- Procedure for the Child Death Review programme thematic reviews document
- Details of venues, dates and times for panel meetings
- Information sheet on what is expected from panel members.

Meetings

There will be 3 meetings; two full day meetings and one shorter meeting.

The **first meeting** will include presentation of information on:

- The Child Death Review programme
- The purpose and scope of this review
- Policy background and epidemiology
- Observatory Evidence Service will present the risks identified through the literature search
- Qualitative & quantitative data relating to the cases will be presented by the professional lead
- The panel will be able to have open discussion and start to draw conclusions and identify key issues.

Between the first and second meeting these key issues will be collated into themes upon which key messages and recommendations could be based.

A **second meeting** will be held within two weeks, at this meeting:

- The panel will be provided with a summary of the content of the first meeting, including an overview of the cases, key risks identified through the literature search, and the draft of the discussions they had at the end of the previous meeting and any conclusions they were forming
- The panel will then be invited to have further open discussions (if required) to finalise their conclusions
- Once conclusions have been reached, the panel will be invited to discuss their views on any aspects which are modifiable and possible interventions
- This will be followed by a presentation of evidence of effectiveness review – by the Observatory Evidence Service
- The panel members will be able to discuss their views about interventions and what interventions should be suggested based on the evidence of effectiveness
- The panel will begin to draft their views into key messages and recommendations
- The core team will develop these suggestions and views into key messages and recommendations which will be presented to the thematic panel at the third meeting.

The **third and final meeting** will be held over a half day to:

- Present overview cases and conclusions
- Present the key messages and recommendations which have been developed. The panel will be invited to comment or amend these to ensure there is full agreement
- Finalise and agree recommendations and audience to be targeted and included in report.

Report Writing

The report will be developed by the core team with the professional lead as the named author. The steering group will have the opportunity to comment on readability and clarity for a wider audience.

Each thematic review report will be launched a minimum of two days prior to the stakeholder event.

Public Health Wales, through the Director of Health Intelligence, has accountability for the report and the recommendations contained within the report and so must approve the final version.

The final report will be bilingual.

Welsh Government submission and engagement

The final report will be made available to Welsh Government six weeks before publication. The core team will engage with Welsh Government to identify policy leads and will offer briefings on the review during this period.

Communications plan

The CDR team will engage with the Public Health Wales Communications team to develop a communications plan for each review.

Stakeholder Event

The findings of the review will be presented at a stakeholder event. These are held on a rotational basis between north, south west and south east Wales.

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