

Wiltshire and Swindon

Child Death Overview Panel (CDOP)

Fourteenth Annual Report

1st April 2018 - 31st March 2023

**Katie Ash
Consultant in Public Health
Swindon Borough Council**

**Hayley Morgan
Consultant in Public Health
Wiltshire Council**

**Ann Farr
Child Death Overview Panel
University of Bristol**

**Hannah McConnell
Public Health Specialist for Intelligence
Swindon Borough Council**

Contents

Contents

- Child Death Overview Panel (CDOP)..... 2
 - Contents..... 2
- Executive Summary 3
 - Summary Statistics:..... 3
 - Key Learning Points and Actions:..... 4
- Introduction 5
- Background to the Child Death Review Process 6
 - The Child Death Review Process..... 6
 - Production of this report 7
- Notifications of child deaths 7
 - Summary Data (five year average data from 2018 – 2023)..... 7
 - Analysis of notifications by year (2018-2023) 8
 - Age at death..... 9
 - Location of death 10
 - Gender 12
 - Ethnicity 12
 - Child Death Overview Panel Review Data 15
 - Reasons for delayed cases between 2018-2023.....16
 - Length of time from death to review 17
 - Categorisation of death for cases reviewed by CDOP 18
 - Mode of death of cases reviewed by CDOP..... 19
 - Additional factors in the Social Environment 20
 - Modifiable Factors – Reducing the Risk of Future Deaths..... 21
 - Family Follow Up..... 22
- Appendix A - CDOP membership April 2022 to March 2023 24

Executive Summary

Whilst child death is a rare event, each one has a devastating impact on the family, friends, community and professionals involved. The Annual Child Death Overview Panel Report provides an opportunity to review the data around child death to identify patterns and trends as well as an opportunity to ensure the Panel is working effectively.

Summary Statistics:

- In 2022 to 2023, the Wiltshire and Swindon CDOP panel reviewed a total of 36 cases (26 of which were Wiltshire resident children and 10 of which were Swindon resident children). This represents a 23% decrease in the number of cases reviewed compared with the previous year (47 cases reviewed in total in the previous year).
- There are currently 24 cases that have been waiting to go to panel for more than 12 months, this is the same as the previous year. The delays occur due to the processes that need to be completed before Panel can review cases. The primary cause being delays in Analysis Forms being completed, followed by awaiting the results of Inquests.
- The most common cause of death for children across Wiltshire and Swindon remains a perinatal or neonatal event. The second most common categorisation was chromosomal.
- In the majority of deaths reviewed no modifiable factors were identified. Modifiable factors were identified in nearly one in five cases in Swindon and in one in three cases in Wiltshire. In a very few cases (2%) there was inadequate information. Nationally, CDOPs identified 37% of all child deaths as having modifiable factors in 2022 and 39% in 2022-2023 identified.
- The majority of child deaths from 2018-2023 occur in the first month of life (48% Swindon and 41% for Wiltshire). A further 17% in Swindon and 18% in Wiltshire of deaths occur in children aged 28 to 365 days. The 2021-22 national report (last published) shows 42% of deaths occurred during the first month after birth and a further 20% of deaths occurred between 28 and 364 days old.
- Nationally, there is an overrepresentation of deaths in children from the Asian or Asian British ethnic group. In 2022 a higher proportion of deaths in the Black African/Black Caribbean/Black British ethnic group was seen in Swindon and Wiltshire, but it is important to note that this a very small number of cases. There is an issue with 11% of cases where ethnic group is not known. Ethnicity recording needs to improve in particular for Wiltshire, in order to provide assurance that there is no disproportionate representation of child deaths by ethnicity.
- The majority of child death cases were recorded as occurring in hospital (72% in Swindon and 71% in Wiltshire).
- Nationally, there is evidence of increasing child mortality across England as measures of deprivation increase, with the implication that a greater proportion of child deaths in more deprived areas are avoidable. However, the most recently available regional data for a three year period from April 2019-March 2022 does not indicate that there is an association between deprivation and child deaths (0-17 years) in the South West or in Swindon & Wiltshire. Any association between child death rates and deprivation in Swindon and Wiltshire should be explored in future reports.

Key Learning Points and Actions:

Much of the key learning in cases will be specific to organisations, and when this is highlighted the organisation is written to by the CDOP Chair and assurance is sought that improvements are now in place. The actions related to this are monitored regularly at the CDOP.

In addition to this:

A review of all Swindon Sudden Unexpected Death in Infants (10%) of cases over the last 5 years was completed to explore themes and learning. This was combined with national evidence and learning to create a SUDI audit which was completed by local stakeholders. This gave each partner a self-assessment to work on to improve practice and prevent future SUDIs.

Police Bereavement Support Packs were reviewed to improve advice and support offered to families.

Suicide awareness training provided in Swindon to over 300 participants who work or volunteer with young people.

CDOP contacted the Hospital Trusts across the BSW footprint to review their processes in place for Advance Care Plan sharing with emergency services and families.

CDOP also produces a newsletter for professionals, this has included:

- The risks of Gastroesophageal Reflux Disease in children, in particular the risk of choking
- Promoting Young Carers Support available in Swindon and Wiltshire and how to refer
- Sharing learning from two deaths by suicide, resulting in additional training for educational settings
- Promoting the usefulness of What3Words in locating a person in need of emergency help
- Reminding partners of the CDOP Reporting Process, requirements and responsibilities
- Promoting the use of translation services and raising awareness of the risks of using family members to translate
- Promotion of the British Association of Perinatal Medicine guidelines (2019) on extreme preterm birth before 27 weeks gestation

Introduction

We are fortunate that a child death is a rare event in our society, however, each death represents a tragedy for the family, community and professionals involved. The purpose of the Child Death Review (CDR) process is to identify potentially modifiable factors which may prevent future deaths from occurring. The CDR process is also able to identify local and regional trends to inform the work of commissioners, providers of services and other relevant organisations. For example, in the case of children with life-limiting conditions the CDR process is able to consider whether these children were in receipt of appropriate care during their life and had access to appropriate support services at the end of life. Where the CDR process identifies learning, this is fed back to the relevant agencies by the Child Death Overview Panel on behalf of the Child Death Review Partners (CDR Partners) in Swindon and Wiltshire respectively. The CDR partners are Local Authorities and Integrated Care Boards and are joined on the Panel by partner from across health, social care and the Police.

The Wiltshire and Swindon Child Death Overview Panel (CDOP) has been in place since April 2008. The processes to be followed when a child dies are currently outlined within Working Together to Safeguard Children 2018: Chapter 5 Child Death Review Processes¹. The statutory guidance was published in July 2018 and must be followed for all deaths occurring after 1st April 2019. For the purposes of this annual report, the previous version of Working Together to Safeguard Children (2015) was in place and governed the process for the children described in this report who died prior to 1st April 2019.

The role of the panel is to review the death of every Wiltshire and Swindon child aged under 18 years using a national methodology. The CDOP has a particular focus on identifying whether there were modifiable factors which may have contributed to the death and what, if any, actions could be taken to prevent future such deaths.

At the beginning of the CDR process in 2008 the CDR Partners (previously Local Safeguarding Children Boards) in Swindon and Wiltshire came together to form a single Child Death Overview Panel (CDOP). This CDOP continues to review the deaths of all children resident in Wiltshire and Swindon. Some of these deaths may occur outside of the region and these will also be reviewed by this panel. In addition, and in line with the 2018 guidance, the panel may choose to review the deaths of non-resident children who die in the Swindon or Wiltshire area if appropriate e.g. in the case of a road traffic collision.

The CDOP is currently chaired by a Consultant in Public Health (Swindon). A full list of panel members can be found in Appendix A.

¹ HM Government Department for Education (June 2013)

Background to the Child Death Review Process

Chapter 5 of “Working Together to Safeguard Children” (WT) (2018) sets out the framework for processes to review all child deaths. The process focuses on identifying ‘modifiable factors’ in the child’s death. Alongside the 2018 revision of WT, Statutory and Operational Guidance for Child Death Reviews (SOG) was published in October 2018. Under WT and the SOG, the CDR Partners are required to put in place arrangements for a Joint Agency Response (JAR). A JAR is a coordinated multiagency response (on-call health professional, police investigator, duty social worker), to be triggered if a child’s death:

- is or could be due to external causes;
- is sudden and there is no immediately apparent cause (including SUDI/C²);
- occurs in custody, or where the child was detained under the Mental Health Act;
- where the initial circumstances raise any suspicions that the death may not have been natural; or
- in the case of a stillbirth where no healthcare professional was in attendance.

The full process for a Joint Agency Response is set out in the SUDI/C Guidelines³ which can be found here:

<https://www.rcpath.org/uploads/assets/874ae50e-c754-4933-995a804e0ef728a4/Suddenunexpected-death-in-infancy-and-childhood-2e.pdf>

The Wiltshire and Swindon, Joint Agency Response and Child Death Overview are two separate processes but are closely linked.

The Joint Agency Response process ensures early notification of the death of a child that meets the above criteria, and a prompt process of investigation. Key professionals come together to enquire into and evaluate each of these deaths. The principal purpose includes:

- to collate and share relevant information.
- to establish, where possible, a cause or causes of death (in conjunction with the coroner)
- to identify any contributing factors.
- to identify any potential learning.
- to provide appropriate support to the family including a co-ordinated bereavement care plan.
- to consider the welfare and support of professionals involved with the child/family.
- to prepare a final report for submission to CDOP and arrange feedback from the family.

² Sudden Unexpected Death in Infancy and Childhood

³ Sudden Unexpected Death in Infancy and Childhood: Multi-agency Guidelines for care and investigation ⁴ Current forms available here <https://www.gov.uk/government/publications/childdeath-reviews-forms-forreporting-child-deaths>

The Child Death Overview Process ensures that every child's death is comprehensively reviewed, and lessons learnt so that action can be taken to prevent future deaths where possible.

The Child Death Review Process

A child's death is reviewed by CDOP after a range of standard information has been collected using statutory forms (Notification Form, Reporting Form, Supplementary Reporting Form and Analysis Form⁴) and the case has been discussed by professionals involved in the child's life at a local child death review meeting (CDRM). Following the Child Death Review Meeting a detailed compilation of data from the statutory forms mentioned above is collated and anonymised by the Child Death Enquiries Office at the University of Bristol for presentation to CDOP. CDOP reviews each case with the aim of identifying modifiable factors and highlights any learning identified. The CDOP panel aims to identify those factors in the course of a child's life, and leading to the child's death, which might have directly led to the child's death or increased their vulnerability, and which might have been amenable to modification. It also makes recommendations which may prevent similar deaths occurring in the future. However, it may also make recommendations related to service improvement, where changes in practice could lead to improved experiences for children and young people at the end of life or during the course of their treatment.

Production of this report

The CDOP is required to produce an annual report each year outlining the work of the panel and relevant learning from the cases reviewed to inform the priorities of the CDR Partners. This report is produced using data collected by the University of Bristol through the Child Death Enquiries Office. Information collected at the point of notification of death is entered onto the eCDOP case management tool. Information collected from statutory forms, Child Death Review Meetings and CDOP reviews is populated onto eCDOP as the case progresses through the child death review process. The eventual CDOP multi-agency dataset is extremely comprehensive. The annual report includes five years of aggregate data to help reduce year on year variations associated with rare events such as a child death. This allows better identification of longer-term trends or key themes which may not have been as apparent within a single year of data.

Notifications of child deaths

Summary Data (five year average data from 2018 – 2023)

This section summarises all the deaths notified between 1st April 2018 and 31st March 2023, of children resident in the Swindon and Wiltshire areas. It is important when looking at the numbers from Wiltshire and Swindon to note that according to Census 2021 data, the size of the population base of Wiltshire is more than twice that of Swindon.⁴ The population composition by ethnic group also differs (see Table 4). The data is presented a rolling total

⁴ [ONS estimates of the population for the UK, England, Wales, Scotland and Northern Ireland, mid-2021](#), published December 2022

across the last five years. Data presented this way helps to “smooth out” the year on year variations that we expect if we are looking at rare events one year at a time.

Analysis of notifications by year (2018-2023)

During the five year period from 2018-2023, there were 167 child deaths notified across Swindon and Wiltshire. There were 58 in Swindon (14 in 2022/23) and 109 in Wiltshire (16 in 2022/23). Crude rates are shown in Table 1.

The National Child Mortality Database calculates all deaths for children under 1 year of age using ONS data for live births, and the rate is represented per 1,000 live births (see Table 2). Child death rates for those aged between 0-17 years are calculated using ONS mid-year population estimates for 0-17 year olds, and are presented per 100,000 population (see Table 1).

Most recently available South West regional data for comparison reveals a fall in the rate of deaths during the pandemic (from 28.9 per 100,000 population of children age 0-17 years in 2019-20 to 25.5 per 100,000 in 2020-21 across all CDOP regions in the South West) followed by an increase in 2021-22 across all areas (to 29.8 per 100,000). Regional data for 2022-23 is not yet available.⁵ This pattern was also seen for England: with a drop in the rate of child deaths from 28.4 per 100,000 population aged 0-17 years old in 2020 to 25.1 in 2021, followed by an increase to 28.4 in 2022.⁶

The rate of infant deaths in cases aged 0-364 days in 2022 was 3.0 per 1,000 live births across all CDOP regions in the South West and 3.6 per 1,000 live births across all other regions in England.⁷ This compares with a rate of 3.9 in Swindon and a much lower rate of 1.3 per 1,000 live births in Wiltshire in 2022-23 (Table 2).

Year on year variation in notifications is to be expected and with rare events such as a child death, small variations can appear to represent a big difference.

⁵ National Child Mortality Database Regional Report – South West, data up to 31st March 2022 p.13

⁶ [National Child Mortality Database: Child death review data release 2022](#), published November 2022

⁷ National Child Mortality Database Regional Report – South West, data up to 31st March 2022 p.3

Table 1: Numbers of deaths notified to CDOP by year 2018 to 2023 in Wiltshire and Swindon, crude rates (per 100,000 population)

		2018-19	2019-20	2020-21	2021-22	2022-23*	Totals
Wiltshire	Number of deaths	23	23	26	21	16	109
	Crude rate of death (per 100,000 population 0-17 year olds)	21.8	21.7	24.5	19.8	20.3	
	Number of deaths	10	12	8	4	10	44
	Crude rate of death (per 100,000 population 1-17 year olds)	10.1	12.2	8.1	4.1	10.1	
Swindon	Number of deaths	11	14	13	6	14	58
	Crude rate of death (per 100,000 population 0-17 year olds)	21.9	27.8	15.1	11.8	27.2	
	Number of deaths	4	2	8	2	4	20
	Crude rate of death (per 100,000 population 1-17 year olds)	8.2	4.1	16.4	4.1	8.2	

Note: Rates calculated using mid-year population estimates

*using most recently available ONS mid-year population estimates for 2021⁸

Table 2: Numbers of deaths notified to CDOP by year 2018 to 2023 in Wiltshire and Swindon, crude rates (per 1,000 live births)

	2018-19	2019-20	2020-21	2021-22	2022-23*	Totals
Wiltshire	13	11	18	17	6	65
Crude rate of death (per 1,000 live births 0-365 days old)	2.8	2.4	3.9	3.7	1.3	
Swindon	7	12	5	4	10	38
Crude rate of death (per 1,000 live births 0-365 days old)	2.7	4.7	1.9	1.6	3.9	

Note: Rates calculated using mid-year population estimates

*using most recently available ONS mid-year population estimates for 2021⁹

Age at death

Figure 1 shows that between 1st April 2018 and 31st March 2023, 48% of child death cases in Swindon and 41% of cases in Wiltshire occurred in the neonatal period (under one month of life), with a further 17% in Swindon and 18% in Wiltshire occurring in the first year of life (28-364 days). Across both areas combined nearly two thirds (62%) of all child deaths occur under one year of age. Nationally, most recently available figures from 2021-2022 show

⁸ [ONS estimates of the population for the UK, England, Wales, Scotland and Northern Ireland, mid-2021](#), published December 2022

⁹ [ONS estimates of the population for the UK, England, Wales, Scotland and Northern Ireland, mid-2021](#), published December 2022

similar percentages of 42% of child death cases occurring in the neonatal period in England, and 20% occurring between 28-364 days.¹⁰ In both Swindon and Wiltshire, the percentage of deaths by age group decreases from the 0-27 day age group to its lowest in the 5-9 years age group, and slowly rises again.

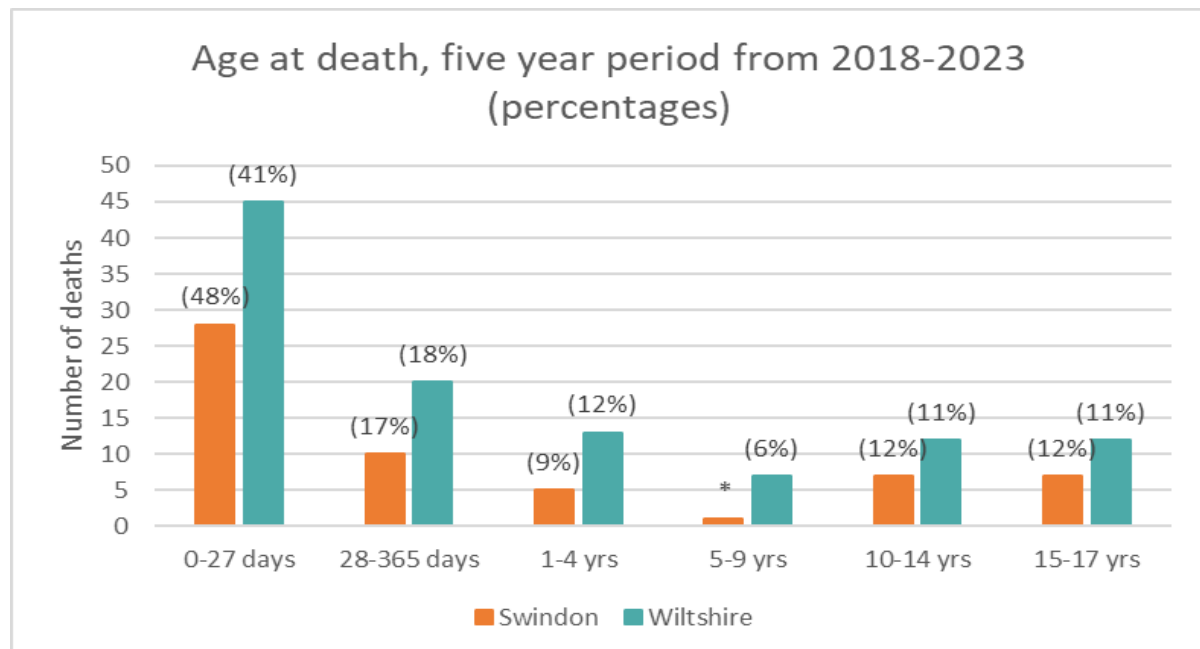


Figure 1: Age at death, Swindon and Wiltshire, five year period 2018-23
 (Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

Location of death

Many children who live in Swindon and Wiltshire may be transferred to tertiary hospitals in other regions for specialist treatment. A number of these children die in these hospitals. The figures in this section represent the total number of deaths at various locations during the five year period.

¹⁰ [National Child Mortality Database: Child death review data release 2022](#), published November 2022

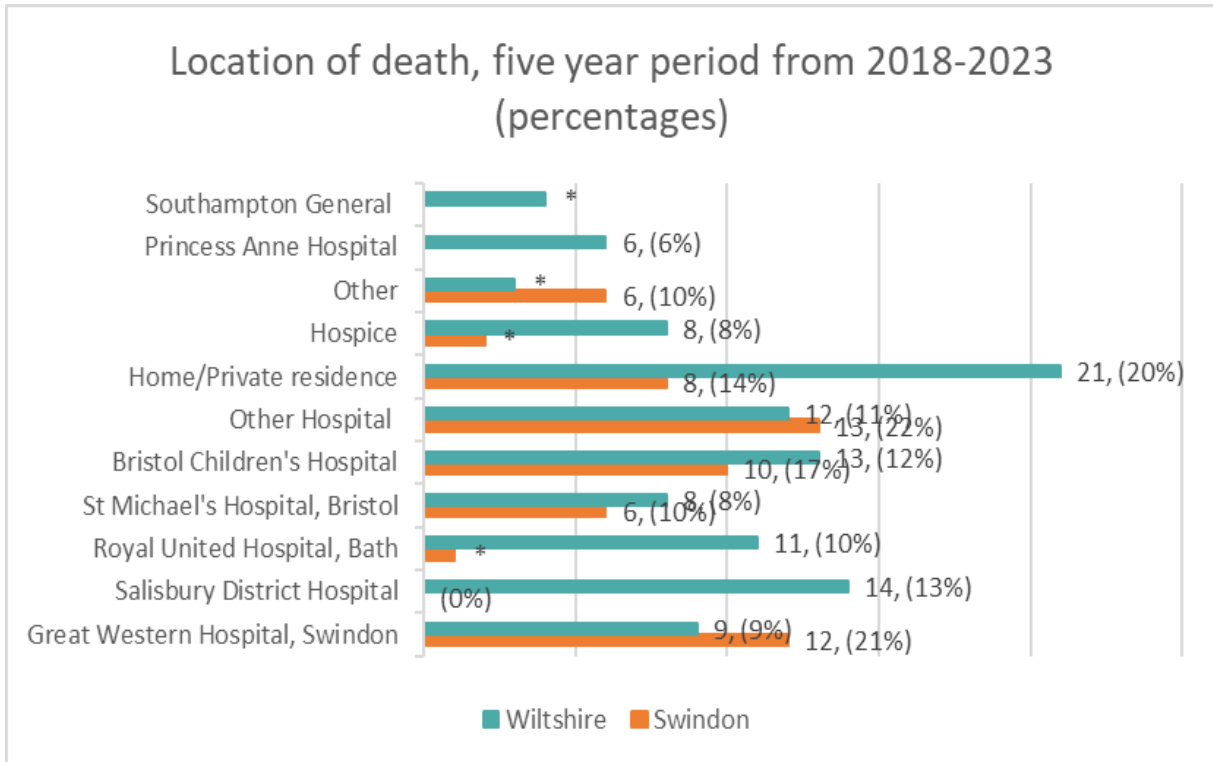


Figure 2: Location of death by area of residence, Swindon and Wiltshire, five year period from 2018-2023
(* values of less than 5 have been suppressed)

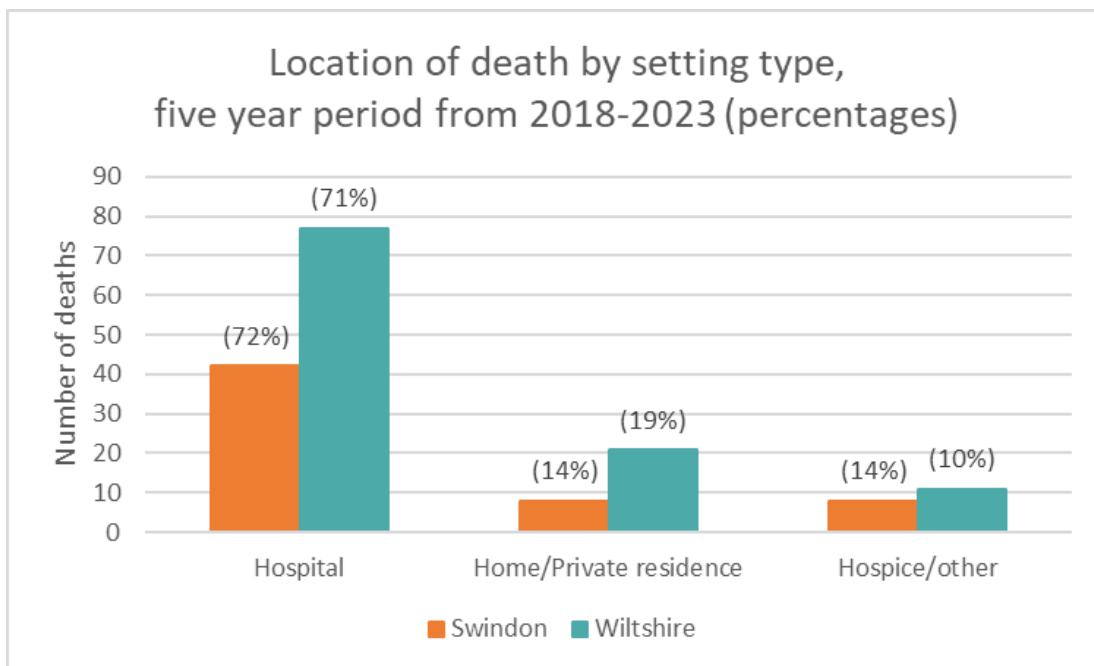


Figure 3: Location of death by setting type, Swindon and Wiltshire, five year period from 2018-2023
(Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

Both in Swindon and Wiltshire, a little over one quarter of child deaths occur outside of hospital i.e. in private residences or hospices (14-19% and 10-14% of all deaths respectively). However, the most common location of death for children resident in Swindon and Wiltshire is in hospital (Figure 3). Children who live in Wiltshire are treated in a greater number of

hospitals than children living in Swindon. This reflects the wide geographical area covered by Wiltshire and the number of counties in which Wiltshire residents receive healthcare services including Hampshire, Bristol, Swindon and Bath. This can present particular issues for Wiltshire for the timely and complete collation of information for the review of children’s deaths due to the wide range of organisations that must be engaged.

Gender

There have been more notifications of deaths notified in males than in females in both Swindon and Wiltshire, as can be seen in Figure 4. In total 55% of deaths in Wiltshire and 62% of deaths in Swindon were male. This is comparable with the national gender split in child deaths for the year ending 2022, of which 57% were male.¹¹

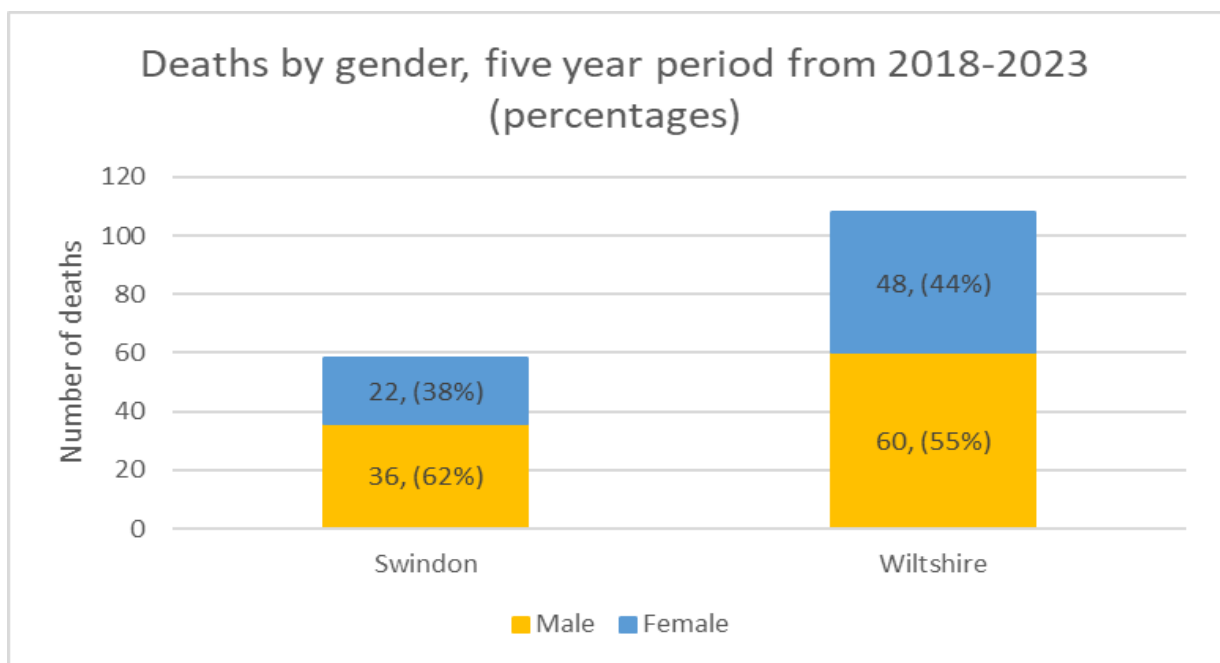


Figure 4: Deaths by gender, Swindon and Wiltshire, five year period from 2018-2023
(Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

Ethnicity

The most recently available National Child Mortality Database (NCMD) data release from 2021-2022 shows that in England where ethnicity was recorded 62% of child death notifications were recorded as being from a White ethnic group, 17% were recorded as children from the Asian or Asian British ethnic group, 8% were from the Black or Black British ethnic group, and 7% were from the Mixed ethnic group.¹²

¹¹ [National Child Mortality Database: Child death review data release 2022](#), published November 2022

¹² [National Child Mortality Database: Child death review data release 2022](#), published November 2022

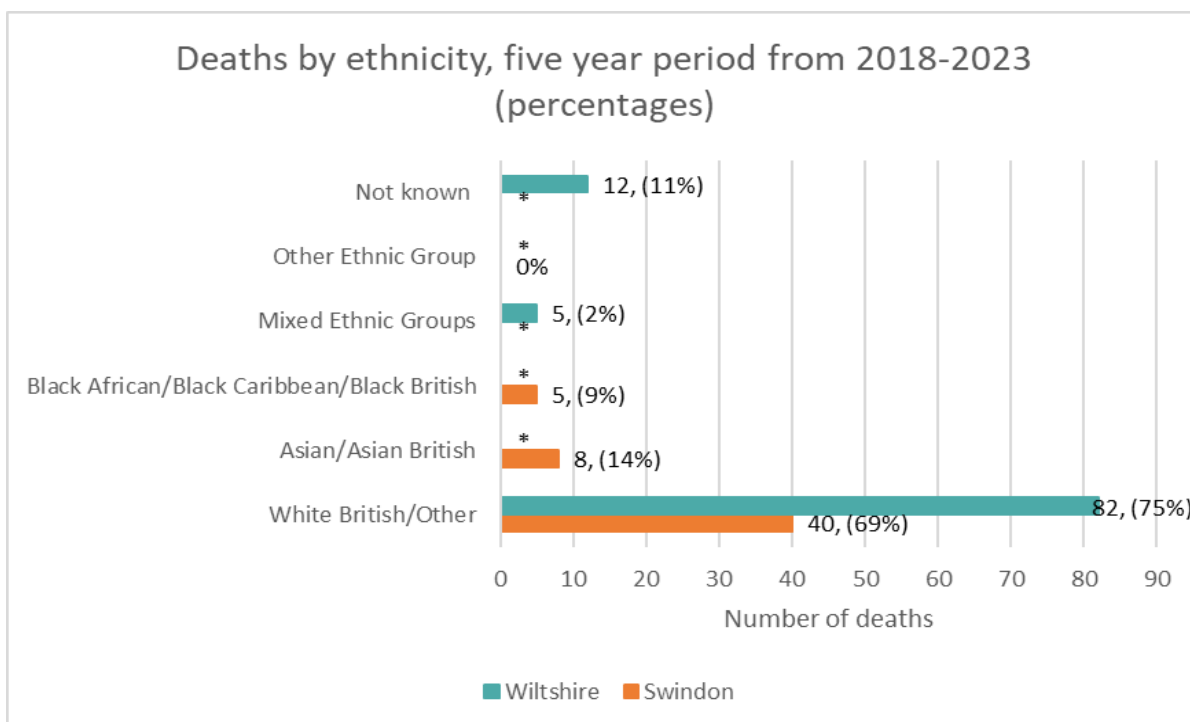


Figure 5: Death notifications by ethnic group, Swindon and Wiltshire, five year period from 2018-2023
(Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

Table 3: Child deaths by ethnic group, five year period from 2018-2023 comparison with Census 2021 population estimates (0-17 years)

	White British/Other	Asian/Asian British	Black African/Black Caribbean/Black British	Mixed Ethnic Groups	Other Ethnic Group	Not known
Swindon	69%	14%	9%	*	0%	*
Census 2021 population (0-17 years)	75%	14%	4%	6%	1.5%	
Wiltshire	75%	*	*	5%	*	11%
Census 2021 population (0-17 years)	91%	3%	2%	4%	1%	

The data presented in Figure 5 shows that the majority of child death cases notified in Swindon and Wiltshire were recorded for those of White British/Other ethnicity. Population ethnicity estimates from the 2021 Census indicate that around 75% of 0-17 year olds in Swindon and 91% of 0-17 year olds in Wiltshire are from a White British/Other ethnic group

(see Table 3), however the percentage of child death cases recorded in either area as being from a White British/Other ethnic group was lower (69% and 75% respectively).¹³

A further 9% of cases notified in Swindon were recorded for children from the Black African/Black Caribbean/Black British ethnic group. This is a higher proportion than local population estimates for children in the Black African/Black Caribbean/Black British ethnic group which is around 4% of the population aged 0-17 years in Swindon. It is worth noting that these are very small numbers of cases, but close attention should be given to this data by the CDOP in future years.

True differences in ethnicity may be obscured due to the fact that there were a small number of cases in Swindon and Wiltshire over the five year period where ethnicity was not recorded (although it should be noted that there were zero cases where ethnicity was 'not known' in Swindon in the last three consecutive years from 2020-2023). 11% of cases in Wiltshire were recorded as unknown ethnicity. The ethnicity of a child may be recorded as 'not known' if, for example, the professionals notifying CDOP did not have it on record or possibly someone was asked their ethnicity and refused to provide that information. Ethnicity recording needs to be complete in order to accurately assess if there is disproportionate representation of child deaths by ethnicity.

Deprivation

A study looking at the relationship between deprivation and child deaths in England between April 2019 and March 2020 using the National Child Mortality Database found evidence of increasing child mortality across England as measures of deprivation increase.¹⁴ The implication of this is that there was a greater proportion of avoidable deaths in more deprived areas.

Nationally in 2022 the child death rate per 100,000 population in the most deprived areas was double that of the rate in the least deprived area of the same deprivation quintile (see Table 4).¹⁵ However, the most recently available regional data for a three year period from April 2019-March 2022 does not indicate that there is an association between deprivation and child deaths (0-17 years) in the South West or in Swindon & Wiltshire combined (see Figure 6).¹⁶ Data for these areas individually was not available for this report by rate and deprivation quintile for comparison with the national data. Future reports should explore more closely any association between rates and deprivation in Swindon and Wiltshire.

¹³ [ONS Ethnic group, England and Wales: Census 2021](#), published November 2022

¹⁴ Odd D, Stoianova S, Williams T, *et al* 'What is the relationship between deprivation, modifiable factors and childhood deaths: a cohort study using the English National Child Mortality Database'. *BMJ Open* 2022; **12**: e066214. doi: 10.1136/bmjopen-2022-066214 [available from: [BMJ Open](#)]

¹⁵ [National Child Mortality Database: Child death review data release 2022](#), published November 2022

¹⁶ National Child Mortality Database Regional Report – South West, data up to 31st March 2022, p.16

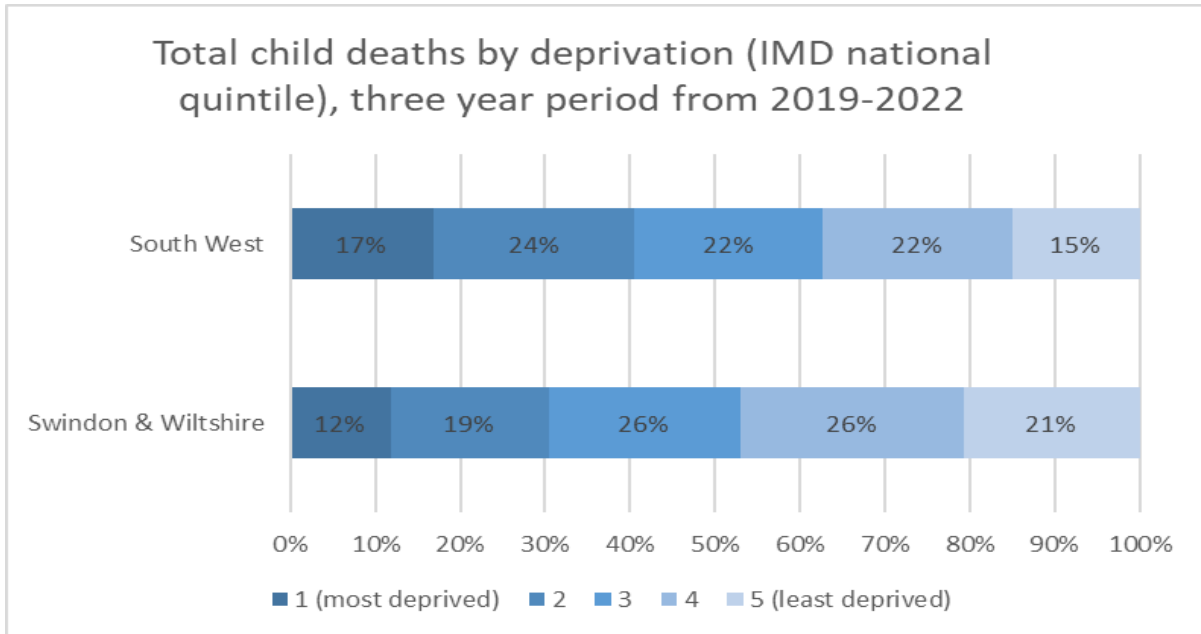


Figure 6: Child deaths by deprivation, Swindon and Wiltshire, comparison with West of England and England, three year period from 2019-2022

(Note: Percentages might not add up to 100% due to rounding)

Table 4: Child death rate per 100,000 population by social deprivation quintile, in England, 2020 to 2022

Social deprivation (IMD Quintile)	2019-20	2020-21	2021-22
1 (Most deprived)	40.1	35.9	40.1
2	31.2	28.0	30.8
3	27.5	23.6	25.5
4	22.3	18.8	22.7
5 (Least deprived)	16.8	15.7	18.9
Unknown	-	-	-

Child Death Overview Panel Review Data

These data summarise the panel’s review decisions for 2018-2023 and its actions for 2022-2023. There is an inevitable time lag between the notification of a child’s death and the discussion at CDOP. There are various factors that contribute to this including return of statutory paperwork by professionals, receipt of the final post-mortem report and receipt of the report from the Child Death Review Meeting. The Wiltshire and Swindon CDOP took the decision in 2009 to wait for the inquest verdict in child deaths that involve the Coroner before reviewing the case. In these cases, there may be a delay of over a year before a case might be brought for review by CDOP. The undertaking of a criminal investigation can also affect when a case is discussed at panel. Whilst this impacts on timeliness it is the opinion of the CDOP that the quality of the review of the cases is better with this information.¹⁷

¹⁷ Note that the number of cases reviewed therefore do not correspond with the number of case notifications in the same time period.

For Swindon cases reviewed during 2018-2023, 21 had a post mortem, 3 had a Police Investigation and 4 were subject to a Safeguarding Review. For Wiltshire cases reviewed during 2018-2023, 35 had a post mortem, 1 had a Police Investigation and 2 were subject to a Safeguarding Review. The Wiltshire and Swindon CDOP has reviewed 159 cases between 1st April 2018 and 31st March 2023. 103 were children resident in Wiltshire and 56 were children resident in Swindon.

During the period 1st April 2022 to 31st March 2023, the Wiltshire and Swindon CDOP panel reviewed a total of 36 cases (26 of which were Wiltshire resident children and 10 of which were Swindon resident children). This represents a 23% decrease in the number of cases reviewed in 2022-23 compared with the previous year (47 cases reviewed in total in the previous year). Figure 7 shows that this decrease was mostly driven by the fall in the number of cases reviewed in Swindon. The reasons for delays in reviewing cases are discussed below. Data for a three year period from 2019-2022 reveals a similar trend in Swindon and Wiltshire compared to England as a whole, with the proportion of reviews completed by year of death falling from 92% in 2019/20 to 0% in 2021/22 in Swindon (from 88% in 2019-20 to 13% in 2021-22 in England).¹⁸ Data for 2022-23 is due for release in November 2023.

LeDeR

CDOP also works with the LeDeR Programme which reviews deaths of children and adults from the age of four years. The total of the cases reviewed which link to LeDeR during 2020/21 was 1. (This is incorporated into our total figures for 2022-23 and was a Swindon case).

Further information regarding LeDeR and their Annual Reports can be found here <https://bswccg.nhs.uk/docs-reports/strategies-and-reports>

¹⁸ National Child Mortality Database Regional Report – South West, data up to 31st March 2022, p.18

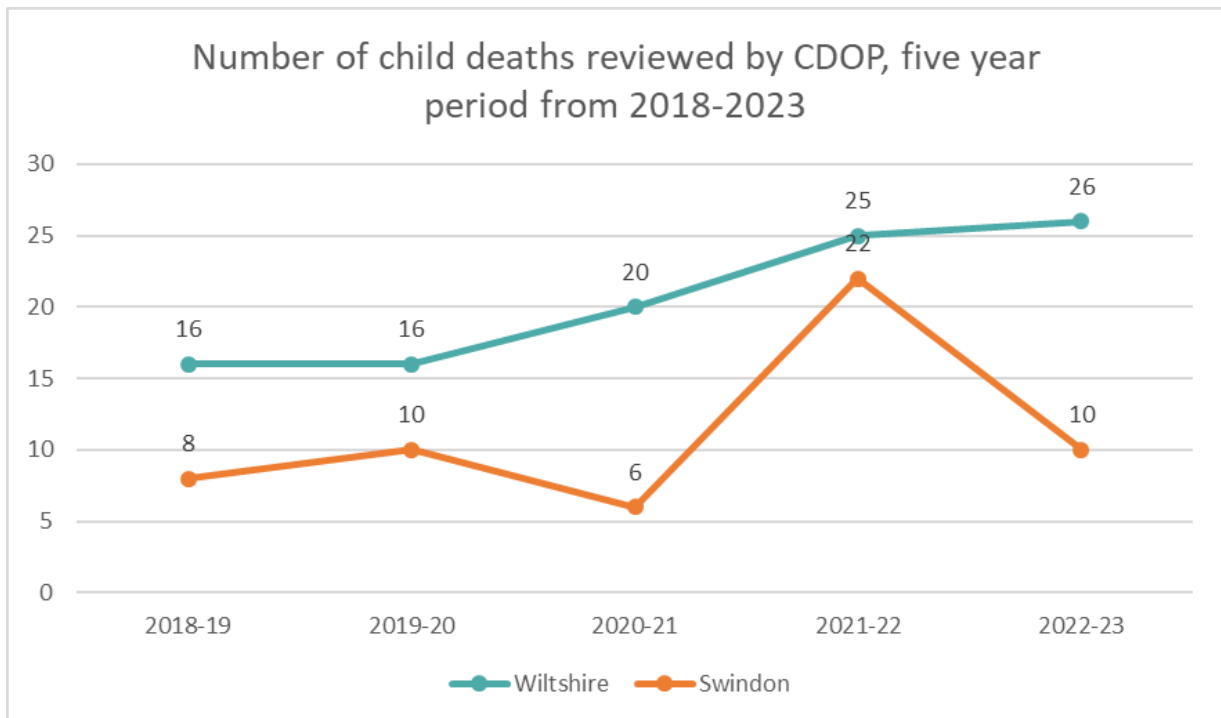


Figure 7: Number of child deaths reviewed by CDOP, Swindon and Wiltshire, five year period from 2018-2023

Length of time from death to review

It can take a number of months for a child's death to be reviewed by CDOP. The third CDOP annual report (2010/11) made a recommendation that CDOP would aim to review every child's death within 1 year, other than where there are outstanding legal procedures.

Figure 8 shows that between 2018-2023, only 9% of cases in Swindon and 10% of cases in Wiltshire were reviewed within 12 months. In both areas, half or more of all cases in this time period took longer than 18 months to be reviewed. Cases are reviewed in date of death order, so cases which were older and ready to go to panel were prioritised over those more recent deaths. In both Swindon and Wiltshire from 2019/20 onwards there was a sharp increase in the number of cases which took over 12 months to review. These increases are due to delays in the process that need to be completed before a case can do to panel as outlined in Table 5.

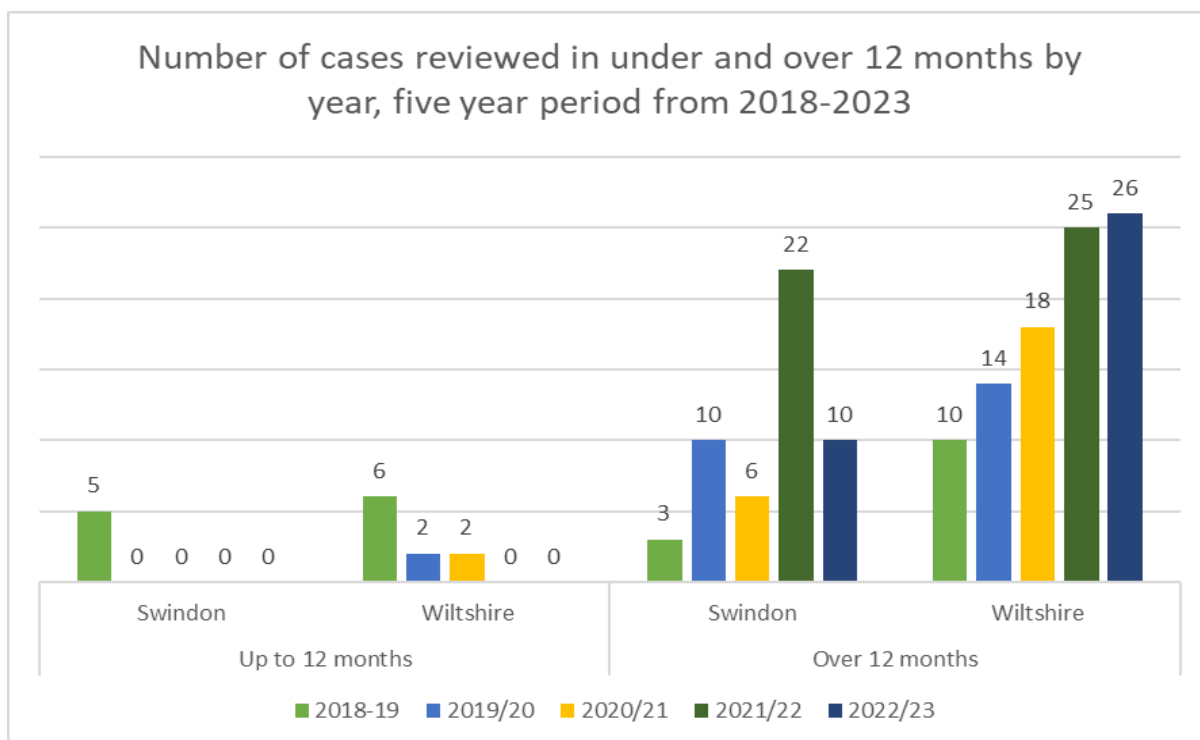


Figure 8: Number of cases reviewed in under and over 12 months by year, Swindon and Wiltshire, five year period 2018-2023

Table 5: Primary reason cases not reviewed within 12 months of death for delayed cases

Reason	Wiltshire	Swindon	Total
Ongoing Police Investigation	4	1	5
Delayed Analysis Forms	7	1	8
Delayed due to having a Post Mortem	2	0	2
Inquest	6	0	6
Serious Investigation	0	2	2
CDRM Delayed	1	0	1
Total	20	4	24

There are currently 24 cases outstanding where the child passed away over 12 months ago for Swindon and Wiltshire.

Categorisation of death for cases reviewed by CDOP

As part of the Child Death Review process each death reviewed by the panel is categorised by the most likely cause of death based on a set of pre-defined CDOP categories. Figure 9 shows the categorisation of deaths in Swindon and Wiltshire over a five year period.

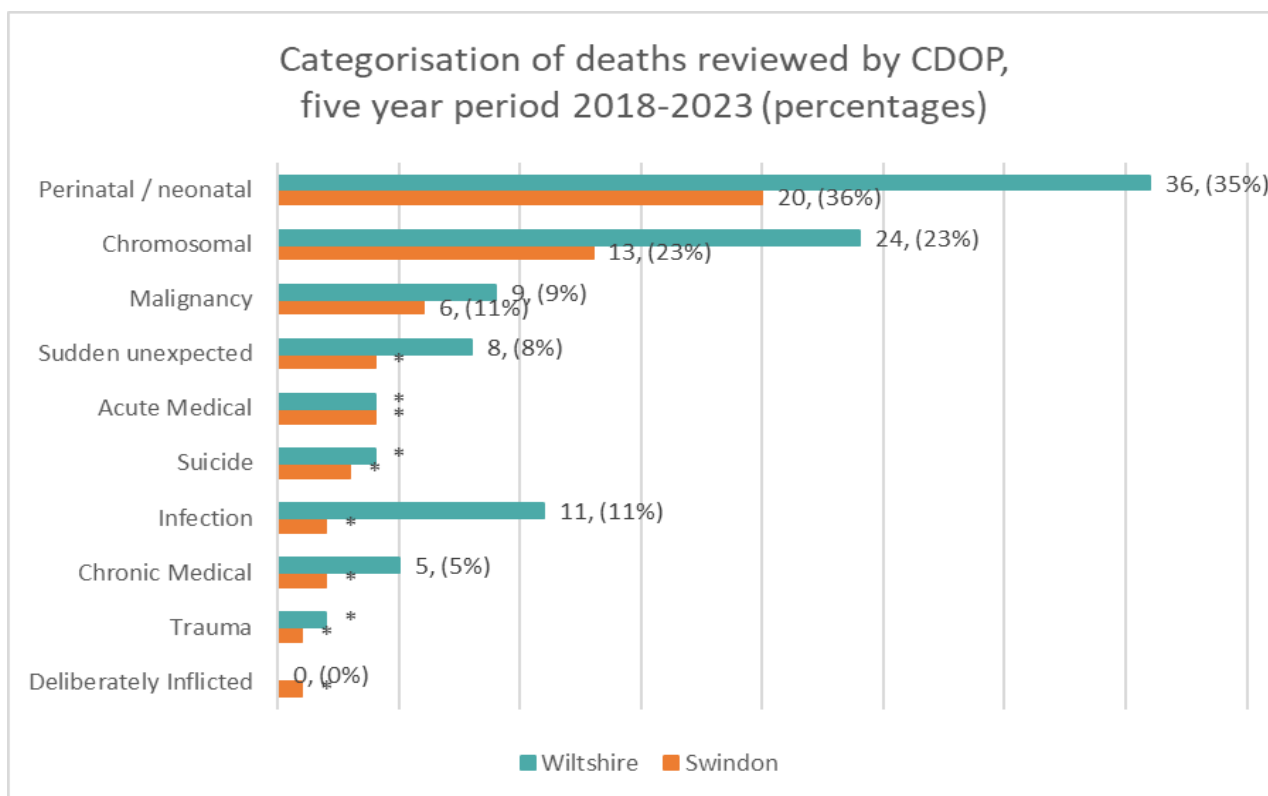


Figure 9: Categorisation of deaths reviewed by CDOP, Swindon and Wiltshire, five year period from 2018 -2023 (Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

Over one third of child death cases reviewed in Swindon and Wiltshire between 2018-2023 were categorised as perinatal/neonatal deaths (defined as the death of a live born baby of 22 or more completed week or within 28 days of birth). 61 of the reviewed cases were babies who were aged 0-1 year in Wiltshire and 32 babies aged 0-1 year in Swindon. Just under one in five deaths in both areas was categorised as chromosomal. In Swindon, 11% of deaths were categorised as malignancy. However in Wiltshire, 11% were categorised as infection and 9% as malignancy. This compares with national figures of 34% of child deaths classed as perinatal/neonatal events, 23% chromosomal or genetic anomalies, and 8% malignancy as the three most common causes of death in 2022.¹⁹

Mode of death of cases reviewed by CDOP

The most common manner of death for both Wiltshire and Swindon children is withholding, withdrawing or limitation of life-sustaining treatment (Figure 10). This decision is always made following careful consideration with the child’s parents and carers. Unsuccessful cardiopulmonary resuscitation accounts for a quarter of cases in Swindon and nearly a quarter of cases in Wiltshire. A further quarter of cases in Wiltshire (25%) were recorded as planned palliative care, recorded as 16% of cases in Swindon.

¹⁹ [National Child Mortality Database: Child death review data release 2022](#), published November 2022

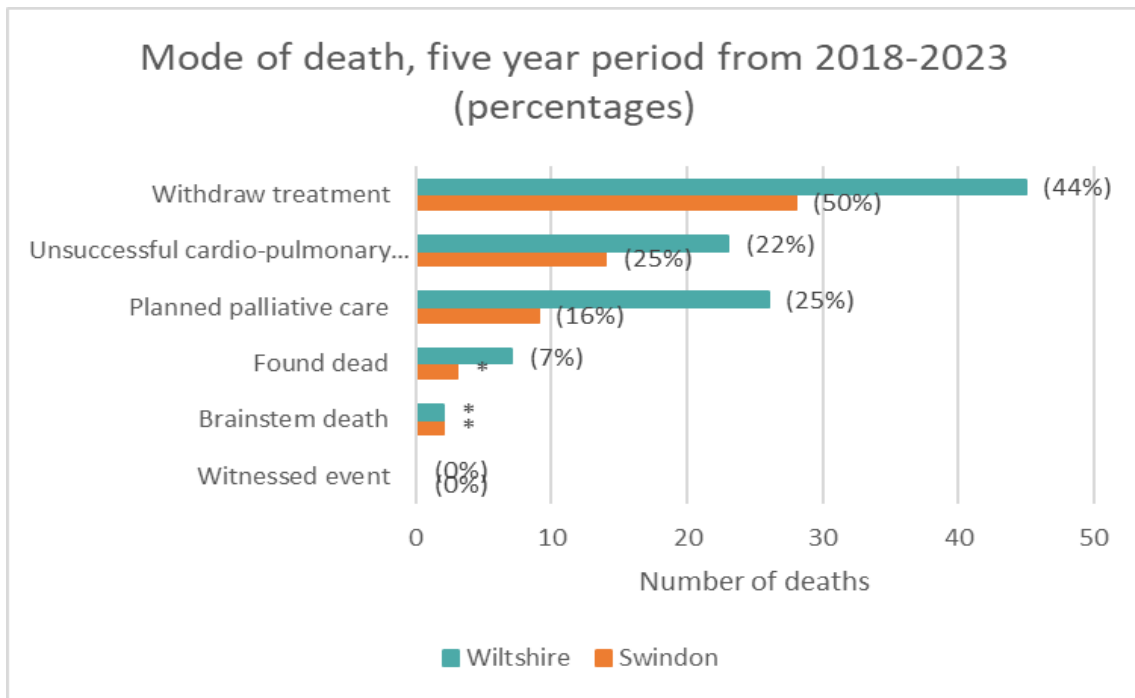


Figure 10: Mode of death, Swindon and Wiltshire, five year period from 2018-2023
 (Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

Additional factors in the Social Environment

The presence or absence of social factors in the family and environment such as mental health issues and drug abuse are routinely collected on the Reporting Form dataset from professionals who have contact with the families. These are summarised on the Analysis Form dataset at the Child Death Review Meeting and carefully reviewed by CDOP. They are shown for Swindon and Wiltshire in Figure 11. Please note that these factors may not have been directly contributory to the child’s death, rather this data reflects the presence or absence of a factor within the social environment.

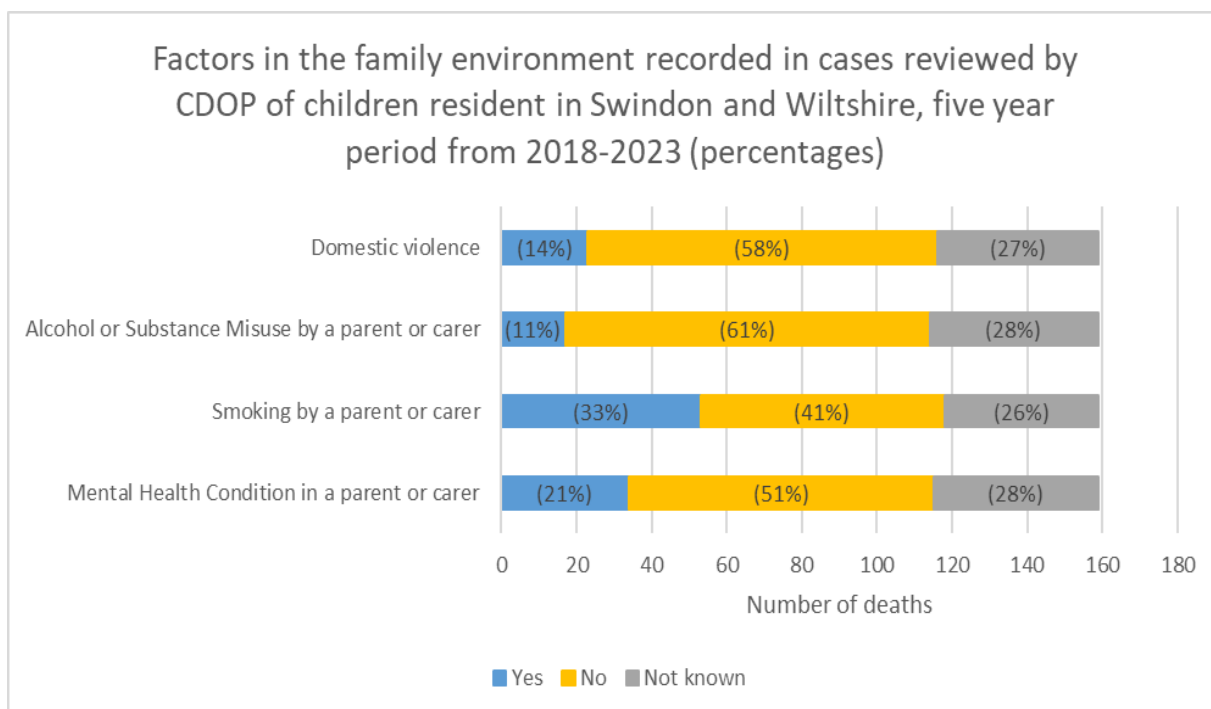


Figure 11: Factors in the family environment recorded in cases reviewed by CDOP of children resident in Swindon and Wiltshire, five year period from 2018-2023

(Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

Figure 11 above shows that for both Swindon and Wiltshire children the most common factors recorded in the social environment are smoking by a parent or carer and mental health issues, consistent with last year's data. The category of smoking includes tobacco as well as other substances, however this data is not always recorded. It should be noted that the existence of one or more of these factors does not necessarily have an impact on the circumstances that led to a child's death.

Modifiable Factors – Reducing the Risk of Future Deaths

A role of the Child Death Review process is to assess modifiable factors in each child's death. Modifiable factors are defined as "one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths". Panels can identify modifiable factors in the child's direct care by any agency, including parent, organisational, systemic or other indirect failure(s) within one or more agency. Therefore, a death identified as having modifiable factors may not necessarily be due to a failure of the agencies to safeguard the child's welfare. An example of a modifiable factor might be a death resulting from a vaccine preventable infection where the vaccine had not been given to the child. In addition, CDOP would regard a death as having modifiable factors if practice had changed due to learning arising from that child's death, even when the outcome for that particular child might not have changed. This allows for a precautionary approach with the aim of using learning identified to limit future deaths.

In both Swindon and Wiltshire during the five year period from 2018-2023, where cases were reviewed and there was adequate information, no modifiable factors were identified for the majority of cases (Figure 12). Modifiable factors were identified in nearly one in three cases

in Wiltshire over the five year period, similar to the most recently available national figure of 37% of case reviews in England with adequate information that identified modifiable factors in 2021-2022. Notably, fewer than one in five cases in Swindon identified modifiable factors.

In England, the latest figures for 2022 report that 37% of child deaths were found to have modifiable factors.²⁰ The percentage of reviews with adequate information that identified modifiable factors has increased steadily over a five year period from 29% in 2018 to 37% in 2022. At national level, modifiable factors were more likely to be identified in cases where the child was recorded to be aged between 0-364 days (68%), male (58%), and in the White (65%) or Asian/Asian British (13%) ethnic group.

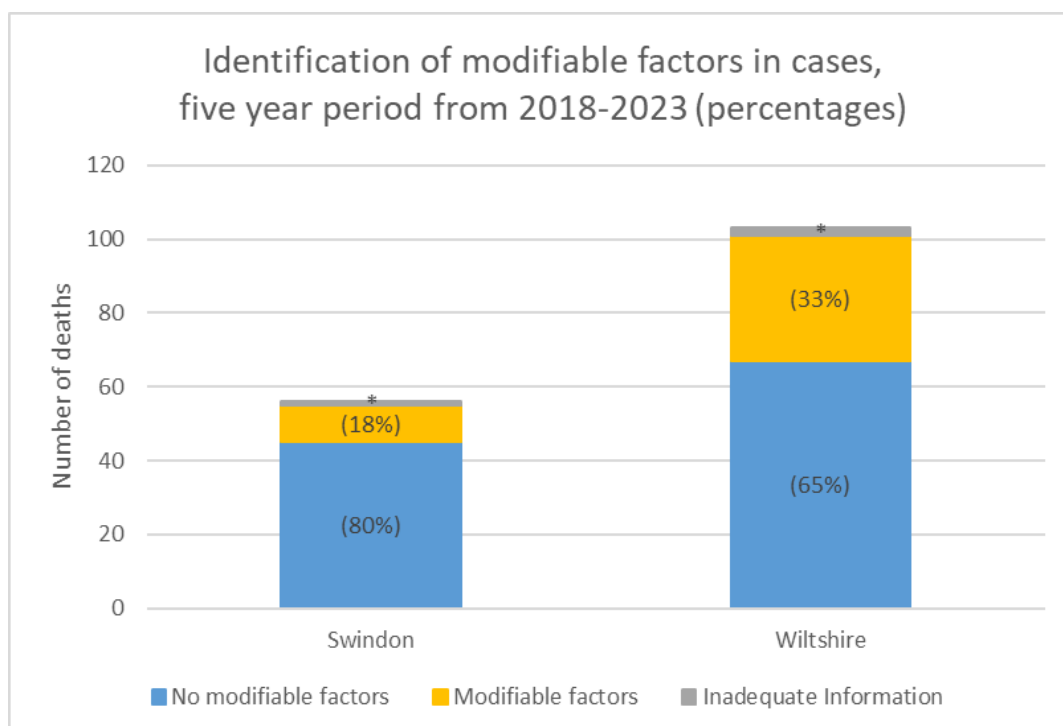


Figure 12: Identification of modifiable factors, Swindon and Wiltshire, five year period from 2018-2023 (Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

Family Follow Up

Active engagement with bereaved parents underpins the entire child death review process. Parental input into the child death review meeting should occur as a matter of course. Parents are invited to submit questions to the local child death review meeting, and feedback by the lead health professional on all aspects of this meeting is then given at a follow-up appointment with the family. Families may access follow-up from more than one professional agency.

Figure 13 shows the percentage of families offered follow up from each agency for cases reviewed by CDOP for Wiltshire and Swindon between 1st April 2022 and 31st March 2023. Families may have been offered follow-up by more than one agency following their child's

²⁰ [National Child Mortality Database: Child death review data release 2022](#), published November 2022

death. The offer of follow-up remains open to families; however, some families may choose not to take-up this offer for months or sometimes years depending on their specific need.

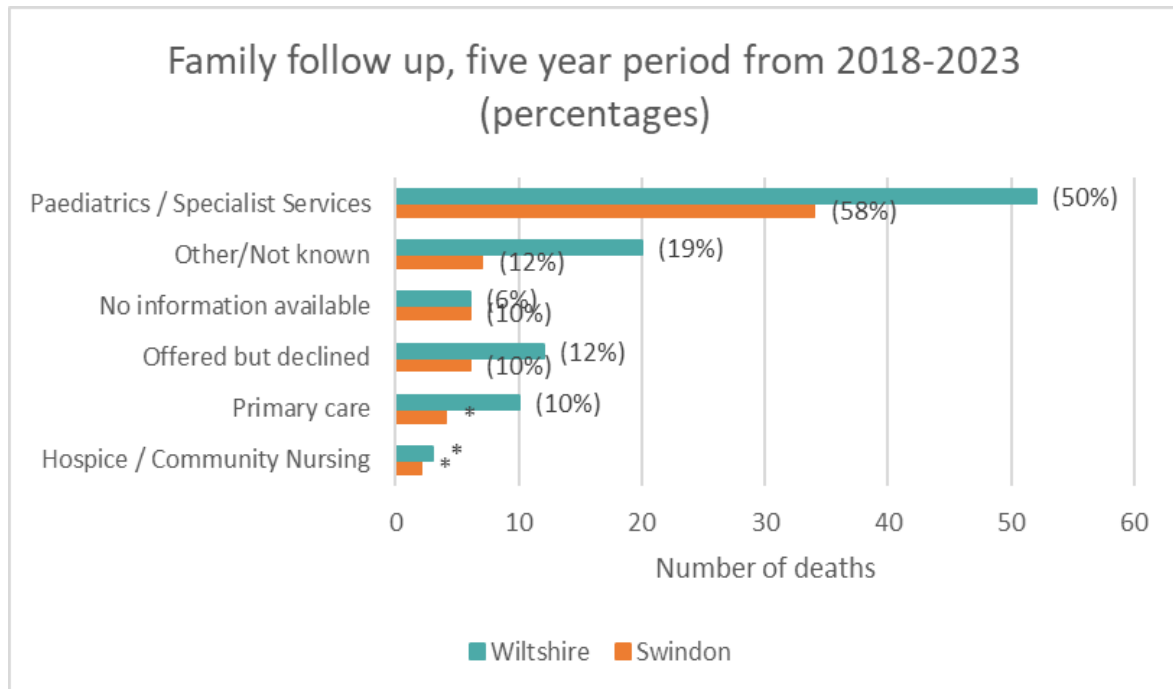


Figure 13: Family follow up, for Swindon and Wiltshire, five year period from 2018-2023
 (Note: Percentages might not add up to 100% due to rounding; * values of less than 5 have been suppressed)

In both Swindon and Wiltshire, half of families received follow-up from hospital or specialist paediatrics (53% of overall cases in both areas combined). This includes obstetrics, neonatology, cardiology and oncology. A further 10% of families received follow up from primary care (GP or health visitor) in both Swindon and Wiltshire. The hospice or community nursing organisations such as CLIC Sargent or the Lifetime Service routinely offer follow-up to any family they work with and between these agencies in both areas they offered follow-up to 3% of families who had a child who died during 2018-2023. More than one in ten families were offered follow-up but declined the offer (11% in both areas combined). Families are routinely given national and local information on charities offering bereavement support. Overall, there was either no information available or follow up status was not known for approximately one in four cases in Swindon and Wiltshire (22% and 25% respectively).

Appendix A - CDOP membership April 2022 to March 2023

	Core member	LSCB/Organisation
Nominated Chair	Katie Ash	Swindon Borough Council
Consultant in Public Health	Hayley Morgan	Wiltshire Council
Designated Doctor for Child Deaths	Fiona Finlay and Paul O'Keefe (Deputy)	BaNES, Swindon and Wiltshire CCG (BSW CCG)
Wiltshire Children's Social Care	Sarah James	Wiltshire Council
Swindon Children's Social Care	Fiona Francis Deputy Sharon Laird.	Swindon Borough Council
Designated nurse safeguarding children	for Robert Mills	BaNES, Swindon and Wiltshire CCG (BSW ICB)
Designated Nurse for Safeguarding Children	Jane Murray, replaced by James Dunne December 2022	BaNES, Swindon and Wiltshire ICB (BSW ICB)
Named Nurse for Safeguarding	Yasmin Gordon Charlotte Hinder	Swindon Borough Council Community Health Services Swindon Borough Council Community Health Services
Midwifery	Rebecca King	Great Western Hospital, Swindon
Obstetrics	Charlotte Sullivan	Great Western Hospital, Swindon
Paediatrics	Paul O'Keefe	Great Western Hospital, Swindon
Paediatrics	Philippa Ridley	Salisbury District Hospital, Wiltshire
Police	Lucy Thorne	Wiltshire Police
Ambulance Service	Chris Rogers	South Western Ambulance Service NHS Foundation Trust
GP Co-Lead (no longer able to attend)	Helen Osborne Michelle Sharma Both until September 2022	BSW CCG BSW ICB