NCMD
National Child Mortality Database

Knowledge, understanding and learning to improve young lives

A thematic review of vulnerability, which increases the risk of poor outcomes, in infants

Sudden, unexpected and unexplained infant deaths (Sudden Infant Death Syndrome, SIDS) over three months, between April 2019 and March 2020

National Child Mortality Database

Executive summary

The authors of this report wish to acknowledge that the death of each child is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family members, friends and professionals.

Purpose

- To describe the factors which may increase the vulnerability of infants.
- To identify the extent to which infants who die suddenly, unexpectedly and for whom cause of death is unexplained following review, are subject to pre-existing risk factors, within themselves, their family or their social or physical environment, which make them more vulnerable than average to poor outcomes or harm.
- To determine which of these pre-existing vulnerability factors increase the risk of sudden, unexpected and unexplained death in infancy the most.

Background

- The public health approach to vulnerability in children (1) defines vulnerable infants as those under the age of 1 at greater risk of experiencing physical or emotional harm and/ or experiencing poor outcomes because of one or more factors in their lives. These risk factors are assembled into 3 domains of vulnerability, as follows:
    - » Clinical vulnerability - underlying diagnosed health conditions and disability or limited access to health services – NHS lead responsibility;
    - » Statutory entitlement for care and support - increased risk due to family and social circumstances (education, health, and care plan and those with a social worker) – social services lead responsibility; and
    - » Social and family vulnerability - higher risk due to being negatively impacted through wider determinants of health and/or family stressors and social circumstances and may not be known to services – public health lead responsibility.

Infants (and children) may be in more than one domain and may move into or out of vulnerable states at different times.

- Universal health services, such as midwifery and health visiting, assess risks for pregnant women and for new parents and their infants in the context of the family and the home environment. These services reach almost the whole of the eligible population. This information, recorded routinely in health records, flows in anonymised format to maternity and community services datasets, which can be used for planning and research.
- Published statistics, from maternity and community services and other sources, including other services and population surveys, describe the extent to which pregnant women and infants experience different aspects of vulnerability. For example, in 2019/20 approx. 2.7 % of infants were identified by community services as vulnerable at some point during their life, i.e., if they have ever been classed as vulnerable, with one or more vulnerability factors identified, and 3.1% during 2020/21.
- These statistics can be used to compare the extent to which vulnerability factors are identified in cases where the category of death assigned, on completion of the child death review process, is sudden infant death syndrome (SIDS) with the extent to which the same or similar vulnerability factors are identified for all infants. This supports estimation of relative risk associated with the different vulnerability factors.

Methodology

- Records from the National Child Mortality Database (NCMD) (2) were identified for infants, from 3 months to less than 1 year, who died suddenly and unexpectedly during 2019/20 and for whom the death was unexplained when the investigation into their death was complete.
- Whist this is not the majority group, as SIDS are more common in those under 3 months, and especially in those under 1 month, the NCMD records for this, less studied cohort, are rich in background information on the infants and their circumstances.
- This selection resulted in 64 cases, which were reviewed in detail to identify vulnerability factors in the infant, their family, the circumstances in which they were living and the extent to which they were known to social services.
- The detailed review covered the coded information collected via the NCMD's standardised data collection forms and any additional detail which had been entered as free text. The vulnerability factors identified in individual cases were assembled into themes.
- This thematic review covered the 3 domains of vulnerability from the public health framework (clinical, statutory, and family or social) and the 4 domains from the NCMD investigations (factors intrinsic to the child, factors in social environment including family and parenting capacity, factors in the physical environment and, to a lesser extent, factors in service provision).
- The extent to which different vulnerability factors were identified in cases was quantified in addition to which domains of vulnerability they corresponded to, and the extent to which multiple vulnerabilities were identified within individual cases, both within domains and across multiple domains of vulnerability.
- Where statistics were available, which provided suitable comparators for the whole population of pregnant women, infants or families, the relative risk of sudden infant death syndrome (SIDS) associated with each vulnerability factor was estimated.
- This study is limited by the small cohort size [N=64] resulting in some data on less commonly identified themes being supressed, to protect confidentiality, and the availability of comparator statistics on the level of vulnerability factors in the whole population.

Results

- Some aspect of vulnerability was found in almost all cases; where 98.1% of cases had at least 1 vulnerability factor identified from the following domains:
  - Any clinical vulnerability factor – identified in 67.2% of cases.
  - Any statutory vulnerability factor – identified in 43.8% of cases.
  - Any family or social vulnerability factor – identified in 85.9% of cases.
  - Any environmental vulnerability factor – identified in 89.1% of cases.
  - Multiple dimensions of vulnerability were common within individual cases.
  - Using the public health framework,
    - 37.5 % have clinical, statutory, and family or social vulnerabilities, a further
    - 21.9% have clinical and family or social vulnerabilities, and a further
    - 21.9% have family or social vulnerabilities only.

- Adding the environmental domain to these,
    - 35.9% have clinical, statutory, family or social, and environmental vulnerabilities, a further
    - 17.2% have clinical, family or social, and environmental vulnerabilities, and a further
    - 20.3% have family or social and environmental vulnerabilities.

- The most commonly occurring clinical vulnerability factors include an underlying health condition (60.9%) and the infant being described by their parents or carers as unwell on the day of death (50.0%). Over a third of cases identify smoking in pregnancy (39.1%), a recent illness (39.1%) and prematurity (37.5%).

- More than four in ten cases are known to social services (statutory domain) (43.8%), either previously or currently.

- The most commonly occurring family or social vulnerability factors, identified in over half of cases, are smoking in either parent (62.5%), mother smoking (51.6%), father smoking (51.6%), poor mental health in either parent (56.2%) and poor mental health in mother (50.0%). Over a third of cases identified previous domestic abuse (not directly related to the death) (40.6%) and smoking in both parents (39.1%). Drug misuse and alcohol misuse have been identified as separate issues; recorded for either parent they are identified in over a quarter of cases (26.6% and 26.6% respectively).

- The most common occurring environmental vulnerability factor, identified in over three quarters of cases, is not necessarily following advice and guidance on safe sleeping (78.1%) and, identified in over half of cases, co-sleeping (51.6%). In 15.6% of cases the co-sleeping was unplanned, and the carer was under the influence of drugs or alcohol. Over a third of cases identify poor home environment (45.3%) and carer under the influence of alcohol or drugs (39.1%).

- It should be noted that NICE guidance [NG194] does not advise against bed sharing per-se but in circumstances involving low birthweight babies, smoking, drinking or drug use, with children or pets, with pillows or duvets nearby or on unsuitable surfaces such as a sofa or chair.

- When compared to the general population of infants, the relative risk of sudden unexpected death is estimated to be elevated by the presence of the following vulnerability factors:
    - 14 times higher – known to social services or with experience of domestic abuse.
    - 12 times higher – extreme prematurity (< 28 weeks) or very low birthweight (< 1,500g).
    - 9 times higher – infant's underlying health condition.
    - 5 times higher – prematurity (< 37 weeks), infant's recent illness, mother's poor mental health or young mother (< 20 years).
    - 4 times higher – mother's drug misuse during pregnancy, low birthweight (< 2,500g) or twin or higher order multiple.
    - 3 times higher – smoking in pregnancy.

Conclusions

- A wide range of pre-existing vulnerability factors, which increase the risk of poor outcomes, can be identified by reviewing cases of sudden infant death syndrome (SIDS) and the extent to which these factors occur in cases quantified. Population measures of child and maternal health, which are derived from routine health datasets and other sources, can be used as comparators to estimate the relative risk of SIDS associated with different types of vulnerability.

- Infants over 3 months old for whom death is classified as sudden infant death syndrome (SIDS) are almost always exposed to vulnerability factors which increase their risk of poor outcomes and/or harm. These may be inherent to the infant, resulting from a poor start due to prematurity or slow growth in the womb, or due to underlying health conditions or illness. These clinical risks may be exacerbated by, and sometimes driven by, vulnerabilities relating to the family or social environment. Household experience of domestic violence and/or abuse and being already known to social services indicate a significant elevation of risk for the infant. Mothers, who may be vulnerable themselves due to young age or poor mental health, further contribute to the vulnerability of their infants, particularly if they misuse drugs while pregnant.

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With very best wishes,

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Contents

Purpose

The overall aim of this work programme is:

- To identify and map the vulnerabilities which apply to, or are experienced by, infants in a way which categorises the vulnerabilities recorded in different datasets to generate insight into which vulnerabilities or combinations of vulnerability increase risk of death, harm or poor development outcomes.
- To quantify the relative risk of death and/or serious harm arising from each type of vulnerability and main combinations compared to having no identified vulnerability.
- To generate options for a more standardised identification and recording of vulnerability across different datasets.

The objectives of this study are:

- To complete a thematic analysis of vulnerabilities for infants who die, using records from the National Child Mortality Database (NCMD) (2), focusing on those modifiable factors (and contributory factors where they are also vulnerabilities) and relevant learning points which have been recorded.
- To develop an approach for quantification of the relative risks of infant death by comparing the prevalence of vulnerability factors for infants experiencing sudden infant death syndrome (SIDS) with those recorded for all infants.

This report will be of interest to policy makers, those commissioning or planning services, public health specialists, healthcare and social work professionals and researchers working in the field of child health and wellbeing, especially those specialising in child protection or the safeguarding of children and vulnerable families.

Background

Following several high-profile child deaths and serious case reviews The Office for Health Improvement and Disparities (OHID) have, in partnership, initiated several studies to determine what is known, across routine datasets, about vulnerable infants and their outcomes. These datasets are secondary datasets (as opposed to clinical records of care) and are extracted or assembled from hospital or community care records for example, for planning and research purposes to inform improvements in the quality of services and outcomes.

The outcomes under consideration across the series of linked studies include child development outcomes aged 2 (Community Services Dataset, CSDS) (3), serious incident notifications (with the Department for Education) (4) and mortality (in collaboration with the National Child Mortality Database, NCMD) (2).

The public health approach to vulnerability in children (1)

'Vulnerable infants' are defined as any children under the age of 1 year at greater risk of experiencing physical or emotional harm and/ or experiencing poor outcomes because of one or more factors in their lives. These factors may exist at the level of individual, family, community, or society. The former Public Health England (PHE), NHS England and partners developed a framework for vulnerability in children comprising three broad domains which are:

- Clinical vulnerability – underlying diagnosed health conditions and disability or limited access to health services – NHS lead responsibility;
- Statutory entitlement for care and support – increased risk due to family and social circumstances (education, health and care plan and those with a social worker) – social services lead responsibility; and
- Social and family vulnerability – higher risk due to being negatively impacted through wider determinants of health and/or family stressors and social circumstances and may not be known to services – public health lead responsibility.

Infants (and children) may be in more than one domain and may move into or out of vulnerable states at different times.

Vulnerability and development outcomes recorded by community services

OHID (includes the former PHE's Health Improvement functions) has published preliminary analyses from community services data (3) which predominantly originates from health visiting services. These clinically led home visiting services report a universal contact, the new birth visit, with population coverage of around 98%, when data for contact within and over 14 days following birth is combined (5). These early contacts by health services, which also start in the antenatal period for approximately 40% of pregnant women, inform risk assessments and identification of any additional needs. In terms of vulnerability these data show:

- Approx. 2.7 % of infants were identified by these services as vulnerable at any time, ever being vulnerable, with one or more vulnerabilities during 2019/20, and 3.1% during 2020/21 (6).
- Children flagged as ever being vulnerable are more likely to have received the prescribed schedule of Universal Health Visitor Reviews (antenatal review, new birth visit, 6-8 week review and 1 year review) than those with no vulnerabilities identified. Odds ratios: 2.6, 1.8, 1.9, 1.7 (7).
- A lower percentage of children flagged as ever being vulnerable reach the expected level of development at age 2 to $2^{1}/_{2}$ years than those who are not flagged as vulnerable, 78% versus 89% (8).

In community services data (CSDS) (3) vulnerabilities can be flagged, and also include additional information on 'safeguarding vulnerability factors', which have been identified and logged by health services as children and their families come into contact with them. The safeguarding vulnerability factors include: diagnosed condition, disability, repeat Accident & Emergency attendances, concerning parent child interaction, worrying parent behaviour/ mental health concerns, worrying child behaviour, self-harm, genital injury (excluding Female Genital Mutilation), referral from social services or police, previously known to social services, significant injury (in last 12 months), domestic abuse, history inconsistent with injury, disclosure of abuse, bullying, delay in presentation to medical staff, Female Genital

Mutilation, other, subject to child protection plan, ever looked after. These safeguarding vulnerability factors apply to all children and not all of them are relevant to infants.

Additional findings on vulnerability in infants (6), as recorded by community services, based on an analysis of approx. 1.1 million CSDS records over 2 years (approx. 550,000 per year), included: -

Older infants are more likely to be recorded as vulnerable, 3.3% of post neonates in 2020/21, than younger infants, 2.6% of neonates in 2020/21.

- Male and female infants were equally likely to be recorded as vulnerable.
- Infants of white ethnicity were more likely to be recorded as vulnerable than infants of any other ethnicity.
- The proportion of infants recorded as vulnerable increases with deprivation. Infants living in the most deprived decile were 3.6 times more likely to be recorded as vulnerable than infants living in the least deprived decile (4.5% compared to 1.2%, 2019/20 and 2020/21 combined).
- For infants with a recorded safeguarding vulnerability factor in any one year, the major reason given was 'domestic abuse' (4,000 to 5,000 records), followed by 'other or unknown reasons' (2,000 to 3,000 records) and 'worrying parent behaviour or mental health concerns' (1,000 to 2,000 records). At an order of magnitude lower (100 to 500 records), and in order of descending magnitude, reasons cited include 'previously known to social services', referral from social services or police' and 'worrying child behaviour'.
- Most infants identified as vulnerable had vulnerability factors from one domain of vulnerability (from the public health vulnerability framework) only, with approximately 4,000 to 5,000 infants in each domain of 'statutory'; 'family or social'; and 'other or unknown'. A smaller number of infants, 600 to 800, were recorded with 'clinical' as the only domain of vulnerability. Even fewer infants were recorded as ever having been subject to or exposed to two or even all three domains of vulnerability.
- Infants can accumulate vulnerabilities over time as more information is added to their records and move from one high level domain to another as their situation changes. Where infants become less vulnerable over time, the historic vulnerabilities will remain on their records. Hence, the cohort of infants who have ever been recorded as vulnerable at any time can only increase. Over time, data quality improvements should reduce the numbers of infants with safeguarding vulnerability factors recorded as 'other or unknown' as records become more specific.

Vulnerability recorded by child death reviews

The National Child Mortality Database (NCMD) (2) has published a thematic report on social deprivation (9) and two annual reports (10).

- The thematic report (9) shows that the risk of death increases as deprivation increases.
- The second annual report (10) identifies modifiable risk factors as – smoking in pregnancy, quality of service delivery, unsafe sleeping arrangements, substance/alcohol misuse, maternal obesity, access to services, poor communication/information sharing, domestic abuse, poor home environment, consanguinity (close relative marriage) and mental health.

Some of these overlap with the vulnerability factors identified in CSDS but not all.

Maternal health and behavioural risks recorded by maternity services

At the maternity booking appointment, ideally within the first 10 weeks of pregnancy, midwives make enquiries into the background circumstances including family and social support, background health conditions, both physical and mental health, obstetric history from previous pregnancies, family history and inherited conditions, lifestyle factors which increase risks such as smoking, drinking and drug use, diet and physical activity and measure body mass index (height and weight) to determine level of overweight or obesity.

These data, recorded within the Maternity Services Dataset (MSDS) (11) have been utilised to produce indicators of preconception health, which describe the health status of women as they become pregnant by focussing on those factors which are associated with poor maternal and neonatal outcomes. These prevalence indicators have been published in the Preconception Report Card for England, 2018/19, from the analysis of over 650,000 records of maternity care in MSDS (12).

Maternity records may have a flag for complex social factors which is used along with other factors to determine the care and payment pathway. Complex social factors include alcohol or drug misuse, recent migrant or asylum seeker status, difficulty reading or speaking English, aged under 20 and domestic abuse and are defined in NICE guidance (13).

Preconception indicators of maternal health which are pertinent to this study are outlined in Table 1.

Table 1 – Extract from Preconception Report Card for England, 2018/19.

Theme	Indicator	Prevalence, %	95% LCI	95% UCI
Wider determinants of health	Complex social factors	12.9	12.8	13.0
Health behaviours	Smoking around time of conception	19.5	19.4	19.6
	Obesity at booking	22.3	22.2	22.4
Pre-existing health conditions	Physical health condition	19.1	19.0	19.2
	Mental health condition	9.3	9.3	9.4

Maternity Services data have also been used to produce indicators of health during pregnancy for the Public Health Outcomes Framework (14) and the Child and Maternal Health Profiles (15), which are published on the OHID Fingertips Platform. These outcomes frameworks are designed for population surveillance, enabling the monitoring of trends over time at national and local level, benchmarking of local services and quantification of inequalities by different population subgroups.

A suite of indicators has been published on health in early pregnancy, which cover self-reported smoking, drinking and drug use during pregnancy and maternal obesity (from height and weight measurements) all recorded during the booking appointment for maternity services.

Health in early pregnancy indicators which are pertinent to this study are outlined in Table 2.

Table 2 – Extract from OHID's Public Health and Child and Maternal Health Profiles for England, indictors of maternal health at time of booking and delivery, 2018/19. (14, 15)

Theme	Indicator	Prevalence, %	95% LCI	95% UCI
Health behaviours	Obesity in early pregnancy	22.1	21.9	22.3
	Smoking in early pregnancy	12.8	12.7	12.9
	Smoking at time of delivery	10.6	10.5	10.7
	Drinking (alcohol) in early pregnancy	4.1	3.9	4.4
	Drug misuse in early pregnancy	1.4	1.3	1.5

All these health behaviours influence the environment in the womb, can impact the developing foetus and are associated with poor health outcomes.

The indicators presented in Table 1 and Table 2 are segmented by demographic factors (age of mother, ethnicity of mother and deprivation of area in which mother lives) and other factors such as whether this is a first or subsequent pregnancy and whether there are any complex social factors. Levels of maternal obesity, smoking (at either time of conception or at time of booking), drinking alcohol and drug misuse all increase as area deprivation increases. These indicators are also all at higher levels in a second or subsequent pregnancy than they are in a first pregnancy. The variation by age and ethnicity is more complex. Younger women are more likely to smoke and misuse drugs in pregnancy whilst older women are more likely to drink alcohol. Women of white ethnicity are more likely to smoke in pregnancy and drink alcohol in pregnancy than other ethnic groups, whilst women of black ethnicity are more likely to be obese in early pregnancy and to misuse drugs in pregnancy (15).

Birth characteristics and outcomes recorded from other health data

Indicators relevant to birth characteristics or birth outcomes are also published in NHS Maternity Statistics (16), some of which are included in the OHID Public Health Outcomes Framework (14) and the Child and Maternal Health Profiles (15). Some are derived from other sources such as the Office for National Statistics (ONS) publication on Birth Characteristics (17) or Birth Cohorts (18) and presented in a uniform format and some are calculated by OHID from Hospital Episode Statistics (HES). The ONS data is constructed mainly from birth registrations and the HES data from hospital admissions, maternity episodes for the mother and neonatal episodes for the infant. Indicators which are relevant to this study are presented in Table 3.

Table 3 – Pregnancy outcomes indicators from other sources, various dates

Indicator	Prevalence, %	Year	Source
Deliveries to teenage mothers, < 20 years	2.9	2019/20	NHS Maternity Statistics (16)
Multiple births (twin or higher order)	1.4	2020	ONS Birth Characteristics (17)
Low birthweight of all live babies (<2,500g) (at term and preterm)	6.5	2020	ONS Birth Characteristics (17)
Very low birthweight of all live babies (<1,500g) (at term and preterm)	0.8	2020	ONS Birth Characteristics (17)
Premature live births (< 37 weeks gestation)	7.4	2020	ONS Birth Characteristics (17)
Extremely premature live births (< 28 weeks gestation)	0.4	2020	ONS Birth Characteristics (17)
Small for gestational age, live births	6.2	2020	ONS Infant Mortality Birth Cohort Tables (18)
Hospital admissions of babies < 14 days	7.8	2020/21	HES – OHID Fingertips (15)

These indicators change over time and the date ranges selected are the closest match to the delivery year for the SIDS cohort in this study.

General health of infants and household smoking

The Health Survey for England (HSE) (19) is reported annually by NHS England, formerly NHS Digital. It is based on surveys of a representative cross section of households, adults (all aged over 16) and children, nurse visits and biological sampling. Relevant to this study, information is available for the prevalence of adult smoking and for children's general health. These are detailed in Table 4.

Table 4 – Child health and adult smoking from Health Survey for England, 2019

Indicator	Prevalence, %	Year	Source
Children in very good or good health, ages 0 and 1	96.0	2019	Health Survey for England (19)
Children with longstanding illness, aged 0 and 1	7.0	2019	Health Survey for England (19)
Children with limiting longstanding illness, aged 0 and 1	3.0	2019	Health Survey for England (19)
Children with acute sickness, aged 0 and 1	8.0	2019	Health Survey for England (19)
Smokers, men	18.0	2019	Health Survey for England (19)
Smokers, women	15.0	2019	Health Survey for England (19)

These statistics are limited by the fact that data for infants (aged 0) is combined with data for 1-year olds; smoking statistics are presented for all ages and don't readily distinguish between those who live in families with children and those who do not. In the past, data have been presented on children living in households where they are exposed to second-hand smoke, which are underpinned by analysis of saliva samples. These are not readily available for recent years but could be derived from the data stored on the National Data Archive to inform future studies.

These indicators change over time and the date ranges selected are the closest match to the delivery year for the SIDS cohort in question. The survey had to be scaled back in 2020 due to the coronavirus pandemic.

Children living with parents in emotional distress

The Department of Work and Pensions (DWP) report on the proportion of children living with at least one parent reporting symptoms of emotional distress, by family type and work status (20).

This information is available at England level from the Understanding Society Longitudinal Survey which uses self-completion of a 12 item General Health Questionnaire (GHQ-12). This is used as a screening tool for common mental health disorders but can also be utilised to identify a lower level of emotional distress with questions on sleep, self-confidence, worry and concentration. The cut off score used to identify emotional distress is a minimum score which relates to minor psychiatric morbidity such as anxiety or depression, and so prevalence estimates also include higher levels of mental ill health such as moderate and severe mental health disorders.

The proportion of children where at least one parent, mother, father, or both mother and father are reporting symptoms of emotional distress are detailed in Table 5.

Table 5 – Children living with parents in emotional distress, 2019/20 (20)

Indicator	Prevalence, %			
	At least one parent	Mother	Father	Both mother and father
Children living with parents in emotional distress	34.3	26.9	14.9	5.6

It is not possible to identify infants separately from the published data.

Perinatal mental health

NHS England, formerly NHS Digital, publish data on numbers of women in contact with mental health services who are new or expectant mothers. This comes from linking the mental health services dataset (MHSDS) (21) with the maternity services dataset (MSDS) (11) to identify women who are pregnant or who have given birth in the last year, from booking to one-year post-delivery. These are published as mental health services monthly statistics (22). The number of women aged over 16 who were in contact with community-based specialist perinatal mental health services was 35,673 (March 2020). This has not been population based and so there are currently no reliable prevalence figures. However, the cohort will be approximately 900,000 women as there are roughly 600,000 deliveries a year and the period in question covers the 6 months before delivery and one year after delivery. This gives a prevalence estimate of around 6%.

Prevalence data on domestic violence and abuse

Data are published on domestic abuse related incidents and crimes by ONS. These include data on offences and incidents recorded by the police in those aged 16 and over. Incidents and offences include threatening behaviour, violence or abuse (psychological, physical, sexual, financial, and emotional) between adults 16 or over who are or have been intimate partners or family members, regardless of gender or sexuality. These are published in OHID's Public Health Outcomes Framework (14), per head of population, see Table 6.

Table 6 – Extract from OHID's Public Health Profiles for England, indictors for wider determinants of health, domestic abuse, 2019/20. (14)

Theme	Indicator	Prevalence, %	95% LCI	95% UCI
Wider determinants of health	Domestic abuse related incidents and crimes	2.9	2.9	2.9

This is per head of adult population. It has not been possible to identify a more focussed prevalence indicator for those living with children.

Prevalence data from children's social care

Statistics on children's social care are published by the Department for Education (DfE) (23).

Out of the 12 million children, aged 0 to 17 years, living in England, just under 400,000 (3%) are in the social care system at any one time. For the year ending March 2020 this equated to 389,260 children out of 12,023,570, i.e., 3.2%. In the same period, 51,510 (0.4%) were subject to a child protection plan (CPP) (23).

In the year ending March 2020, there were 18,460 infants in need, i.e., in contact with children's social services. Based on ONS mid-year population estimates (24) for 2020, 601,913 aged 0 years, this is 3.1% of all infants. These population estimates are based on the 2011 Census and are due to be updated from the 2021 Census in due course.

Across all ages within children's social care, the main reason identified for referral into the system was abuse or neglect, cited in 55.8% of cases. The next most common reasons were family dysfunction (14.1%), family in acute stress (8.4%) and child's disability or illness (8.2%).

At the end of assessment by children's social care, the main risk factors identified across all cases were domestic violence by the parent (32.5% of cases) and the parent's mental health (29.8% of cases). These were followed by parental alcohol misuse (13.9% of cases) and parental drug misuse (13.6% of cases). These risk factors were associated with emotional abuse (21.1% of cases) and physical abuse (13.5% of cases).

Methodology

Review of the NCMD records which have been recorded by Child Death Overview Panels (CDOP) and further coded by NCMD staff plus more detailed thematic analysis of the free text entries.

The study population

Sudden unexpected, unexplained death in infancy are deaths that remained unexplained at the end of the CDOP review. These deaths are assigned the category of "Sudden unexpected, unexplained death" by the CDOP on the statutory analysis form. The definition of this category is: "Where the pathological diagnosis is either 'sudden infant death syndrome (SIDS)' or 'unascertained'.

For ease of reading, the term SIDS is used for the whole category including all sudden unexpected and unexplained death in infancy. The study population was initially proposed as infants who died under the age of 1 year in the period 1st April 2019 to 31st March 2020 (inclusive). This period is selected to predate the coronavirus pandemic and to provide sufficient elapsed time so that the vast majority of CDOP investigations will have been concluded. This resulted in an initial study population of 1,843. As this was too many for a thematic analysis which involves processing of free text it was decided to narrow the scope to focus only on infants who were classified on completion of review as experiencing sudden infant death syndrome (SIDS). These deaths were sudden, unexpected and unexplained. This is supported by the fact that the specific, supplementary child death review data collection form for this category of death provides more extensive detail on vulnerability factors than the forms associated with specific medical conditions, which are more focussed on clinical guidelines, patient pathway and service response.

Included in this study were any issues relating to:

- NCMD Domain A: Factors Intrinsic to the Child.
- NCMD Domain B: Factors in social environment including family and parenting capacity.
- NCMD Domain C: Factors in the physical environment.

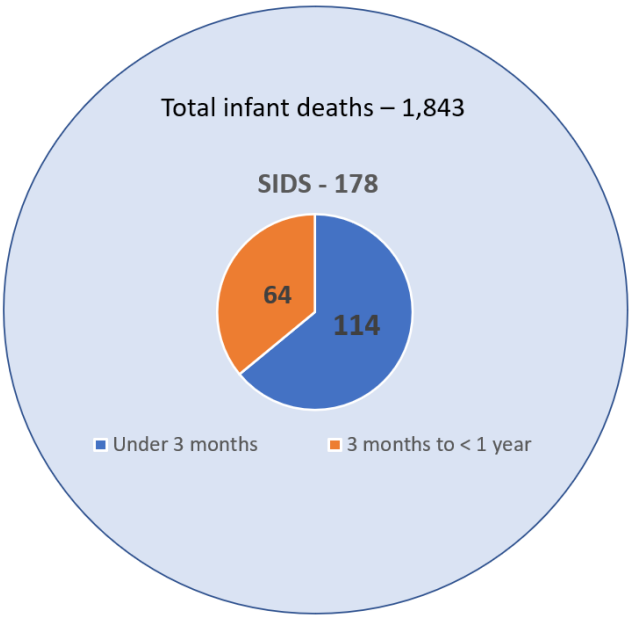
Whilst excluded were any issues relating to:

- NCMD Domain D: Factors in Service Provision

In the NCMD 2019/20 cohort of infant deaths with completed reviews 1,843 were recorded of which 178 had been classified as sudden infant death syndrome (SIDS). To make the study manageable the population was further reduced to infants who died in the post neonatal period (28 days to <1 year), and then narrowed further to only those over 3 months. This yielded a study population of 64 completed reviews, with age at death ranging from 90 days to 330 days.

The cohort on which this thematic review is based is depicted in Figure A.

Figure A – Study population



Themes of enquiry

The initial themes of enquiry were proposed as follows:

- **Demographics** – Age of mother (young mother <20, older mother >35), ethnicity of mother/infant, decile of deprivation, country of birth of mother.
- **Complex social factors** (13) – alcohol or drug misuse, recent migrant or asylum seeker status, difficulty reading or speaking English, aged under 20, domestic abuse (NICE definition, Overview | Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors | Guidance | NICE).
- **Health behaviours in pregnancy** – unplanned and/or unwanted pregnancy, late booking for antenatal care (> 13 weeks), very late (> 20 weeks) or no booking for antenatal care, smoking in pregnancy (at booking and at time of delivery), maternal obesity, alcohol use, substance misuse.
- **Circumstances of birth** – multiple birth, low birthweight at term (< 2,500g), low birthweight (< 2,500g), very low birthweight (< 1,500g), premature (< 37 weeks), extremely premature (< 28 weeks).
- **Family circumstances** – mother and/or father – consanguinity, relationship status, young mother <20 years, mental health problems, current smoker, substance misuse, substance misuse in treatment, domestic violence and/or abuse (with police involvement, without police), educational level, employment status, learning disability, physical disability, long term health condition, life limiting health condition, parent in prison, ex-offender, in contact with criminal justice system, experienced violence abuse or neglect as a child, financial worries (food bank, unserviceable debt etc).
- **Housing tenure** – unstable accommodation, homelessness.

- **Home environment** – smoking in the home, overcrowding, number in household, multigenerational, damp, too hot or cold, sleeping arrangements, lack of cot, co-sleeping, lack of safety equipment (smoke alarms, stair gates, window locks, cupboard locks etc).

- **Clinical** – diagnosed health condition, disability.

- **Statutory** – child in need, child protection plan, looked after child, in contact with social services.

The selected NCMD cases were reviewed, by reading through the detailed records, to identify any mention of these themes or the vulnerability factors which relate to them. If information pertinent to a particular theme or vulnerability was not identified, it was dropped, and others were added as the analysis progressed in response to the information recorded. In this way the themes and vulnerability factors were refined as the analysis progressed.

The prevalence of vulnerability factors was then quantified by the number and proportion of individual cases in which they appeared. The prevalence of vulnerability factors identified in the SIDS cases were then compared to the best available published prevalence for all pregnant women, infants, or families, from other sources. These comparators were predominantly sourced from official statistics or experimental statistics published as research and analysis, produced in line with the code of practice for official statistics, from ONS, the NHS or a government department.

Results

Vulnerability domain relating to clinical or health needs (factors intrinsic to the child)

Pregnancy environment

Cases were reviewed for any mention of vulnerability factors relating to the mother's health status or health behaviours which can influence the environment in the womb and affect the growth and development of the foetus, irrespective of whether these were hard coded via NCMD's standardised data collection forms or added to the NCMD database as free text. The results are shown in Table 7, with smoking during pregnancy identified in 39.1% [N=25] of cases.

Table 7 – Cases with vulnerability factors affecting the pregnancy environment

Vulnerability factor	Number of cases, N	Proportion of cases, %
Smoking in pregnancy	25	39.1
Alcohol misuse	3	4.7
Drug misuse	4	6.2
Maternal obesity	5	7.8

Other health behaviours which pose a risk to the unborn child are drug misuse and alcohol misuse during pregnancy, which were identified in 6.2% [N=4] and 4.7% [N=3] of cases respectively. The mother's weight status, in particular maternal obesity, measured at the antenatal booking appointment, is another risk factor associated with poor birth outcomes, is identified in 7.8% [N=5] of cases.

Other obstetric risks are conditions which are recorded as having developed during pregnancy including severe pre-eclampsia, gestational diabetes, and inter-uterine growth restriction (IGUR).

Birth characteristics or outcomes

Cases were reviewed for any mention of vulnerability factors relating to the birth which are risk factors for poor outcomes including multiple birth, prematurity, low birthweight, small for gestational age, and whether the infant was admitted to hospital for neonatal care, irrespective of whether these were hard coded or free text.

The results are shown in Table 8, 4.7% [N=3] involving a twin or higher order multiple.

Table 8 – Cases with vulnerability factors relating to birth characteristics

Vulnerability factor	Number of cases, N	Proportion of cases, %
Twin or higher order	3	4.7
Premature, <37 weeks	24	37.5
Extremely premature, < 28 weeks	3	4.7
Low birthweight, < 2,500g	16	25.0
Very low birthweight, < 1,500g	6	9.4
Small for gestational age	10	15.6
Neonatal care following birth	13	20.3

In 37.5% [N=24] cases the infant who died was born prematurely at < 37 weeks gestation; included in these numbers are 4.7% [N=3] of infants who were extremely premature, < 28 weeks gestation, at birth.

In 25% [N=16] cases the infant who died was born with a low birth weight at < 2,500g; included in these numbers are 9.4% [N=6] infants who were born with a very low birthweight, 1,500g.

In 15.6% [N=10] of cases the infants who died were small for gestational age when they were born. This possibly indicates failure to thrive or growth restriction in the womb.

In 20.3% [N=13] the infants were admitted to hospital for neonatal care following their birth. Most births were in hospital, but babies were occasionally delivered at home. Conditions treated following birth included jaundice [N=11], glucose stability [N=4], hypothermia, respiratory difficulties, suspected sepsis, and opiate dependency. Some cases [N=6] record treatment with antibiotics following birth.

Health status of infant

Cases were reviewed for any mention of vulnerability factors describing the health of the infant. These may be diagnosed health conditions or descriptions of ill health, whether these were hard coded or free text. The results are shown in Table 9, with 60.9% [N=39] cases reporting that the infant has an underlying health condition.

Table 9 – Cases with vulnerability factors relating to health status of the infant

Factor	Number, N	Percentage, %
Underlying health condition	39	60.9
Recent illness reported	25	39.1
Described as poorly on day of death	32	50.0

These underlying health conditions are not necessarily ones which would increase the risk of death and have not in any of the cases been identified as the cause of death. However, they all would place additional burden on the family in terms of caring responsibilities and additional appointments for assessment, treatment, and review, with healthcare professionals.

A formal diagnosis is referred to in 17.2% [N=11] cases and these cover cardiac conditions [N=6] and respiratory conditions, with some infants on home oxygen.

Poor growth and weight gain is identified in 12.5% [N=8] cases. Feeding difficulties are mentioned in a small number of cases [N=3] but there are also some diagnosed conditions which can impact on the action of feeding and absorption of food. These include 12.5 % [N=8] of infants with gastro oesophageal reflux (GOR), and some with tongue tie [N=4] and cow's milk protein allergy [N=4].

Some infants are identified as having an underlying development impairment or disability [N=4] and congenital anomalies or malformations [N=3].

It was also noted that in 12.5% [N=8] cases the infants were not up to date with their immunisations.

A recent illness in the infants who died was also identified in 39.1% [N=25] cases. In 17.2% [N=11] cases this recent illness was identified as respiratory tract infection. These were described as a cough or wheeze [N=7], a blocked or runny nose [N=3] and bronchiolitis [N=4]. Other infections included oral thrush [N=4].

Other symptoms identified during recent illness were high temperature or fever [N=3] and vomiting and/or diarrhoea [N=3] and sometimes a rash.

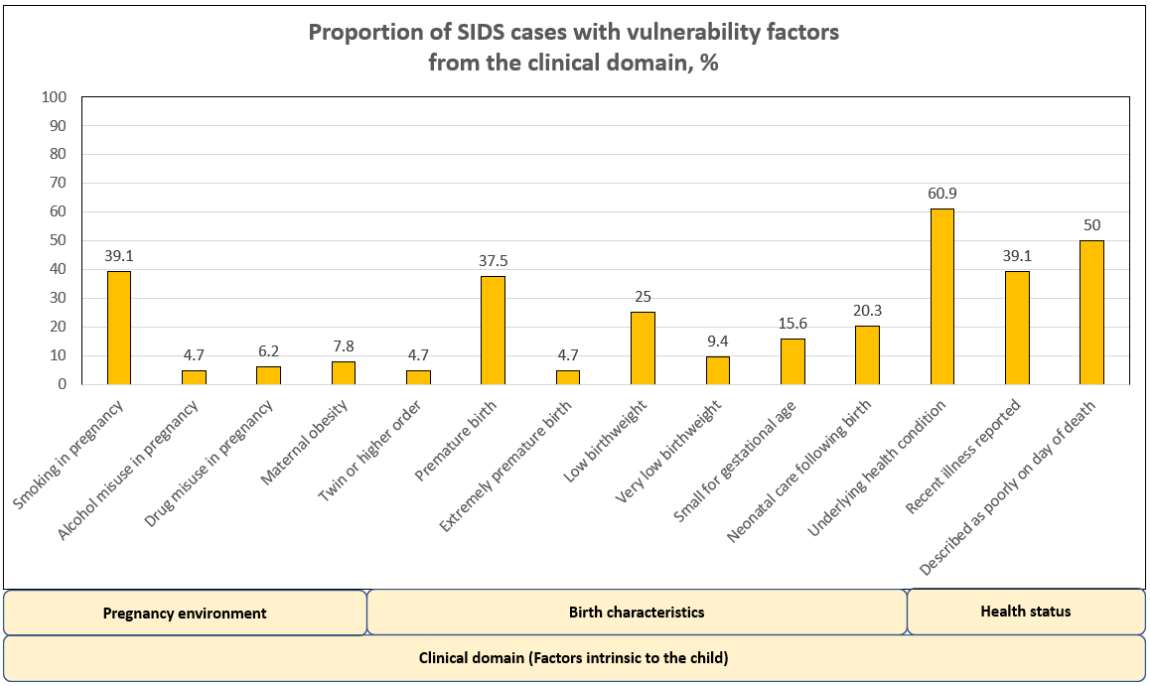
As a result of this recent illness, some attended the GP [N=6], some attended A&E [N=4], some were admitted to hospital [N=3], and some were prescribed a course of antibiotics [N=5].

On the day they died, 50.0% [N=32] of infants were described by those caring for them as poorly or behaving in a way which was not normal for them. In some cases, parents named or described the symptoms of common childhood illnesses. These included chest infections such as a cold [N=3], with a cough [N=6], blocked or runny nose [N=4] or a sniffle, in addition to descriptions of breathing difficulties such as breathing funny, being breathless or raspy. In some cases, the infant was described as off food or slow to feed [N=9], with vomiting [N=3] or with diarrhoea , sleepy or tired [N=4] or hot [N=3]. Some parents thought their infant was teething [N=4] as they were chewing, appeared hungry or were putting their hands in their mouths. Some parents described their infants as unsettled [N=6] and in more general terms as fidgety, grizzly, crying, whingey, fussy, or wriggly. Descriptions also included unwell or sickly, clingy, not normal self [N=3], not right and pale, floppy, or unresponsive.

Overview of clinical vulnerability factors

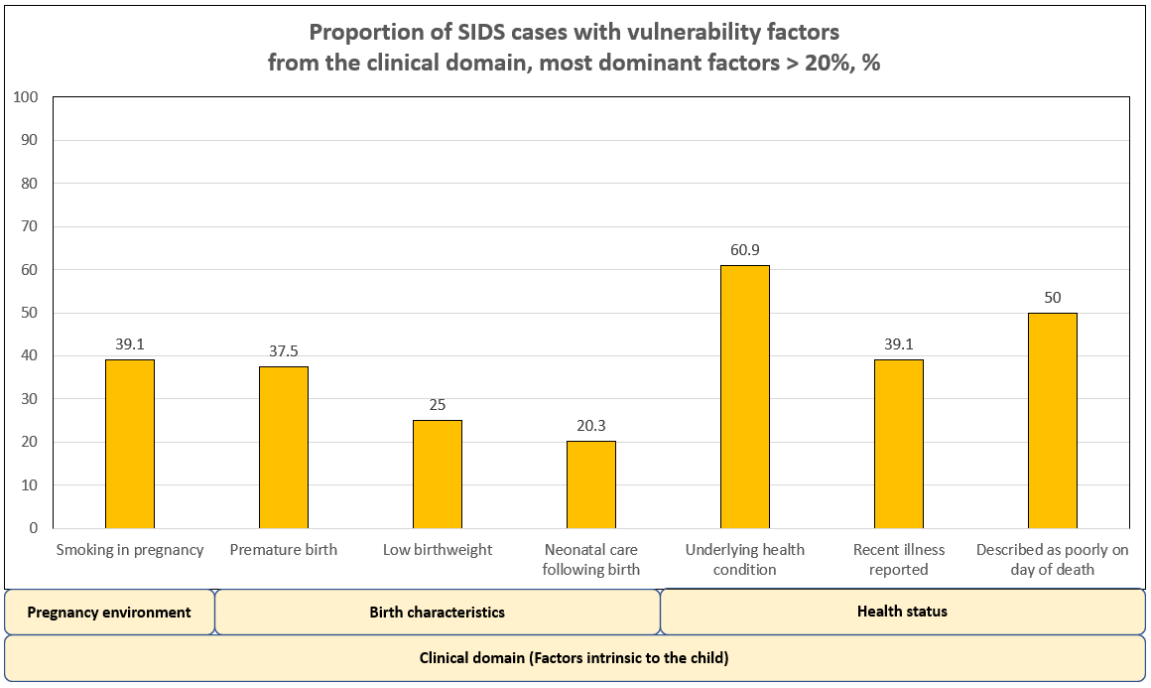
The proportion of cases with vulnerability factors identified relating to the themes of pregnancy environment, birth characteristics or outcomes and the health status of the infant are summarised in Figure B.

Figure B – Overview of vulnerability from the clinical domain



The vulnerability factors which are most common in the clinical domain, identified in at least 20% of cases are depicted in Figure C.

Figure C – Most common vulnerability factors in the clinical domain



Underlying health condition and the infant being described as poorly on the day of death are the most dominant factors identified in cases. These are followed by a recent illness reported, smoking in pregnancy, premature birth, and low birthweight.

Vulnerability domain relating to statutory entitlement to support

Cases were reviewed for any mention of contact with social services or statutory entitlement to support which relates to safeguarding of the infant and/or their siblings, whether these were hard coded or free text. This excludes any mention of social services contact or entitlement to support which relates to the parent/s, because in some cases the parents themselves are vulnerable as individuals in their own right. This is addressed separately in the section on parenting capacity.

The results are shown in Table 10, with 43.8% [N=28] cases reporting that the infant who died was known to social services, either previously, 25% [N=16] or currently, 18.8% [N=12].

Table 10 – Cases with vulnerability factors relating to social services

Vulnerability factor	Number of cases, N	Proportion of cases, %
Known to social services	28	43.8
Previously known to social services	16	25.0
Previous CIN, CPP or LAC	5	7.8
Currently known to social services	12	18.8
Current CIN, CPP or LAC	9	14.1

Of those previously known to social services (25% [N=16]), a smaller number of records (7.8% [N=5]), included specific mention of a previous status as a Child in Need (CIN), Child Protection Plan (CPP) or Looked After Child (LAC). Of those currently known to social services (18.8% [N=12]), again a smaller number of records included specific mention of CIN, CPP or LAC, (14.1% [N=9]).

The case records describe referrals to social services and risk assessments which are pending, ongoing or complete, which in many cases do not reach the threshold for the infant to be classified as a CIN or require a CPP. A classification as CIN or CPP would require continued engagement, monitoring and intervention from children's social care.

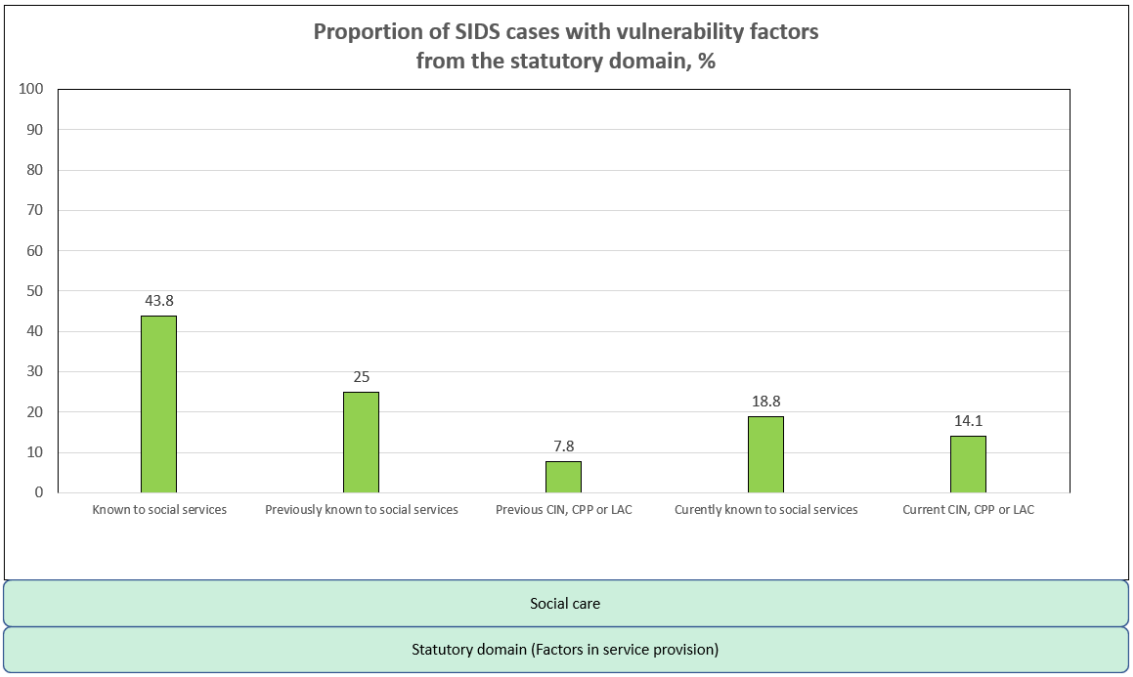
Reasons for a referral to or contact with social services start in some cases with the unborn child. This is especially relevant where the family, including older siblings, have a history with social care or where antenatal appointments or antenatal care is missed. Reasons for referral detailed in cases include child neglect, including concerns of underfeeding in cases of poor growth, both physical and emotional abuse and risk of sexual abuse. The cases identify issues of homelessness, poor home conditions or a chaotic home life with many family and/or social factors contributing to risks. These include domestic violence, parental drug misuse and dealing drugs, poor parental mental health and other concerns regarding poor parenting or parenting capacity, such as very young parents.

In some cases, family support is already in place and there is early help for older siblings. Examples include older siblings with additional needs, poor school attendance or sexualised behaviours and some siblings have already been removed into kinship or state care. Sometimes there are examples of a young mother and her infant together in foster care and some are in supported accommodation.

Overview of statutory vulnerabilities

The proportion of cases with vulnerability factors identified relating to the themes of known to social care and access to services are summarised in Figure D.

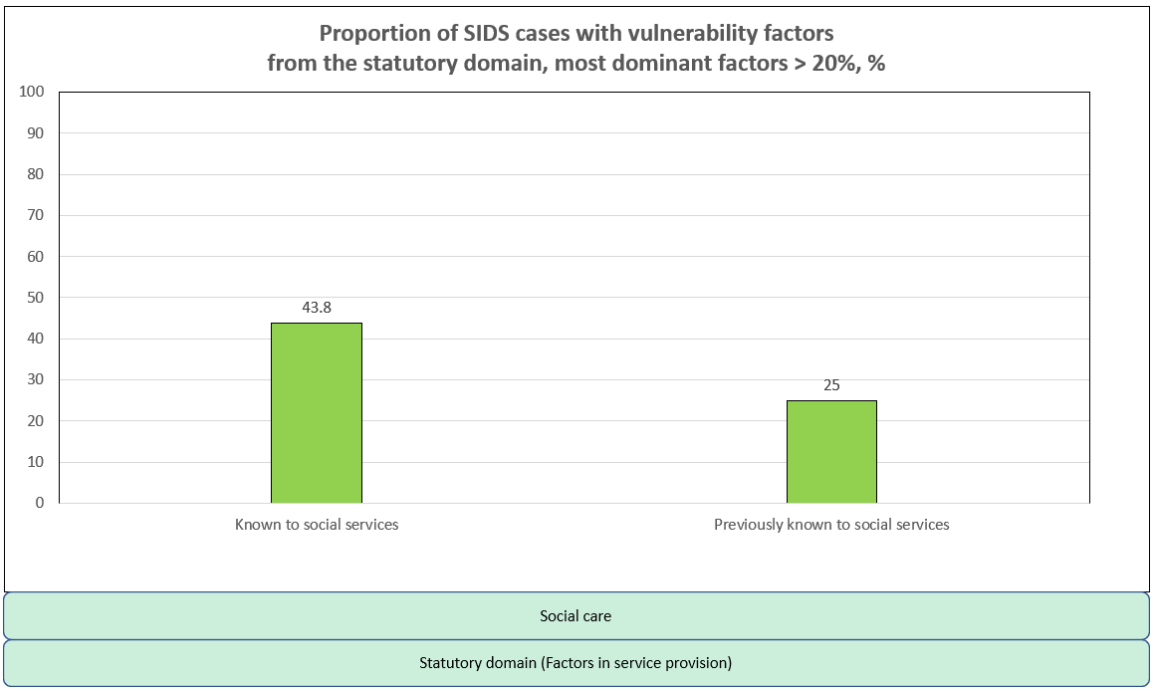
Figure D – Overview of vulnerability from the statutory domain



The NCMD domain D: Factors in Service Provision has been excluded from this study, from the perspective of the service, and issues to do with service response have not been considered. However, the extent to which parents and families engage with the universal and relevant specialist services has been covered. A statutory entitlement to care, or known to social services, a statutory vulnerability from the public health vulnerability framework would be classified by NCMD as related to service provision.

The vulnerability factors which are most common in the statutory domain, identified in at least 20% of cases are depicted in Figure E.

Figure E – Most common vulnerability factors in the statutory domain



Known to social services is the most dominant factor identified in cases.

Vulnerability domain relating to family or social factors

Smoking, drinking and drug use

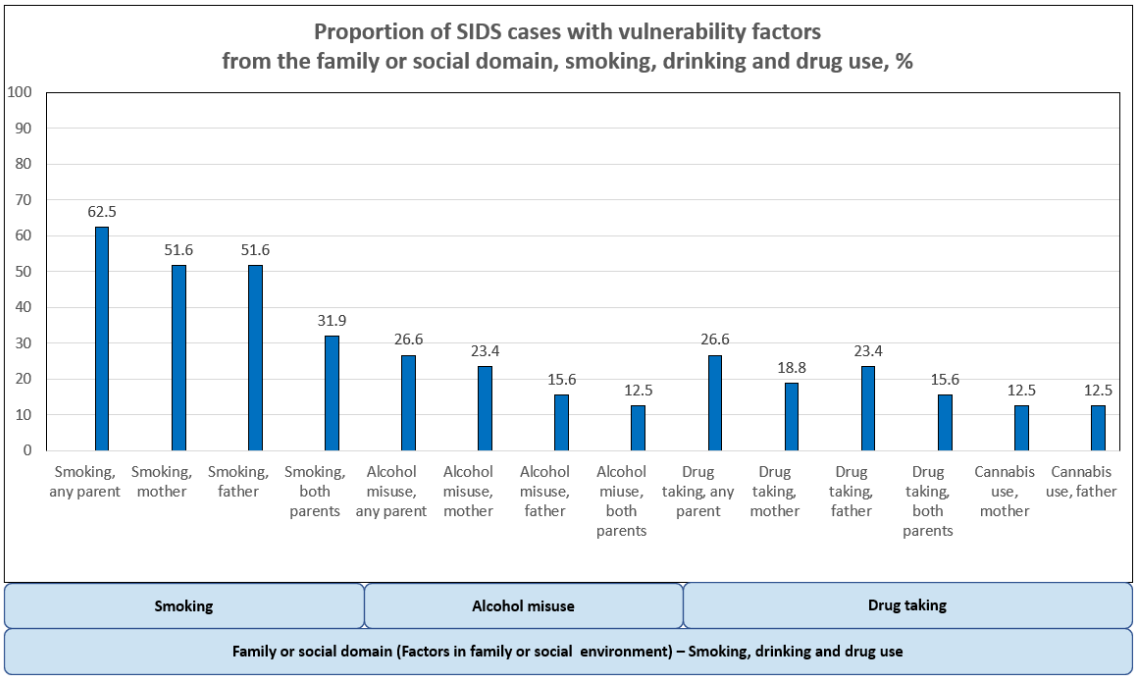
Cases were reviewed for any mention of smoking, drinking or drug use amongst the mother and father, irrespective of whether these were hard coded or free text. This excludes any information on smoking, alcohol misuse or drug misuse during pregnancy which are dealt with separately in the section on pregnancy environment.

The results are shown in Table 11 and Figure F, with 51.6% [N=33] of mothers and 51.6% [N=33] of fathers recorded as current smokers at the time of the infant death. In addition, 62.5% [N=40] of all cases had a least one parent, either mother or father, reported as a smoker and 39.1% [N=15] cases had both parents, both mother and father, reported as smokers.

Table 11 – Cases with vulnerability factors related to smoking, drinking and drug use

Vulnerability factor	Mother		Father		Any parent – Mother OR Father		Both parents – Mother AND Father	
	Number, N	Proportion, %	Number, N	Proportion, %	Number, N	Proportion, %	Number, N	Proportion, %
Smoking	33	51.6	33	51.6	40	62.5	25	39.1
Alcohol misuse	15	23.4	10	15.6	17	26.6	8	12.5
Drug taking	12	18.8	15	23.4	17	26.6	10	15.6
Cannabis	8	12.5	8	12.5	-	-	-	-

Figure F - Cases with vulnerability factors related to smoking, drinking and drug use



Some cases noted alcohol misuse by the mother (23.4% [N=15]) and some noted alcohol misuse by the father (15.6% [N=10]). In addition, 26.6% [N=17] of all cases had a least one parent, either mother or father, reported as drinking alcohol and in 12.5% [N=8] cases had both parents, both mother and father, reported drinking alcohol.

Some cases noted drug taking and/or misuse by the mother (18.8% [N=12]) and by the father (23.4% [N=15]). In addition, 26.6% [N=17] of all cases had a least one parent, either mother or father, reported as misusing drugs and in 15.6% [N=10] cases had both parents, both mother and father, reported as misusing drugs. Cannabis was the drug identified most often occurring with 12.5% [N=8] of mothers and 12.5% [N=8] of fathers. This is followed by cocaine identified separately for both mothers [N=3] and for fathers [N=4].

For the mother other drugs identified were amphetamines [N=3] and ecstasy, often with multiple different drugs being used by one individual. The range of drugs in use also included steroids, crack cocaine, ketamine, opiates, prescribed and non-prescribed sedatives and pain killers (such as benzodiazepine, used to treat anxiety and insomnia, and Tramadol, a synthetic opiate used to treat pain).

In the case records for fathers, the pattern of drug misuse was different to that of mothers. For fathers, there was no mention of amphetamines or sedatives but more detail on opiates including heroin and methadone. Details on fathers also included information on drug treatments services, in particular noting failure to engage with, failure to attend or disengagement from these services, whist there is no mention of the provision of or use of these services by mothers.

Mental health

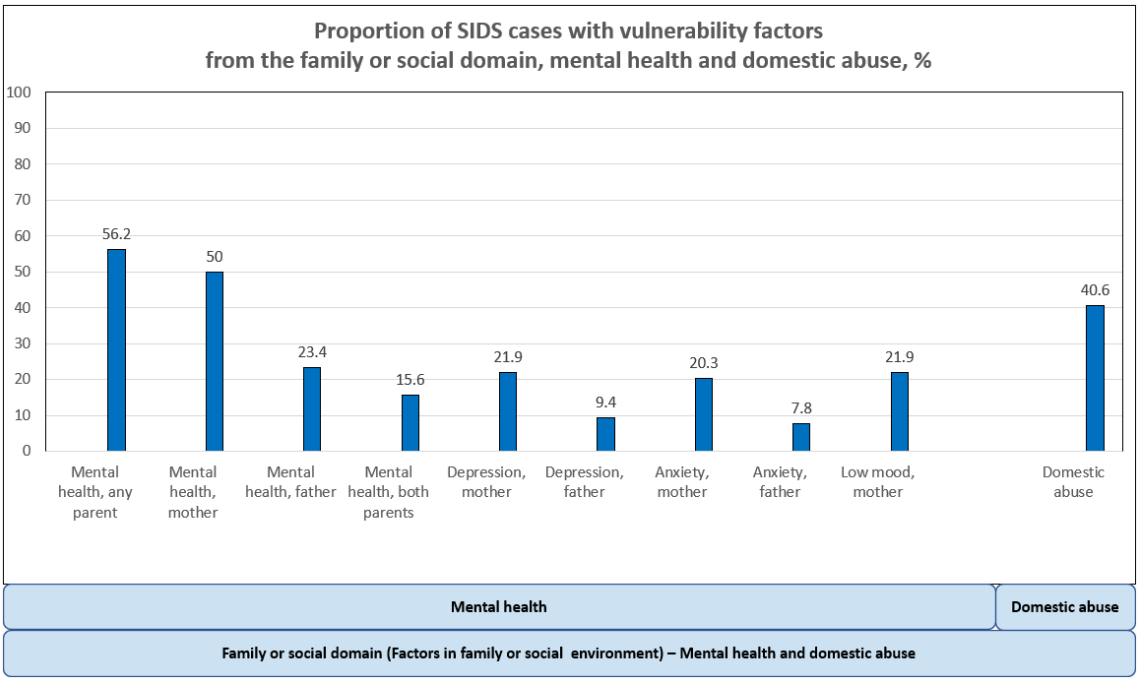
Cases were reviewed for any mention of mental health issues or poor mental health for the mother and father, irrespective of whether these were hard coded or free text.

The results are shown in Table 12 and Figure G, with 50.0% [N=32] of mothers and 23.4% [N=15] of fathers recorded as having problems with their mental health. In addition, 56.2% [N=36] of all cases had a least one parent, either mother or father, reported as having mental health problems and 15.6% [N=10] cases had both parents, both mother and father, reported as having mental health problems.

Table 12 – Cases with vulnerability factors related to metal health

Vulnerability factor	Any parent – Mother OR Father		Both parents – Mother AND Father	
	Number, N	Proportion, %	Number, N	Proportion, %
Any mental health issues	36	56.2	10	15.6
Vulnerability factor	**Mother**		**Father**	
	Number, N	**Proportion, %**	**Number, N**	**Proportion, %**
Any mental health issues	32	50.0	15	23.4
Mental health symptoms and/or diagnoses	25	39.1	11	17.2
Mental health services and/or treatments	19	29.7	9	14.1
Depression	14	21.9	6	9.4
Anxiety	13	20.3	5	7.8
Low mood/down	14	21.9	-	-

Figure G – Cases with vulnerability factors related to mental health and domestic abuse



The symptoms of poor mental health and/or diagnoses of mental health conditions are detailed in 39.1% [N=25] of cases for mothers and in 17.2% [N=11] of cases for fathers. Also contact with mental health services and/or treatments for mental health conditions are detailed in 29.7% [N=19] cases for mothers and 14.1% [N=9] cases for fathers.

The most common symptoms mentioned are depression for 21.9% [N=14] of mothers and 9.4% [N=6] of fathers and anxiety for 20.3% [N=13] of mothers and 7.8% [N=5] of fathers. Having low mood or feeling down is also reported in significant numbers for mothers at similar levels to depression, occurring in 21.9% [N=14] of cases, less so for fathers. Some cases also mention stress or distress [N=3], self-harm [N=5] and overdoses [N=4] in mothers, less so for fathers.

Further mental health diagnoses are recorded for mothers including postnatal depression or perinatal mental health issues [N=4] or post-traumatic stress disorder (PTSD) [N=3]. Cases of attention deficit hyperactivity disorder (ADHD) [N=3] are also recorded for mothers or fathers.

Additional detail for mothers includes reference to postpartum psychosis, personality disorders and difficulties with emotional regulation or anger management, agoraphobia, eating disorder and suicidal thoughts.

Additional detail for fathers includes reference to paranoia, bipolar disorder, behavioural problems or compromised functioning, emotional and psychological vulnerability and suicidal thoughts or ideation.

Family structure

Cases were reviewed for any mention of family structure, irrespective of whether these were hard coded or free text.

The results are shown in Table 13, with 57.8% [N=37] of families living in a nuclear family with parents co-habiting with their children and sometimes also children from previous relationships. In some cases, the parents are cohabiting, also living with extended family members in a multi-generational household.

Table 13 – Cases with factors related to family structure

Vulnerability factor	Number of cases, N	Proportion of cases, %
Parents cohabiting as nuclear family	37	57.8
Mother lives with children, no/ minimal father/partner contact	6	9.4
Mother lives with children, father lives separately	8	12.5

In 12.5% [N=8] of cases the mother lives with the children and the father lives separately. This includes fathers who are working away, including working abroad, living with their own extended family, living in their own homes or it is not clear where they live. In these cases, the father sometimes stays with the mother and child/children either because he is in an ongoing relationship with the mother or for the purposes of childcare. In these cases, the mother and her child/children sometimes [N=4] live with extended family members mainly but not always in a multi-generational household which includes grandparents.

In 9.4% [N=6] cases, the mother lives with the children and has no or minimal contact with the father. This includes cases where the father is working away on a permanent basis, is in prison or no information on the father is provided as part of the investigation.

Parenting capacity – physical health, disability, criminal history, adverse childhood experiences and other vulnerabilities

This section explores factors which may impinge on the capacity of the mother and/or father to successfully parent their children. It includes physical limitations due to the parents own ill health or disability, cognitive limitations which may be due to a learning disability or development disorder and emotional capacity related to their own young age, adverse experiences in their own childhood or their own vulnerabilities and need for care and support.

Also included in this section is whether the mother and/or father have any criminal record or history of crime, which can put additional strain on the parenting relationships. For example, having a parent in prison is known to be a risk factor associated with poor outcomes for children.

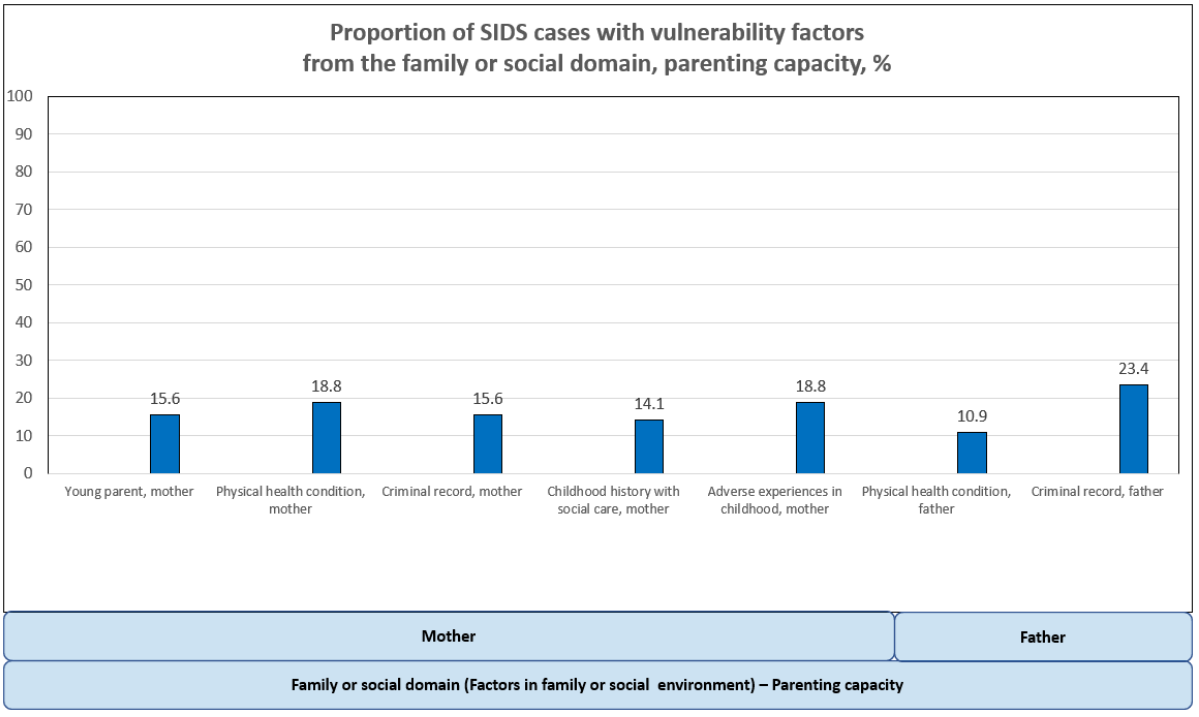
Excluded from this section are the factors found to be prevalent in serious case reviews, domestic abuse, mental health, and substance misuse, which are covered separately, and may have significant impact on parenting capacity depending on the circumstances.

The results are shown in Table 14 and Figure H, with 15.6% [N=10] of cases involving a young mother, under 20 years of age. Fewer cases have fathers under 20 years of age.

Table 14 – Cases with vulnerability factors related to parenting capacity

Vulnerability factor	Mother		Father	
	Number of cases, N	Proportion of cases, %	Number of cases, N	Proportion of cases, %
Young parent, < 20 years	10	15.6	-	-
Physical health condition	12	18.8	7	10.9
Criminal record or history of crime	10	15.6	15	23.4
Childhood history with social care	9	14.1	-	-
Adverse childhood experiences (ACEs)	12	18.8	-	-

Figure H – Cases with vulnerability factors relating to parenting capacity



In 18.8% [N=12] cases, the mother is recorded has having a physical health condition or disability and in 10.9% [N=7] cases the father. These health conditions are very variable but mostly of a long term, chronic nature or a physical disability which may impinge on everyday life and the delivery of routine tasks.

In the cases reviewed, some fathers [N=4] were recorded as having a learning disability or development disorder. These include Asperger's syndrome [N=3] and special educational needs or learning difficulties to the extent that they would find it difficult to parent alone, in some cases having their own legal guardian/s despite being of adult age. There is no information of this nature on any of the mothers' records in the cases reviewed.

In 15.6% [N=10] of cases, mothers had a criminal record or a history of crime and were at minimum known to the police. For fathers, this was 23.4% [N=15] of cases. For mothers, there were a wide range of incidents involving the police which led to few charges or convictions, some with suspended sentence or trial pending. The range of criminal incidents recorded for mothers included drunk and disorderly, anti-social behaviour, drug use, drug possession and selling sex for drugs, fighting in a public place, assault and battery, bodily harm including with intent, actual bodily harm, property damage, theft and domestic violence.

For fathers, the range of incidents was similar but potentially more serious including possession of class A drugs, drug dealing, conspiracy to supply heroin, actual bodily harm, gross bodily harm with intent, murder and domestic abuse including sexual assault on children. Fathers were more likely to have been charged and/or convicted than mothers. Some fathers had been in prison, some were currently in prison, and some were on bail or probation or had been placed on the sex offenders' register.

In 18.8% [N=12] the record for the mother included details of her own adverse experiences in childhood, with 14.1% [N=9] having her own childhood history with children's social care.

In some cases, the mother has support from social services for her own individual vulnerabilities and needs [N=4]. The reasons include experience of homelessness, being a very young parent or with additional vulnerabilities in her own right and receiving support from a social worker and in some cases a family support worker.

The records contain much less information about the childhood history and background circumstances of the father; however, for fathers there is the occasional noting of adverse experiences in childhood, including experience of physical and emotional neglect, and their own history of children's social care.

For mothers, the adverse childhood experiences described are wide ranging and themes include description of chaotic home environments, family discord, problematic drinking amongst carers, domestic violence and abuse, physical neglect and abuse, emotional neglect and abuse, sexual abuse, sexual assault and witness to this, sexual exploitation, risk of sexual exploitation and risk of other types of exploitation. Behavioural difficulties and risk-taking behaviours are also described during the mother's own childhood and safety or safeguarding concerns resulting in moves into kinship care or even being placed alone into temporary accommodation.

Domestic violence and/or abuse

Cases were reviewed for any mention of domestic violence and/or abuse, irrespective of whether these were hard coded or free text. In this case the violence and/or abuse relates to the adults in the family and their current and past relationships, experienced as adults. Their childhood experiences are considered separately in the section on parenting capacity which includes adverse childhood experiences (ACEs). The results are shown in Table 15 and Figure G (included in mental health section), with 40.6% [N=26] of cases flagging some record of domestic violence and/or abuse.

Table 15 – Cases with vulnerability factors relating to domestic violence and/or abuse

Vulnerability factor	Number of cases, N	Proportion of cases, %
Domestic abuse	26	40.6

Where additional information was available in records some violence/abuse was recorded as historic [N=8] or relating to a previous relationship [N=8]. Some records of violence/abuse were recorded as current [N=9] with acrimonious or volatile relationships [N=3], with verbal arguments involving shouting or screaming [N=5], and sometimes including extended family [N=4].

In some cases, police involvement for domestic violence/abuse was recorded [N=8], with some linked to social care referrals, assessments, or further action [N=5] and some cases involving a multi-agency risk assessment conference (MARAC) for high-risk individuals.

Some cases mentioned restraining or non-contact orders being in place or domestic violence protection notices (DVPN).

Controlling or coercive behaviour was mentioned in some cases [N=3].

Perpetration was found predominantly within intimate partner relationships but occasionally recorded as emanating from the wider family or community.

Access to services

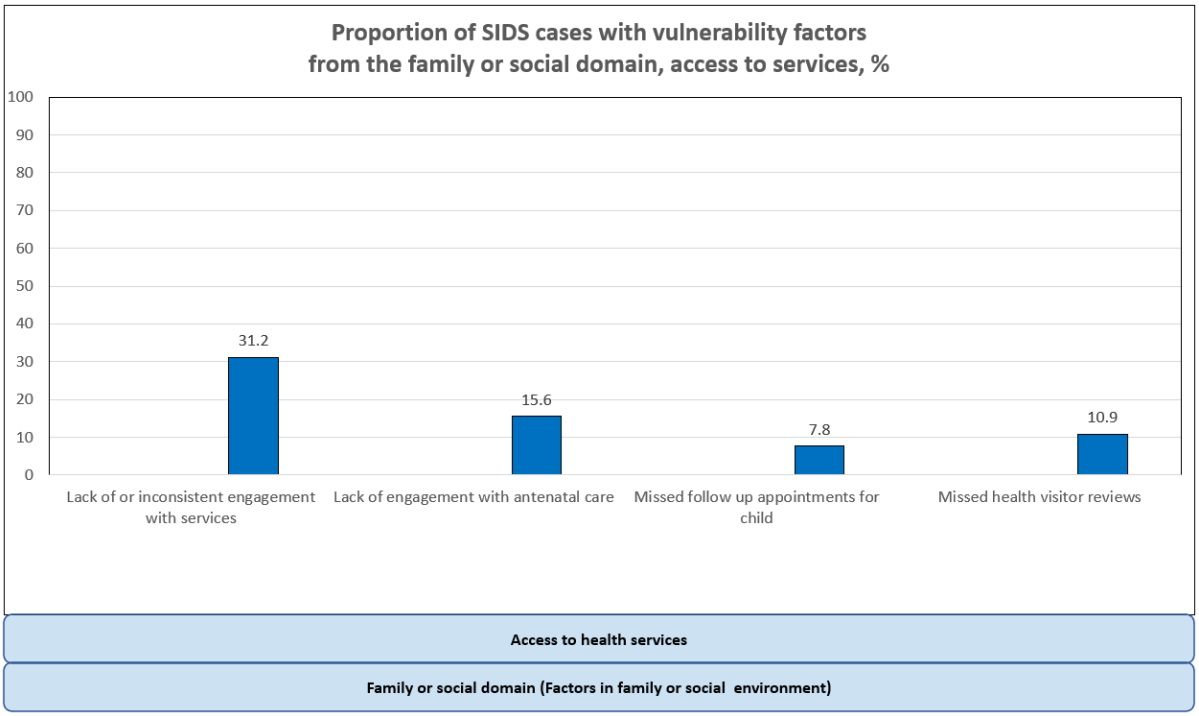
Cases were reviewed for any mention of failure to engage with universal services (such as maternity services or health visiting services) or services relevant to the health needs of the infant (such as paediatric services) in an appropriate or timely manner. The results are shown in Table 16, with 31.2% [N=20] of cases flagging a lack of or inconsistent engagement with relevant health services.

Table 16 – Cases with vulnerability factors relating to access to services

Vulnerability factor	Number of cases, N	Proportion of cases, %
Lack of or inconsistent engagement with services	20	31.2
Lack of engagement with antenatal care	10	15.6
Missed follow up appointments for child	5	7.8
Missed health visitor reviews	7	10.9

This data is presented graphically in Figure I.

Figure I – Cases with vulnerability factors related to access to services



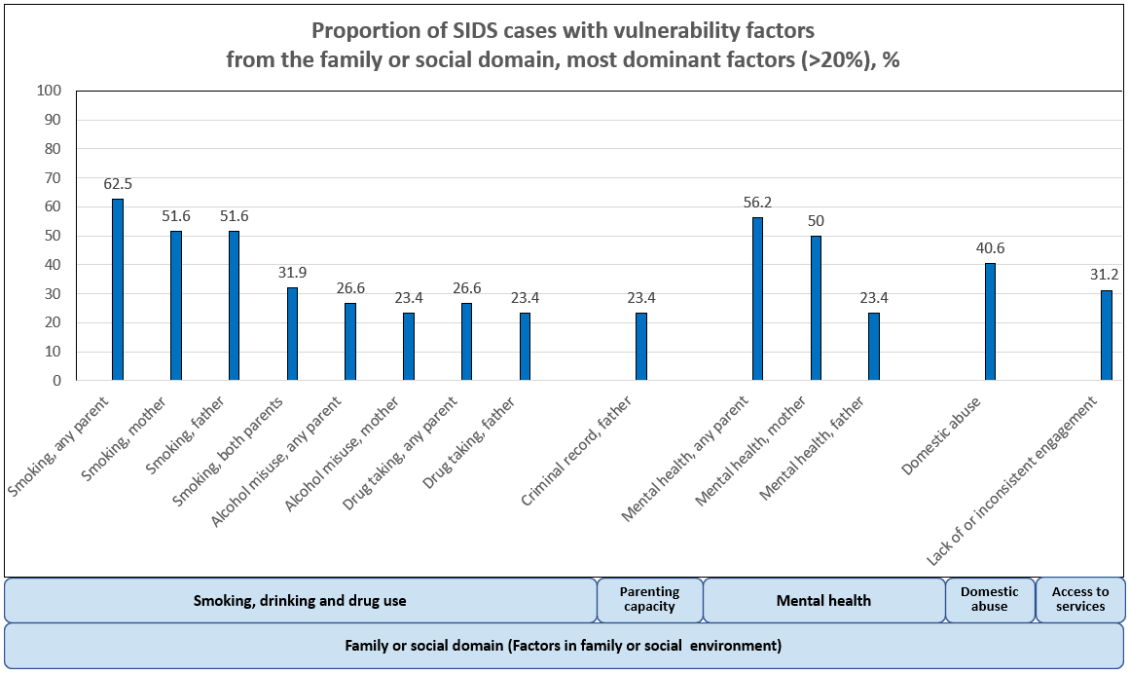
In 15.6% [N=10] cases, a lack of engagement with the antenatal care provided by midwifery services was noted. NICE recommends an antenatal booking appointment with midwives happens before 10 completed weeks of pregnancy in order to benefit from the full range of antenatal screening (including ultrasound scans and blood tests for infectious diseases etc). In some cases [N=4], booking for antenatal care was either very late (> 20 weeks of pregnancy) or did not happen at all and in some cases [N=4], missed antenatal appointments were noted.

All pregnant women and their children are eligible for a universal series of health reviews conducted by health visitors and their teams. The schedule consists of five health reviews – antenatal, new birth visit, 6–8 week review, 1 year review and 2 to 2$^{1}/_{2}$ year review. At these reviews, the health needs of the mother and infant are assessed in the context of the family and the home environment, and additional ad-hoc contacts arranged in line with the level of support required. In some cases (10.9% [N=7]) it was noted that the mother and infant had missed health visitor reviews. In addition, some families had missed specialist health appointments tailored to the specific health needs of their infant (7.8% [N=5]).

Overview of family or social vulnerability factors

The proportion of cases with vulnerability factors identified relating to the themes of smoking, drinking and drug use, parenting capacity, mental health and domestic abuse are summarised in Figure J. Due to the large number of vulnerability factors identified in this domain only the most commonly occurring, identified in over 20% of cases, are depicted.

Figure J – Overview of vulnerability from the family or social domain



Smoking and mental health are the most dominant factors identified in over half of all cases, five out of ten cases. These are followed by experience of domestic violence and/or abuse a factor which is identified in four out of every ten cases. Lack of or inconsistent engagement with services, either for antenatal or infant care, is identified in three out of ten cases and may also be considered as a commonly occurring vulnerability factor in this domain.

Vulnerability relating to the physical environment (Factors in the physical environment)

Home safety and conditions

Cases were reviewed for any mention of poor home environment or issues relating to safety within the home environment, irrespective of whether these were hard coded or free text. The results are shown in Table 17, with a poor home environment flagged in 45.3% [N=29] of cases.

Table 17 – Cases with factors relating to the home environment

Vulnerability factor	Number of cases, N	Percentage of cases, %
Poor home environment	29	45.3
Not in usual place of residence	11	17.2
Staying with extended family or friends	8	12.5

Additional detail on home environment was recorded on individual cases where the risk factors were identified as overcrowding [N=7], i.e., there were too many people for the space available, with unsuitable sleeping arrangements [N=4], i.e., insufficient beds for the number of people and a poor state of repair.

The home was also described as cluttered [N=10], untidy [N=6], muddled [N=3] or messy. Some homes were described as dirty and/or unhygienic [N=6], with dirty nappies on the floor. In some cases, large and/or multiple dogs or other pets were recorded as being at the home [N=5], sometimes with dog faeces around the house.

In 17.2% [N=11] of cases the infant was recorded as not in their usual place of residence at the onset of the incident or illness which led to their death. In 12.5% [N=8] of cases they were away from home and staying with extended family or friends. In addition, some were abroad or travelling at the time.

Unsafe sleeping

Cases were reviewed for any mention of the circumstances of the infant's final sleep which is not in line with national guidance on safe sleeping, whether hard coded or in free text. Whilst NICE guidance [NG194] does not advise against bed sharing per-se, it is not recommended in circumstances involving low birthweight babies, smoking, drinking or drug use, with children or pets, with pillows or duvets nearby or on an unsuitable surfaces such as a sofa or chair. It is not known how closely CDOPs adhere to this precise definition.

The results are shown in Table 18, with 78.1% [N=50] possibly not following at least one aspect of the guidance on safe sleep.

Table 18 – Cases with vulnerability factors relating to unsafe sleeping

Vulnerability factor	Number of cases, N	Proportion of cases, %
Not following advice and guidance on safe sleeping	50	78.1
Unsafe sleeping - planned	25	39.1
Unsafe sleeping - unplanned	13	20.3
Carer under influence of alcohol or drugs	25	39.1
Inconsistent account given	11	17.2
Co-sleeping	33	51.6
Co-sleeping - planned	16	25.0
Co-sleeping – unplanned and carer under influence of alcohol or drugs	11	15.6
Inappropriate/unsuitable surface or situation	41	64.1
Co-sleeping on an adult bed	20	31.2
Co-sleeping on sofa	8	12.5
Not following guidance on positioning or wrapping	12	18.8
Position for sleep – on back	22	34.4
Position for sleep – on side	5	7.8
Position for sleep – on front	5	7.8
Position in which found – on back	12	18.8
Position in which found – on front	22	34.4
Room hot, over 20 degrees C	8	12.5

Unsafe sleeping which is planned is recorded in 39.1% [N=25] of cases and that which is unplanned is recorded in 20.3% [N=13] of cases.

In 39.1% [N=25] of cases, the carer was under the influence of drugs or alcohol at the time of the sudden, unexpected, unexplained death or circumstances which led up to it. Also, in 17.2% [N=11] of cases, an inconsistent account of the circumstances leading up to the final illness or death was given to professionals attending the scene or providing care in a hospital setting.

In 51.6% [N=33] cases, co-sleeping was recorded, that is the infant who died was sharing a sleeping surface with one or more adults or children. In 25% [N=16] cases, the co-sleeping is recorded as planned and in 15.6% [N=11] cases the co-sleeping is recorded as unplanned and with a carer who is under the influence of drugs or alcohol. In some cases [N=4], there was potential overlay of the infant by an adult or child.

In 64.1% [N=41] cases, the infant was placed on or in an inappropriate or unsuitable surface or situation. This included co-sleeping in an adult bed in 31.2% [N=20] cases, which is not considered unsafe if no other risk factors are present, and co-sleeping on a sofa in 12.5% [N=8] cases, which is considered unsafe. Other unsuitable or potentially unsuitable sleeping surfaces which featured in the cases were detailed as follows: air bed, reclining sofa chair, cushions on floor, shaggy rug on floor, travel cot, baby bouncer, outgrown Moses' basket and a rear facing car seat.

In 18.8% [N=12] cases, the guidance on positioning or wrapping the infant for sleep was not followed. In some cases, positioning for sleep was recorded with 34.4% [N=22] cases in line with the guidance where the infant was placed for sleep on their back. Out of line with the guidance were cases of positioning for sleep on the side, 7.8% [N=5] and on the front, 7.8% [N=5]. In addition, a small number of cases the infant was propped up, including some unsupervised self-feeding. In some cases, the infant was recorded as being left unattended or unsupervised in the care of a sibling.

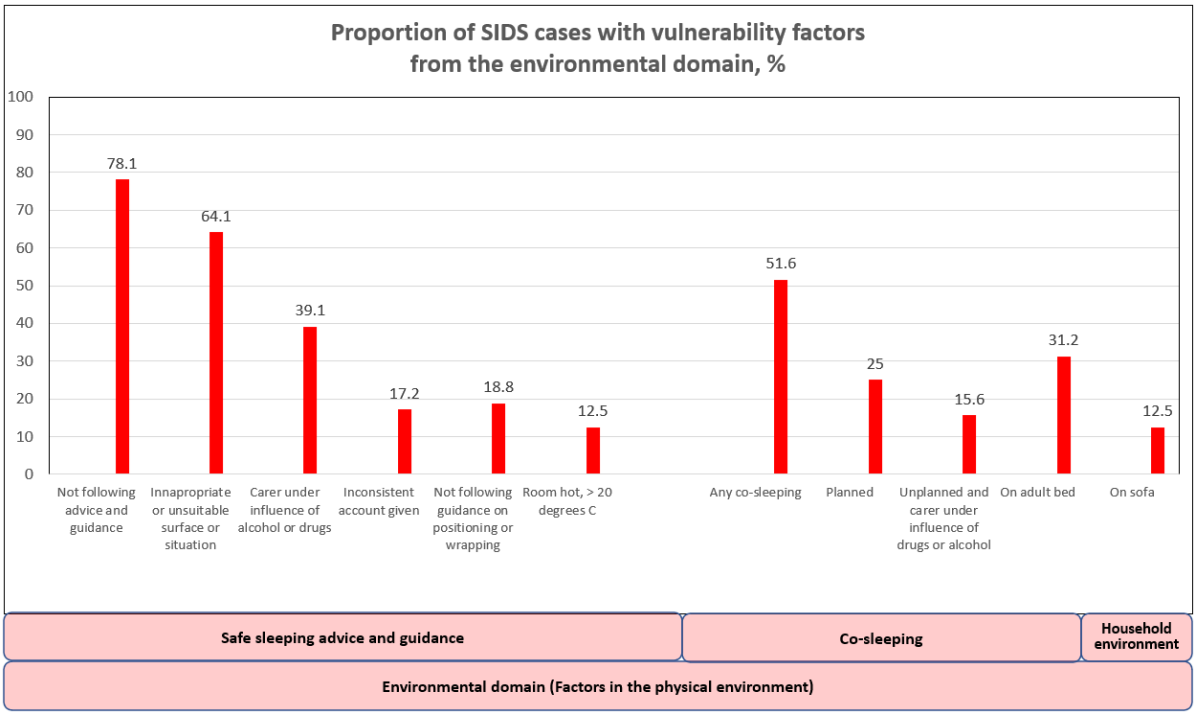
In some cases, the position in which the infant was found was recorded, with infants being found on their back in 18.8% [N=12] of cases and on their front in 34.4% [N=22] of cases. In addition, some infants were recorded as being found between the bed and the wall, with a sibling lying on top of them [N=3], with a pillow on top or with a blanket over or partially covering their head [N=3].

In 12.5% [N=8] cases the room temperature was recorded as being hot, that is over 20 degrees Celsius.

Overview of factors in the physical environment

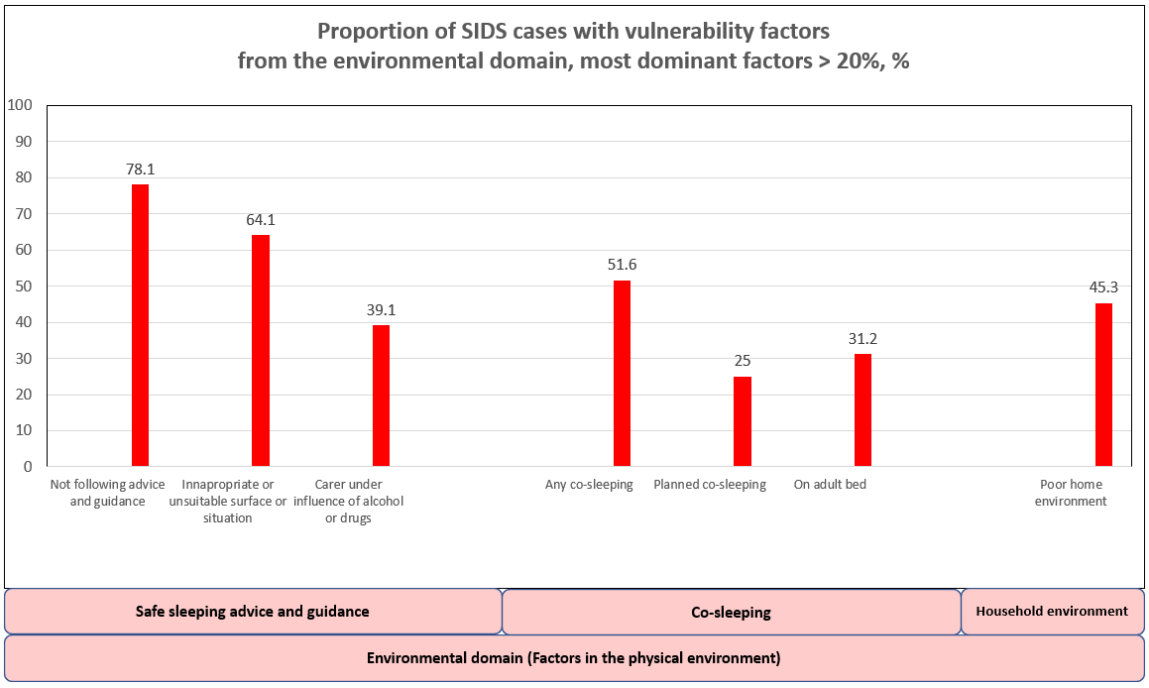
The proportion of cases with vulnerability factors identified relating to the themes of not following safe sleeping advice and guidance, co-sleeping and household environment are summarised in Figure K.

Figure K – Overview of vulnerability from the environmental domain



The vulnerability factors which are most common in the environmental domain, identified in at least 20% of cases are depicted in Figure L.

Figure L – Most common vulnerability factors in the environmental domain



Not following advice and guidance on safe sleeping, inappropriate or unsuitable surface or situation and any co-sleeping, which may be safe or unsafe according to the definition from the 2021 NICE guidance, are the most dominant factors identified in cases. These are followed by poor home environment and carer under the influence of drugs or alcohol.

Any vulnerability factors

The SIDS cases were reviewed using the framework developed for a public health approach to vulnerability in children, which considers three broad domains of vulnerability as follows:

- PH Clinical vulnerability domain – underlying diagnosed health conditions and disability or limited access to health services
- PH Statutory vulnerability domain – statutory entitlement for care and support - increased risk due to family and social circumstances (education, health and care plan and those with a social worker)
- PH Social and family vulnerability domain – higher risk due to being negatively impacted through wider determinants of health and/or family stressors and social circumstances and may not be known to services

The SIDS cases were reviewed for any mention of any vulnerability factors grouped under the PH vulnerability domains of:

- PH Clinical vulnerability domain – pregnancy environment, birth outcomes, access to services and underlying health conditions
- PH Statutory vulnerability domain – statutory entitlement – any contact with or known to social care and
- PH Family or social vulnerability domain – smoking, drinking or drug misuse, poor mental health, domestic violence and/or abuse and factors impacting on parenting capacity

The results are presented in Table 19, with 95.3% [N=61] of cases having at least one of these vulnerability factors and 4.7% [N=3] of cases having none of these vulnerability factors.

Table 19 – Cases with vulnerability factors identified within the public health domains of vulnerability

PH Vulnerability Domain(s)	Number of cases, N	Proportion of cases, %
Any clinical, statutory, family or social	61	95.3
Any clinical	43	67.2
Any statutory	28	43.8
Any family or social	55	85.9
No clinical, statutory, family or social	3	4.7

Of the reviewed SIDS cases, 67.2% [N=43] had at least one clinical vulnerability factor, 85.9% [N=55] had at least one family or social vulnerability factor and 43.8% [N=28] had a statutory vulnerability factor in that they were known to social services. Most of the cases known to social services also had family and/or social vulnerability factors identified but not all the cases with family and/or social vulnerability factors were known to social services.

In 3 out of the 64 cases reviewed no clinical, statutory, or family/social vulnerability factors were identified in the CDOP reports. In these low-risk cases, safe sleeping guidance was sometimes not followed.

Environmental risks in the home environment are considered separately as they are not covered by the framework developed for a public health approach to vulnerability in children, neither do they feature in mainstream health datasets which originate with midwifery or community-based health services. The findings are presented in Table 20.

Table 20 – Cases with vulnerability factors identified within the NCMD domains of vulnerability

NCMD Vulnerability Domain(s)	Number of cases, N	Proportion of cases, %
Any environmental	57	89.1
Any clinical, statutory, family or social, or environmental	63	98.4
No clinical, statutory, family or social, or environmental	1	1.6

Of the reviewed SIDS cases, 89.1% [N=57] had a least one vulnerability factor from the environmental domain. This domain includes risks in the home environment or not following national guidance (NG194) on safe sleeping. This guidance covers provision and use of a safe sleeping environment including a suitable sleeping surface (cot with correct type of mattress), not co-sleeping when other risk factors are present (in line with the 2021 NICE guidance), positioning, wrapping and room temperature.

Of the SIDS cases reviewed, almost all (98.4% [N=63]), had at least one vulnerability factor identified from the domains of either clinical, statutory, family or social, or environmental risks. In only 1 case were no vulnerability factors identified from any domain either clinical, statutory, family or social, or environmental.

These findings are summarised in Figures M and N.

Figure M – Cases with any vulnerability factor identified

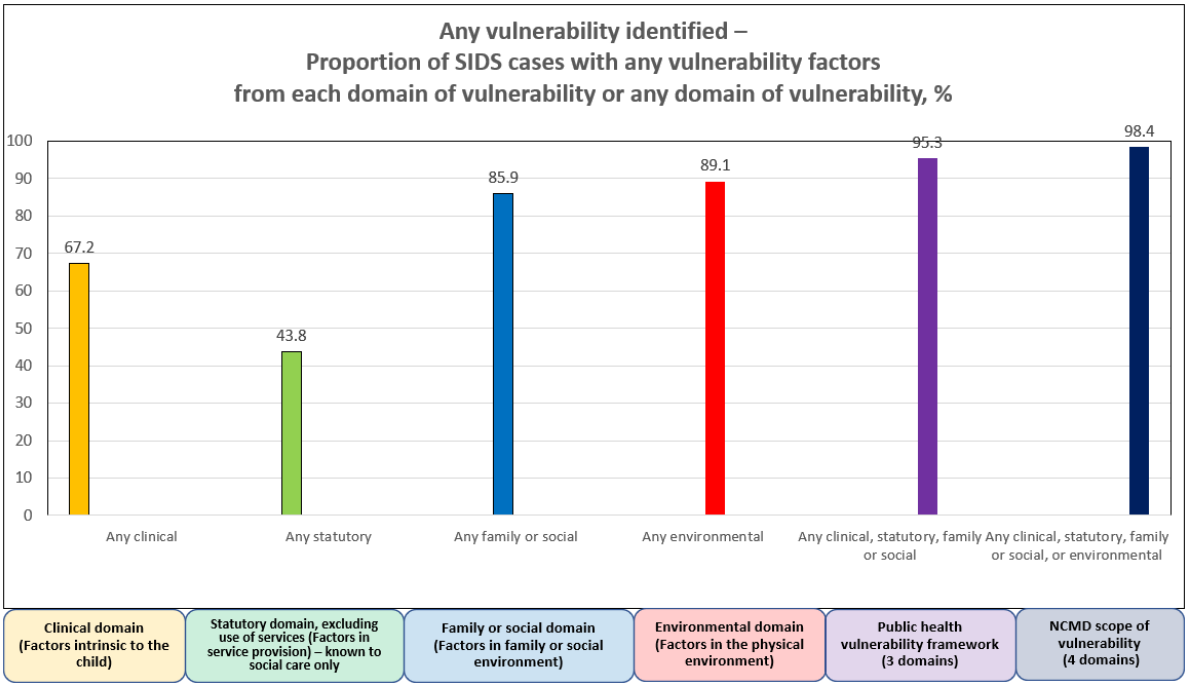
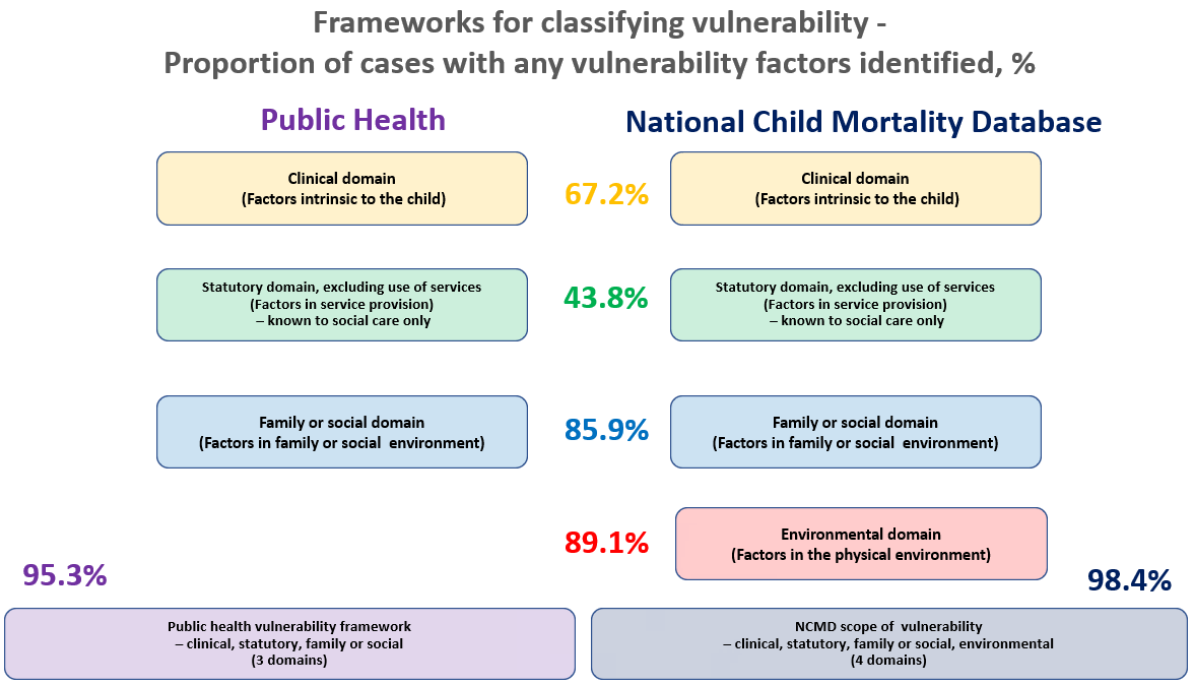


Figure N – Cases with any vulnerability factor identified



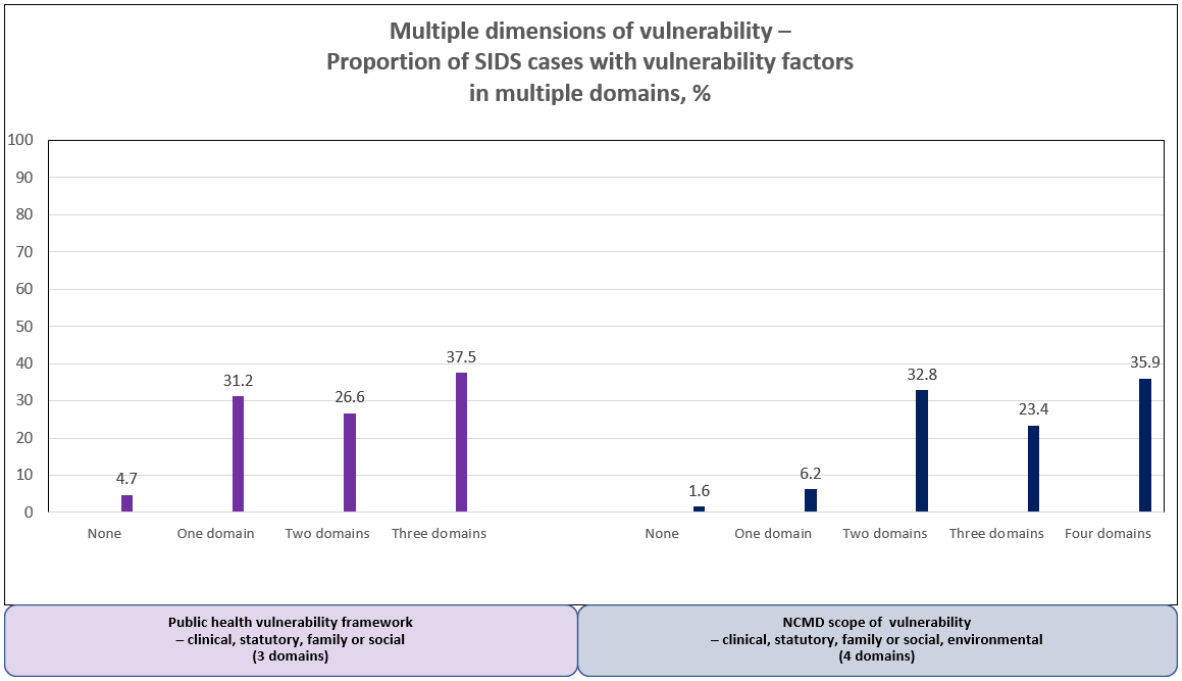
Multiple vulnerability factors

Overall, the infants in the SIDS cases reviewed carry a very high burden of vulnerability factors, risk factors which make them more vulnerable than the average to poor outcomes or harm, including death. In most cases one or more vulnerability factors are identified and, in many cases, multiple vulnerability factors are identified which span across the different domains of vulnerability including clinical, statutory, family or social and environmental. Table 21 and Figure O outlines the extent to which vulnerability factors from the different domains of vulnerability co-exist within cases.

Table 21 – Cases with multiple vulnerability factors across multiple domains of vulnerability

Vulnerability domain(s)	Number of vulnerability domains across which vulnerability factors are identified	Number of cases, N	Proportion of cases, %
Clinical, Statutory, Family or Social	0	3	4.7
	1	20	31.2
	2	17	26.6
	3	24	37.5
Clinical, Statutory, Family or Social, Environmental	0	1	1.6
	1	4	6.2
	2	21	32.8
	3	15	23.4
	4	23	35.9

Figure O – Cases with multiple vulnerability factors across multiple domains of vulnerability



Using the framework developed for a public health approach to vulnerability in children, with its three domains of vulnerability, clinical, statutory, and family or social, 31.2% [N=20] of cases identify risks within one domain only, 26.6% [N=17] across two domains and 37.5% [N=24] across three domains.

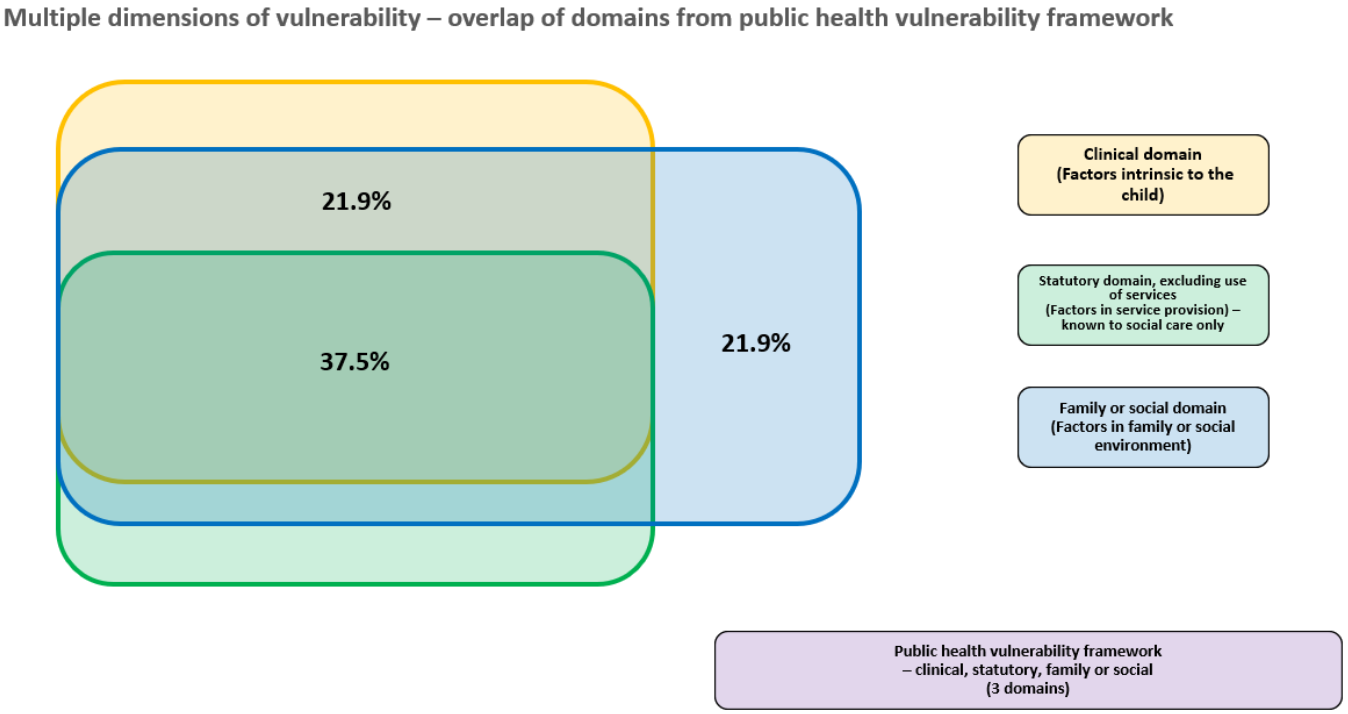
Adding the environmental domain to these, 6.2% [N=4] of cases identify vulnerability factors within one domain only, 32.8% [N=21] across two domains, 23.4% [N=15] across three domains and 35.9% [N=23] cross four domains.

The way in which these domains of vulnerability overlap within cases is also of interest. Most of the cases identified have risks in multiple domains of vulnerability. Table 22 outlines the way in which vulnerability domains overlap in both the public health vulnerability framework (3 domains) and the NCMD scope of vulnerability (4 domains, including environmental). Figures P and Q depict these overlaps for the public health framework of vulnerability and the NCMD scope of vulnerability respectively.

Table 22 – Cases with overlapping domains of vulnerability

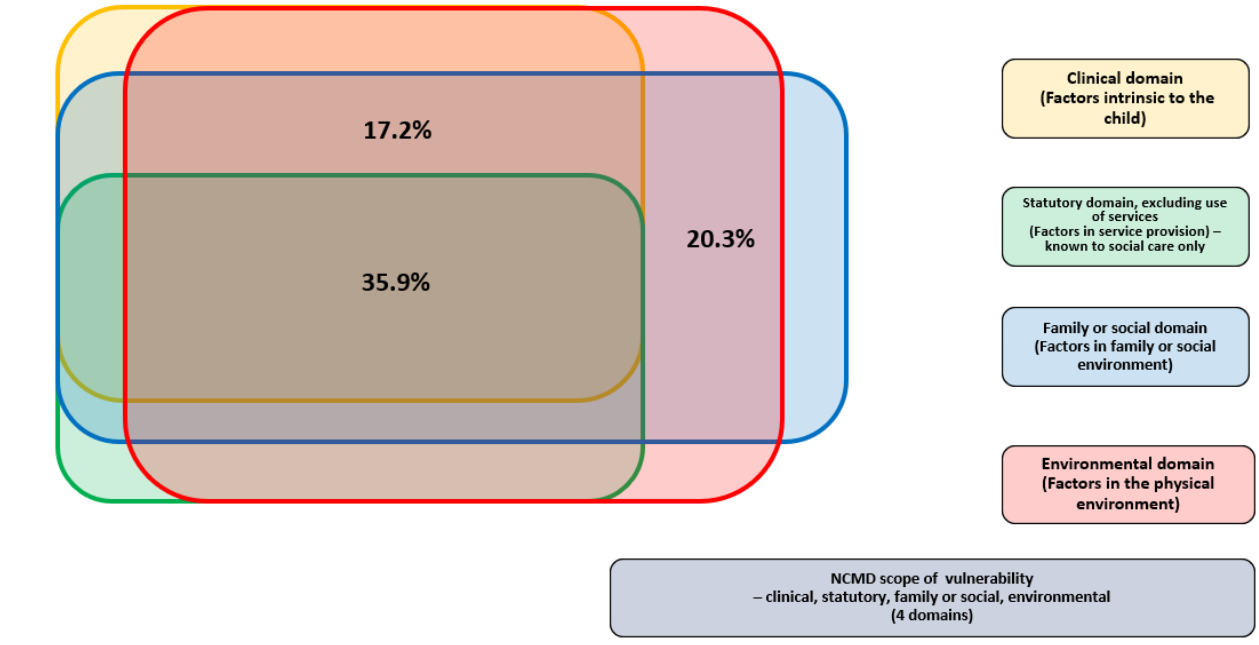
Framework/ Scope	Vulnerability domains in which vulnerability factors are identified				Number of cases, N	Proportion of cases, %
	Clinical	Statutory	Family or social	Environmental		
Public health vulnerability framework	Yes	Yes	Yes	n/a	24	37.5
	Yes		Yes	n/a	14	21.9
			Yes	n/a	14	21.9
NCMD scope of vulnerability	Yes	Yes	Yes	Yes	23	35.9
	Yes		Yes	Yes	11	17.2
			Yes	Yes	13	20.3

Figure P – Cases with overlapping domains of vulnerability, public health vulnerability framework



Using the framework developed for a public health approach to vulnerability in children, with its three domains of vulnerability, clinical, statutory, and family or social, 37.5% [N=24] of cases identify risks across all three domains, a further 21.9% [N=14] identify risks across the clinical and family or social domains, and a further 21.9% [N=14] identify risks from the family or social domain only.

Figure Q – Cases with overlapping domains of vulnerability, NCMD scope of vulnerability



Considering the NCMD scope of vulnerability by adding the environmental domain, 35.9% [N=23] of cases identify risks across all four domains. In addition, 17.2% [N=11] identify risks across clinical, family or social and environmental domains and a further 20.3% [N=13] of cases identify risks from the family or social domain and the environmental domain.

Relative risks associated with domains of vulnerability

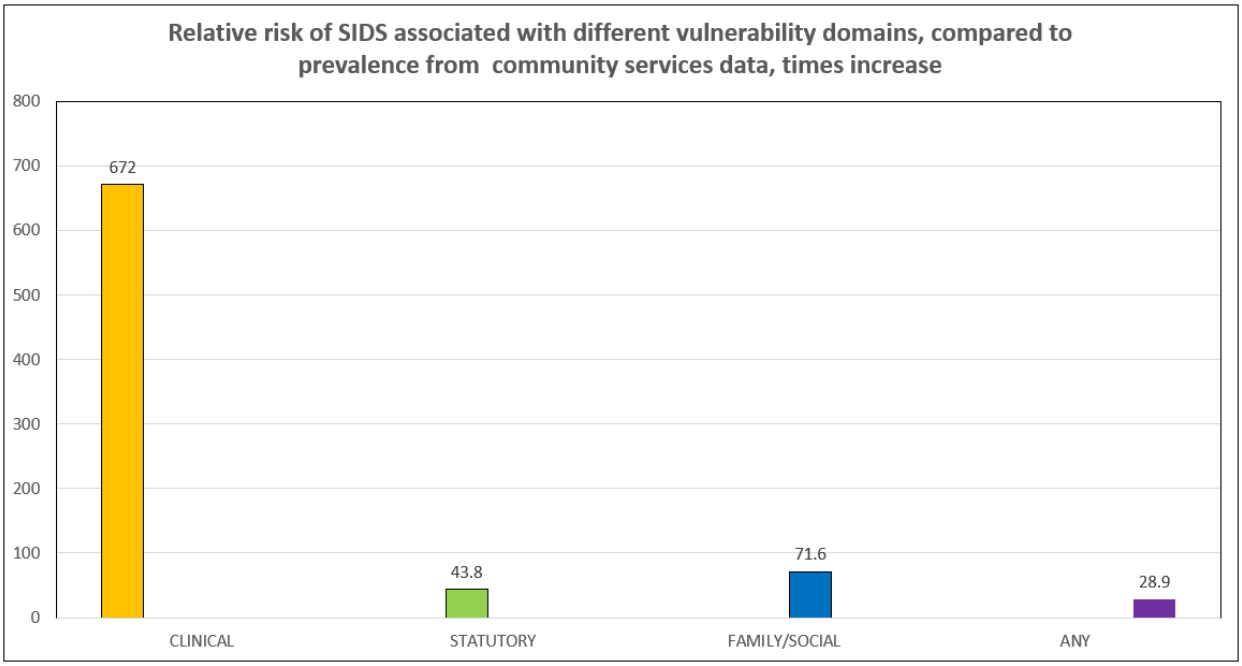
Some of the safeguarding vulnerability factors which occur frequently in the child death records are also found in routine datasets for children (community services data), pregnant women (maternity services data) and in other statistics and survey data for families. These vulnerability factors are not recorded in the same way in different professional settings, in that the data items and definitions may not be identical, but they are broadly similar and intended to monitor the same aspect of vulnerability. In any event, the health data is all ultimately derived from the same source, i.e., medical or clinical records of care.

The public health vulnerability domains recorded in the SIDS cases and their selected comparators from the general population of infants recorded in the community services dataset are outlined in Table 23 and depicted in Figure R.

Table 23 – Relative risk of SIDS associated with vulnerability domains, when compared to the general population recorded in the community services dataset.

Vulnerability domain	Vulnerability theme	Vulnerability factor	Proportion in SIDS cases, %	Proportion in comparator population/s from CSDS, %	Relative risk	Source of comparator
Any vulnerability – clinical, statutory, family or social			95.3	3.3	28.9	OHID – vulnerability in infancy, post neonates (6)
Clinical vulnerability			67.2	0.1	672	
Statutory vulnerability			43.8	1.0	43.8	
Family or social vulnerability			85.9	1.2	71.6	

Figure R - Relative risk of SIDS associated with vulnerability domains, when compared to the general population recorded in the community services dataset.



Relative risks associated with individual vulnerability factors

The individual vulnerability factors recorded in cases of SIDS and their selected comparators from the general population of infants, mothers or families (with statistical source identified), are outlined in Table 24.

Table 24 – Relative risk of SIDS associated with vulnerability factors, when compared to the general population.

Vulnerability domain	Vulnerability theme	Vulnerability factor	Proportion in SIDS cases, %	Proportion in comparator population(s), %	Relative risk	Source of comparator
Clinical vulnerability	Pregnancy environment	Smoking in pregnancy	39.1	12.8	**3.0**	OHID PH profiles, maternal health at booking, pregnant women
		Alcohol misuse	4.7	4.1	**1.1**	
		Drug misuse	6.2	1.4	**4.4**	
		Maternal obesity	7.8	22.1	-	
		Twin or higher order	4.7	1.4	**3.6**	OHID PH profiles, ONS Birth characteristics
		Premature live births, <37 weeks	37.5	7.4	**5.1**	
		Extremely premature live births, < 28 weeks	4.7	0.4	**11.8**	
		Low birthweight live births <2,500g	25.0	6.5	**3.8**	
		Very low birthweight live birth, <1,500g	9.4	0.8	**11.8**	
		Small for gestational age, live births	15.6	6.2	**2.5**	ONS birth cohort tables
		Neonatal care following birth	20.3	7.8	**2.6**	OHID PH profiles, HES, hospital admissions < 14 days old
	Health status of infant	Underlying health condition	60.9	7.0	**8.7**	Health survey for England, infants and 1-year olds
		Recent illness reported	39.1	8.0	**4.9**	Health survey for England, infants and 1-year olds
Statutory vulnerability		Known to social services	43.8	3.1	**14.1**	Education statistics – characteristics of children in need

Vulnerability domain	Vulnerability theme	Vulnerability factor	Proportion in SIDS cases, %	Proportion in comparator population(s), %	Relative risk	Source of comparator
Family or social vulnerability	Smoking, drinking or drug use	Smoking, mother	51.6	19.5	**2.6**	OHID, preconception report card, smoking at time of conception, pregnant women
	Mental health	Emotional distress, at least one parent	56.2	34.3	**1.6**	DWP, children living with parents in emotional distress, children
		Emotional distress, mother	50.0	26.9	**1.8**	
		Emotional distress, father	23.4	14.9	**1.6**	
		Emotional distress, both mother and father	15.6	5.6	**2.8**	
		Mental health, mother	50.0	9.3	**5.4**	OHID, preconception report card, mental health condition, pregnant women
	Parenting capacity	Young mother at birth, < 20 years	15.6	2.9	**5.4**	NHS Maternity Statistics, new mothers
		Physical health condition, mother	18.8	19.1	**1.0**	OHID, preconception report card, physical health condition, pregnant women
	Domestic violence/ abuse		40.6	2.9	**14.0**	OHID, PH profiles, domestic abuse incidents and crimes, adults

Discussion

Overall risks when compared to community services data

The death review documentation for cases of infants over 3 months who died suddenly, unexpectedly and for whom the death was unexplained following review [N=64] during 2019/20 reveals a very high level of vulnerability with 98.4% [N=63] cases having at least one vulnerability factor identified, either clinical, statutory, family or social, or environmental, which is associated with increased risk of poor outcomes or harm.

95.3% [N=61] cases of SIDS had a least one vulnerability factor identified from the public health framework, either clinical, statutory, or family or social. This is comparable with the 3.3% of all post neonates recorded by community services as having at least one safeguarding vulnerability from these categories, suggesting an overall 28.9 times increased risk of SIDS being associated with any vulnerability. This is a tentative exploration of relative risk of death using data, which is available from routine sources, administrative data collected as a by-product of health service and care activity. It is important to consider the mechanisms and lenses through which the data are collected to evaluate the extent to which it may or may not be a valid comparator.

Clinical vulnerability

Comparing all post neonates from community services data with the SIDS cases reviewed suggests that a 672 times increased risk of death (67.2% compared with 0.1%) is associated with identification of any clinical vulnerability. The range of clinical vulnerabilities identified by the CDOP process is extensive covering the pregnancy environment, birth outcomes and characteristics as well as admission to neonatal care and underlying health conditions. In the SIDS cases none of these vulnerability factors are identified as being causal in the death, but many are known to be associated with increased risks of SIDS. Consequently, they are relatively well documented by the CDOP process.

Conversely, community services when recording clinical risks will be engaged in the assessment, diagnosis and on-going management of symptoms, health conditions and disabilities. These will require referrals, for example to community paediatrics, continued clinical management, input and support. Once under the care of community services, the infant will have been discharged from midwifery services and any acute neonatal care and will be sufficiently stable, from a health point of view, to be managed in the community. Community services are therefore less likely to flag factors in the pregnancy environment or the infant's condition at birth as safeguarding vulnerability factors. As a result, the clinical vulnerabilities identified by CDOP may be overrepresented and those identified by community services underrepresented. Whilst this broad comparison is unreliable there is still merit in considering the relative risks of death associated with individual vulnerability factors from the clinical domain as more specific comparator statistics for the whole population of infants are more robust.

Statutory vulnerability

Comparing all post neonates from community services data with reviewed SIDS cases suggests that a 43.8 times increased risk of death (43.8% compared with 1.0%) is associated with identification of a statutory vulnerability. This is defined in broad terms by the published framework on vulnerability in children as a statutory entitlement to care and support, however it may be simply that the infant and their family is known to social services currently or in the past.

SIDS cases were reviewed for any mention of social services contact or being known to social services, which relates to the family and/or the infant. This is a very broad definition including all stages of notification and referral, ongoing risk assessments, classifications of children in need, child protection plans and looked after status, either current or in the past. It simply means that the family was known to social services in some way at some point for the purposes of protecting the infant and/or their siblings. This is because cases can escalate and de-escalate depending upon circumstances, mitigations, and adherence to or co-operation with improvement plans and or treatment. This results in a high proportion, 43.8% of the SIDS cases reviewed being know to social services in some way at some point.

Health based community services will have information on child protection status from the Child Protection Information System (CP-IS). This flows information on children with looked after status (LAC) and those with a child protection plan (CPP) from local authorities to NHS England (formerly NHS Digital) from where it is automatically disseminated to front line health services. The information passing across this boundary in bulk is limited to these formal statutory classifications as they are determined by legal process and are not subject to interpretation. Health services may not know about the lower-level classifications or ongoing risk assessments unless they are disclosed by the parents themselves. Thus, the recording of contact with social services in community services data for 1.0% of post neonates is likely to be an underestimate and the relative risk of SIDS over 3 months associated with statutory vulnerability when compared to prevalence from community services data – an overestimate.

Family or social vulnerability

Comparing all post neonates from community services data with SIDS cases suggests that a 71.6 times increased risk of death (85.9% compared with 1.2%) is associated with identification of any vulnerability from the family or social domain. The range of family and social vulnerabilities identified by the CDOP process is extensive, covering smoking, drinking and drug use, mental health, parenting capacity and domestic violence and/or abuse. Many of these family or social factors are known to be associated with increased risks of SIDS, and as a result they are relatively well documented by the CDOP process, especially so in the free text commentary.

Conversely, community services when recording risks which are in the family or social environment of the infant are working from the prescribed, data set specific, list of safeguarding vulnerability factors which is less extensive. The specific safeguarding vulnerabilities recorded by community services under this domain of vulnerability include ‘domestic abuse’ and ‘worrying parent behaviour or mental health concerns’.

There are also a significant number of community records having an ‘unknown reason’ for the safeguarding concern. This is a data quality issue. However, there is no option in the community services dataset for recording anything about parental smoking, drinking or drug use or concerns relating to parenting capacity such as the parents’ own vulnerability, learning disability or development disorder. It is most likely that this information is captured in local clinical records and experts from general practice have confirmed this is the case. Health visiting services may record this information, potentially as free text, but is not flowing centrally as community services data because it is not included in the relevant NHS information standards notice. The recording of family or social vulnerability in community services data for post neonates is likely to be an underestimate at 1.2% and so the relative risk of SIDS associated with any family or social vulnerability an overestimate.

Clinical vulnerability factors

Vulnerability factors recorded during pregnancy, from the pregnancy environment theme, are recorded in the maternity records of the mother, which in most of the SIDS cases reviewed seem to have been available to the CDOP panel.

Smoking in pregnancy is associated with the foetus growing at a slower rate in the womb and can result in babies being small for gestational age (small given the number of weeks of pregnancy) and having a low birth weight at term. Smoking during pregnancy is also associated with higher rates of stillbirth and infant mortality. Government advice is for no smoking during pregnancy (25).

Smoking in pregnancy, a well-documented modifiable risk factor in SIDS cases, is reasonably well recorded in maternity services data, with good data quality. Data quality improvements for maternity services data are incentivised via rebates in the insurance premiums paid by hospital trusts for clinical negligence.

Smoking in pregnancy gives a 3.0 times increased risk of SIDS (39.1% compared to 12.8%). The 12.8% comparator figure used is smoking at time of booking in 2018/19, the year in which the SIDS cohort would have been in the womb. The prevalence of smoking falls as pregnancy progresses and so a lower relative risk (2.0) could be obtained by comparing with smoking at conception (19.5% in 2018/19) and a higher relative risk (3.7) by comparing with smoking at time of delivery (10.6% in 2018/19). In the SIDS cases reviewed the prevalence of smoking in pregnancy, 39.1% of cases, is lower than the prevalence of the mother being a smoker in general, 51.6% of cases, suggesting that a proportion of regular smokers do stop smoking during pregnancy and return to smoking afterwards. However, there is no record of when during the pregnancy journey these women might have stopped smoking, hence the selection of the midpoint comparator of smoking at the time of booking. The 3.0 times increase in relative risk of SIDS associated with smoking in pregnancy seems reasonably robust. In time, records of smoking in pregnancy will improve with the move to carbon monoxide monitoring for all pregnant women and new indicators for smoking in pregnancy can be developed from this clinical observation which will generate more reliable data than the current self-reported smoking status.

Alcohol misuse in pregnancy is also documented in SIDS cases as a modifiable factor. The advice from the Chief Medical Officer is that it is safest not to drink alcohol at all during pregnancy. Comparing SIDS cases involving alcohol misuse in pregnancy with records of consuming alcohol in early pregnancy, recorded in maternity services at the booking appointment, there is very little difference. Relative risk of 1.1 calculated by comparing alcohol use at 4.7% in the SIDS cases with 4.1% in all pregnancies. The SIDS cases document problematic alcohol use during pregnancy in a small number of cases [N=3] whist the population indicator of alcohol in early pregnancy encompasses any consumption of alcohol during pregnancy, as that is in line with the CMO's guidance. In addition, any record of consuming alcohol or not in pregnancy is missing from 39% of records in MSDS from 2018/19, so the data quality is poor.

The figures from the SIDS cases and the routine MSDS data are not directly comparable as they are measuring different things. In maternity services, problematic drinking during pregnancy is recorded as a complex social factor but as that factor is a bundle of risks including alcohol or drug misuse, recent migrant or asylum seeker, not speaking or reading English, domestic violence, young age etc, it is not possible to readily identify cases of problematic drinking in the general maternal population. Maternity services data does however contain information on units of alcohol consumed and it may be possible in future to develop national level indicators for problematic alcohol use in pregnancy. However, this current comparison between the SIDS population and the whole population is tentative, and the relative risks generated are unreliable.

Drug misuse in pregnancy is documented in SIDS cases as a modifiable factor. As all drug use except over-the-counter medicines and those which have been prescribed by a medical professional is illegal, they can be treated differently from alcohol in datasets. Advice would be to avoid all drugs in pregnancy except those which are prescribed and necessary for ongoing treatment as directed by a medical professional. Indeed, some medicines can be harmful for the development of the foetus and may be stopped or substituted during pregnancy, but this will be under close medical supervision.

Drug misuse in pregnancy gives a 4.4 times increased risk of SIDS (6.2% compared to 1.4%). Drug misuse in pregnancy as well as contributing to the complex social factors bundle is recorded separately and reasonably consistently by maternity services, although still involving some self-reporting by mothers. Data quality in MSDS is fair, with data on whether or not substance misuse was present missing from 20% of records in 2018/19. This current comparison between the SIDS population and the whole population seems reasonably valid, and the relative risks generated could be considered somewhat reliable.

In the SIDS cases reviewed the prevalence of drug taking in pregnancy (6.2% of cases) is lower than the prevalence of the mothers being recorded as regularly using drugs (18.8% of cases). This suggests that a proportion of mothers who regularly take drugs do stop during pregnancy and return to drug misuse afterwards. Overall, the drug misuse in pregnancy tends to involve harder drugs with more established physical addictions. For example, in some of the SIDS cases reviewed the infants were born opiate dependent and taken through a managed withdrawal following birth. The more general drug taking by the mother outside of pregnancy ranges from hard dependency on opiates to what is described as recreational use, most often of cannabis and sometimes cocaine.

Maternal obesity is a risk factor for complications during pregnancy and birth, and the babies have a higher risk of stillbirth and congenital abnormalities. This is not a modifiable factor during pregnancy, where healthy weight gain is encouraged but something to be addressed between pregnancies or at a population level by health improvement initiatives involving diet and physical activity, to become fit for pregnancy. Maternal obesity (obesity during pregnancy) is not well recorded in the SIDS cases reviewed, featuring in 7.8% of cases. This is much lower than the prevalence of maternal obesity found in the general maternal population, 22.1%, as recorded in maternity services data. Body mass index (BMI) is calculated from the height and weight measurements made by midwives at the booking appointment, this is a clinical observation and so is more reliable than the self-reported information on smoking, drinking and drug use. It seems CDOP reviews are not generally picking out this information from maternity records and so maternal obesity may be under-reported in the SIDS cases reviewed. This could be improved. As a result of this underreporting, it will not be possible at this time to make any reasonable assessment of the relative risks of SIDS associated with maternal obesity.

Multiple pregnancy

When compared to singletons, babies from multiple births have much higher rates of stillbirth, neonatal mortality, infant mortality, preterm birth, low birth weight, congenital anomalies, and subsequent developmental problems. This is a high-risk scenario. Infants who are twins or higher order multiples are 3.6 times overrepresented in the SIDS cases compared with the whole population (4.7% compared to 1.4%). The comparator data on twins and higher order multiples comes from ONS, with the statistics produced from data obtained at birth registration, which is a legal process. This is an extremely reliable comparator and so the calculation of relative risk of SIDS considered robust.

Prematurity

On a global scale, premature birth (less than 37 weeks gestation) is the leading cause of death for children under the age of 5. This is a high-risk scenario. Infants who are born prematurely are 5.1 times overrepresented in the SIDS cases compared with the whole population (37.5% compared to 7.4%). The comparator data on premature births comes from ONS, with the statistics produced from data obtained at birth notification and birth registration, which is a legal process. The comparator selected also only includes data for live births.

Infants who are born extremely premature (less than 28 weeks gestation) are 11.8 times overrepresented in the SIDS cases compared with the whole population (4.7% compared to 0.4%). The comparator again comes from ONS for extremely premature live births.

The comparators for premature births are extremely reliable and so the calculation of relative risk of death considered robust. However, those born alive but prematurely are also more likely to die during the neonatal period. The relative risks of SIDS over 3 months for prematurity (5.1 times higher) or extreme prematurity (11.8 times higher) is only relevant for those who already survived the neonatal period. Adjusting for this is outside the scope of this study.

Low birthweight is an enduring aspect of childhood morbidity, a major factor in infant mortality and has serious consequences for health in later life (NICE). Again, this can be a high-risk scenario. Infants who are born at low birthweight, <2,500g, are 3.8 times overrepresented in the SIDS cases compared with the whole population (25.0% compared to 6.5%). The comparator data on low birthweight births comes from ONS, with the statistics produced from data obtained at birth notification. The comparator selected only includes data for live births.

Infants who are born very low birth weight, < 1,500g, are 11.8 times overrepresented in the SIDS cases compared with the whole population (9.4% compared to 0.8%). The comparator again comes from ONS and only includes data for live births.

This is an extremely reliable comparator and so the calculation of relative risk of SIDS considered robust. As with prematurity, low birth weight is also a risk factor for death during the neonatal period, so again only relevant for those who survived this period.

Small for gestational age is an important factor to consider because it is not always easy in the health services data available to distinguish between low birthweight associated with prematurity and small for gestational age, which may result in low birthweight at term. Low birthweight at term is generally considered to be a useful indicator of public health because it flags a failure to thrive in the womb which is independent of gestational age. Low birthweight at term increases the risk of childhood mortality and of developmental problems for the child and is associated with poorer health in later life. In this case the definition of the comparator indicator is live births under 2,500g and a gestational age of at least 37 complete weeks as a percentage of all live births with recorded birth weight and a gestational age of at least 37 complete weeks.

Infants who are born small for gestational age are 2.5 times overrepresented in the SIDS cases compared with the whole population (15.6% compared to 6.2%). The comparator data, live births which are small for gestational age comes from ONS birth cohort tables. It includes only live births, which is important as stillbirths will have a higher proportion small for gestational age, but is presented for England and Wales together. It is likely to be an underestimated prevalence for the infant cohort included in this study, those 3 months to under 1 year, as those born small for gestational age have an increased risk of stillbirth and of death in the neonatal period.

Neonatal care following birth was considered in a 2022 report from the NCMD which investigated illness around the time of birth and its effects on the health of children up to 10 years of age (26). This report found that in 83% of all cases of infant death, from any cause, the infant had been admitted to hospital for neonatal care following their birth. There was also a clear association between child death and neonatal illness.

Admission to neonatal care gives a 2.6 times increased risk of SIDS over 3 months (20.3% compared to 7.8%). Hospital care following birth was identified in 20.3% of the SIDS cases reviewed; this is compared with published statistics on any hospital admission for babies under 14 days old, 0.78 per 1,000 or 7.8%, which is derived from Hospital Episode Statistics (HES). Most of these admissions will be for neonatal care but can also cover the whole range of infections, illnesses, and accidents. This gives a good sense of the extent to which new-born babies require medical support in their early life and hence is a reasonably reliable comparator. HES data is also reasonably good quality because it is linked to the hospital's payment pathways, covering episodes of care with dates, medical specialty, diagnoses, and procedures.

The general health of adults and children is monitored via the Health Survey for England, which in 2019 reported that 96 % of those under 2 years old (infants and 1-year olds combined) were in good or very good health (19). The survey also reports on longstanding illness, life limiting longstanding illness and episodes of acute sickness. These data can be used as comparators for aspects of infant health identified in post-neonatal SIDS cases.

Underlying health condition when identified in the infant gives 8.7 times increased risk of SIDS (60.9% compared to 7.0%). The comparator used is the general prevalence of infants and 1-year olds with a longstanding illness. A comparator for infants alone is not readily available. Also, the survey data is based on relatively small numbers compared to NHS data so statistically less precise. The prevalence for limiting longstanding illness, at 3%, has not been selected as a comparator as this would be expected to more closely align with cases of death which are explained rather than SIDS cases, which are unexplained.

Recent illness reported in the infant gives 4.9 times increased risk of SIDS (39.1% compared to 8.0%). The comparator used is the general prevalence of infants and 1-year olds with an episode of acute sickness recorded. The comparator from the Health Survey for England is subject to all the same limitations as those outlined above.

There is no comparator for the infant being **described as poorly on the day of death** as that information is only available from child death reviews and is expressed in a multitude of different ways. Although 50.0% of the SIDS cases reviewed are described as being poorly on the day they died, it is not known how many infants in general would be described as poorly by their parents or carers on any one day.

Statutory vulnerability factors

Comparing all infants from children's social care data with SIDS cases suggests that a 14.1 times increased risk of death (43.8% compared with 3.1%) is associated with any identification of a statutory entitlement to care and support or **known to social care**. This comparator is much more robust than the one from community services data, which is clearly underreporting on contact with children's social care, identifying any contact at a prevalence of 1% (6) rather than 3.1% (23). This is not surprising as these data provided from health services are second hand in that they rely on this information being communicated from another agency or being elicited and disclosed during a healthcare consultation. In addition, the Child Protection Information System (CP-IS) focuses on automated sharing of information on children with a protection status that has been defined by a legal process, CPP or LAC, and does not capture the larger cohort in contact with children's social care. This suggests an opportunity for extending the scope of CP-IS so that information on any contact with children's social care is available to health professionals in real time to provide

context for any safeguarding concerns which may arise during a healthcare contact.

Family or social vulnerability factors

Family or social vulnerability factors are well recorded by the CDOP investigation, and many are captured by specific questions in the NCMD database. However, much of the background and context is also recorded as free text, analysis of which supports a more extensive identification of vulnerabilities and elaboration of the circumstances which surround them.

Mother smoking, or any household smoking whether mother, father, older sibling or another relative or friend, is a known risk factor for SIDS. However, smoking in the main carer, most often the mother, who spends most time with the infant or sleeps in close contact with the infant poses the highest risk. The focus here is on the mother's general smoking habits, irrespective of whether she stopped smoking during pregnancy or not, because of the availability of a good comparator from maternity services data. This identifies 19.5% of women who were smokers around the time of conception, i.e., as they are becoming pregnant. This presumes that regular smokers who do stop smoking during pregnancy but resume smoking afterwards will not stop in preparation for pregnancy, during the 12 months before conception, but may stop once they know they are pregnant.

The increased risk of SIDS for those infants with mothers who are regular smokers is 2.6 times higher (51.6% compared with 19.5%) than for the general population of infants. This is similar in magnitude to the increased risk of smoking in pregnancy, although the biological mechanisms of impact will be different, which was found to be 3.0, ranging from 2.0 to 3.7 depending on which comparator is selected. The range of comparators here arises from the fact that the proportion of women who smoke during pregnancy falls as the pregnancy progresses.

No attempt has been made to quantify the relative risks of SIDS associated with any household smoking, fathers or other household members smoking, or both mother and father smoking as it has not been possible to identify suitable comparators. However, it can be assumed that household smoking is a significant risk factor when any household smoking is identified in 62.5% [N=40] of the SIDS cases reviewed.

The Health Survey for England estimates 18% of men and 15% of women are smokers (18). This is for all ages of men and women irrespective of whether they live with infants and children or not. The age profile of those living with infants, the majority being between 20 and 40, is very different from the general HSE population which is all those over 16. Smoking at the time of conception, at 19.5% is a better comparator for mothers who smoke as it targets the exact population of interest.

A detailed medical report on passive smoking and children was published by the Royal College of Physicians in 2010 (27). This study quantified passive smoking using data from the Health Survey for England to look at the cotinine levels in the saliva of children, aged 4 to 15 years, exposed to household smoking. Higher levels were found in younger children compared to older children and where two parents smoked compared to one. Where one parent smoked levels were higher where this was the mother rather than the father, but the most significant issue was whether the main carer was a smoker. NHS advice (28) warns that passive smoking in children increases the risk of developing asthma, respiratory and ear infections, coughs, and colds. Both any parental smoking (62.5%) and recent illness (39.1%) or descriptions of current illness (described as poorly on day of death, 50.0%) in this broad range feature significantly in the post-neonatal SIDS cases reviewed.

Mental health of parents and carers is a known risk factor for poor outcomes and has been identified in serious incident notifications and SIDS cases. Data on the mental health status of members of the household is routinely collected via the child death overview process. Comparators from different sources, produced for different purposes, are available for mental health.

DWP publishes statistics on children living with parents in emotional distress as part of the work programme on reducing parental conflict (20). This is produced from survey data where parents self-report on their level of emotional wellbeing. The cut off for emotional distress is subclinical and would not lead to a formal diagnosis of mental ill health but the scale would include the diagnosable mental health conditions at the higher end. This, plus the fact that the statistics are based on children rather than households means that the prevalence in any parent, mother, father or both parents is relatively high at 34.3%, 26.9%, 14.9% and 5.6%. The prevalence for emotional distress may be slightly different if it were based on parents or households rather than children. Using this comparator infants with parents living with emotional distress have increased risk of SIDS as follows:

- Any parent – 1.6 times higher (56.2% compared to 34.3%)
- Mother – 1.8 times higher (50.0% compared to 26.9%)
- Father – 1.6 times higher (23.4% compared to 14.9%)
- Both parents – 2.8 times higher (15.6% compared to 5.6%)

This suggests elevated risks associated with the emotional wellbeing of any parent, either mother or father, which are all elevated to a similar extent. However, increased risks are further elevated in scenarios where both parents are in emotional distress, presumably impacting through general family functioning, ability to cope and exacerbation of stress arising from interaction with a partner who is also struggling with their own emotional wellbeing.

The statistics on emotional distress are a reasonable comparator as the thematic analysis of the SIDS cases takes a broad perspective on the identification of mental health issues within the family. These range from noting of symptoms such as self-reporting of low mood, through to formal diagnoses ranging across mild, moderate, and severe mental health issues, medication, treatments and contact with mental health services. It is not possible from the free text entries in the SIDS cases, which are variable in focus and content, to properly distinguish between cases which are subclinical and those with a formal diagnosis of a mental health condition.

Another comparator for any mental health condition or **mental health diagnosis for the mother** is available from maternity services data. At the maternity booking appointment, midwives enquire about any pre-existing mental health conditions irrespective of whether they would potentially have an impact on the pregnancy or not. These are recorded as pre-existing health conditions, an optional data field which can be left blank if there is nothing relevant to record. The only way to assure the coverage and quality of these data would be to undertake a clinical audit of case notes and compare these with maternity services data.

There is an increased risk of SIDS over 3 months associated with a **pre-existing mental health diagnosis** in the mother when comparing the SIDS cases which identified poor mental health in the mother with health information on pre-existing mental health diagnoses from maternity services data (risk ratio = 5.4, 50.0% compared with 9.3%). The prevalence of a pre-existing mental health diagnosis of 9.3% is recorded at the maternity booking appointment and this prevalence is likely to increase as the pregnancy progresses and during the first year following the birth, as cases of postnatal depression are diagnosed. Whilst postnatal depression may be time limited and prospect of recovery good, the timing is pertinent to this study of vulnerability in infants. As a result, the relative risk calculated

here can only be an overestimate when using this comparator of a mother's pre-pregnancy mental health diagnosis.

NHS England (formerly NHS Digital) publish data on the numbers of pregnant women and those in the postnatal period, one year following the birth, in contact with NHS mental health services. There are currently no reliable population prevalence statistics published from these data. This study estimates the prevalence of **perinatal mental health** at approximately 6%. This will be an underestimate as the threshold for referral to community-based specialist perinatal mental health services is quite high and the capacity of the service has been expanding in recent years to meet demand. As a result, this figure has not been used to estimate the relative risks associated with poor maternal mental health. With the underlying prevalence of pre-existing mental health diagnoses in the maternal population at 9.3%, the prevalence of poor mental health in the postnatal period, covering high, medium, and low levels of severity will be higher than this. Good prevalence estimates of poor maternal mental health in the postnatal period would help to further our understanding of the implications of this risk factor.

Parenting capacity or the lack of parenting capacity or inability to parent effectively can be influenced by a range of factors which are inherent to the parent, such as learning disability or development disorder, rooted in their own upbringing such as adverse childhood experiences or experience of care, their own vulnerability due to physical ill health, disability (physical, emotional, or cognitive) or their own criminal record or engagement with crime. The relative risks of SIDS for most of these factors cannot be estimated at this time due to lack of suitable comparators.

A comparator for having a **young mother, aged under 20 years**, is available from NHS Maternity Statistics, where annual data on deliveries by age is published. Infants with a young mother, aged under 20 years at time of birth have a 5.4 times higher risk of SIDS (15.6% compared to 2.9%).

A comparator for any physical health condition or **physical health diagnosis in the mother** is available from maternity services data. At the maternity booking appointment, midwives enquire about existing physical health conditions irrespective of whether they would potentially have an impact on the pregnancy or not. These are recorded as pre-existing health conditions, an optional data field which can be left blank if there is nothing relevant to record. The only way to assure the coverage and quality of this data would be to undertake a clinical audit of case notes and compare these with maternity services data.

There is no increased risk of SIDS over 3 months associated with a physical health diagnosis in the mother when comparing the SIDS cases reviewed with maternal health information from maternity services data (risk ratio = 1.0, 18.8% compared with 19.1%). This is not surprising as both cover any physical health condition, irrespective whether that condition has any impact on daily life. However, the physical health conditions described in SIDS cases are more likely to be of a long-term nature which may impinge on everyday life.

No attempt has been made to quantify the relative risks of SIDS associated with any other factors which may affect parenting capacity as it has not been possible to identify suitable comparators.

Domestic violence and/or abuse in the family environment is a known safeguarding risk and is known to be associated with SIDS. Relevant data is collected via the CDOP process in both categorised form and as free text. Any domestic violence or abuse at any time, whether current or historic, can raise stress levels within the home environment and put infants at risk of harm. It also features regularly in cases where social services are involved.

The increased risk of SIDS is 14.0 times higher if domestic violence or abuse is or has been a feature of the family environment (40.6% of SIDS cases compared with a rate of 2.9% in

the general population of adults). This is not an ideal comparator because it is based on a rate of incidents and offences recorded per adult population (0.29 per 1,000) where the population is considered as everyone over aged 16, in any one year. It would be better if this were a rate per household with children, which would potentially result in a higher value. As the comparator is an underestimate of experience of domestic violence or abuse in families with young children and infants then the associated relative risk of death can only be an overestimate.

Limitations of this study

The size of the cohort in the study is relatively small [N=64], being narrowed down to infants, over 3 months old, who die suddenly, unexpectedly and for whom the death is unexplained, during one year (pre-pandemic) and have had their child death review process completed. The study was limited by the resources available as thematic review, especially covering the free text entries, is very labour intensive. As a result, it has been necessary to supress some small numbers, to prevent disclosure which might breach confidentiality, the value of thematic review being that where some numbers might be supressed the rich descriptive detail remains. However, in some circumstances a vulnerability factor, which the research evidence base suggests may have a significant impact on poor outcomes including neonatal and infant mortality, has been identified in a small number of cases. Where this occurs and where there are suitable whole population comparators to enable estimation of relative risk the data has been presented. Examples include alcohol or drug misuse in pregnancy, where study numbers are small but where risks of disclosure are balanced against the benefits of developing a new methodological approach and the insights generated, which may in turn contribute to prevention of future deaths.

Numerical detail has not been presented in situations where the same vulnerability factor has been identified in fewer than 3 cases, unless the finding is negative, in that no vulnerability factors were identified. This is in line with ONS guidance on the management of small numbers and the risks of disclosure. This allows the case numbers to balance to 64 whilst minimising risks of identification.

The other main limitation is the availability of good comparator statistics which provide information on the level of vulnerability factors experienced by the whole population of pregnant women, infants, or families. These have improved significantly in recent years with the development and implementation of NHS datasets, including those for maternity services and community services. However, there is still room for improvement in health, social care and wider family-based statistics and recommendations have been made to this effect.

Conclusions

A public health approach to the identification of vulnerability where a wide range of risk factors are considered across clinical, statutory, and family or social domains can be applied in cases of infants who die suddenly, unexpectedly and for whom the cause of death is unexplained, using records from completed child death reviews.

A very high level of background vulnerability was identified in post-neonatal SIDS cases where 95.3% had at least one factor which could increase the risk of poor outcomes. In these cases, the most commonly occurring type of risk was in the family or social domain (85.9%), followed by the clinical domain (67.2%) and the statutory domain (43.8%). Environmental risk factors were also found in 89.1 % of post-neonatal SIDS cases and any risk factor, including environmental, in 98.4% of cases, almost all.

Multiple vulnerabilities are common both within and across domains. Over a third of the SIDS cases (37.5%) had vulnerabilities identified in all three domains from the public health framework (clinical, statutory, family/social). In addition to this around a fifth of cases (21.9%) had overlapping vulnerabilities in both the clinical and family or social domains and a further fifth of cases (21.9%) had vulnerabilities only in the family or social domain.

Over a third of cases (35.7%) had vulnerabilities identified in all four domains of enquiry using the NCMD framework (clinical, statutory, family/social, and environmental). In addition to this almost a fifth of cases (17.2%) had overlapping vulnerabilities in the clinical, family or social and environmental domains and a further fifth (20.3%) had vulnerabilities in both the family or social and environmental domains.

In post-neonatal SIDS cases some vulnerability factors dominate and are identified in over a third of cases and sometimes in over half of cases.

The most prevalent vulnerability factors which are intrinsic to the child (clinical domain), identified in at least half of cases, include an underlying health condition (60.9%), which was not the cause of death, and the infant being described as poorly on the day of death (50.0%). Over a third of cases identify smoking in pregnancy (39.1%), a recent illness (39.1%) and prematurity (37.5%).

Over a third of cases are known to social services (statutory domain) (43.8%), either previously or currently. These cases overlap almost entirely with risks in the family or social domain, which is not surprising as the predominant family or social vulnerabilities are the very things that will bring these families to the attention of social services in the first place.

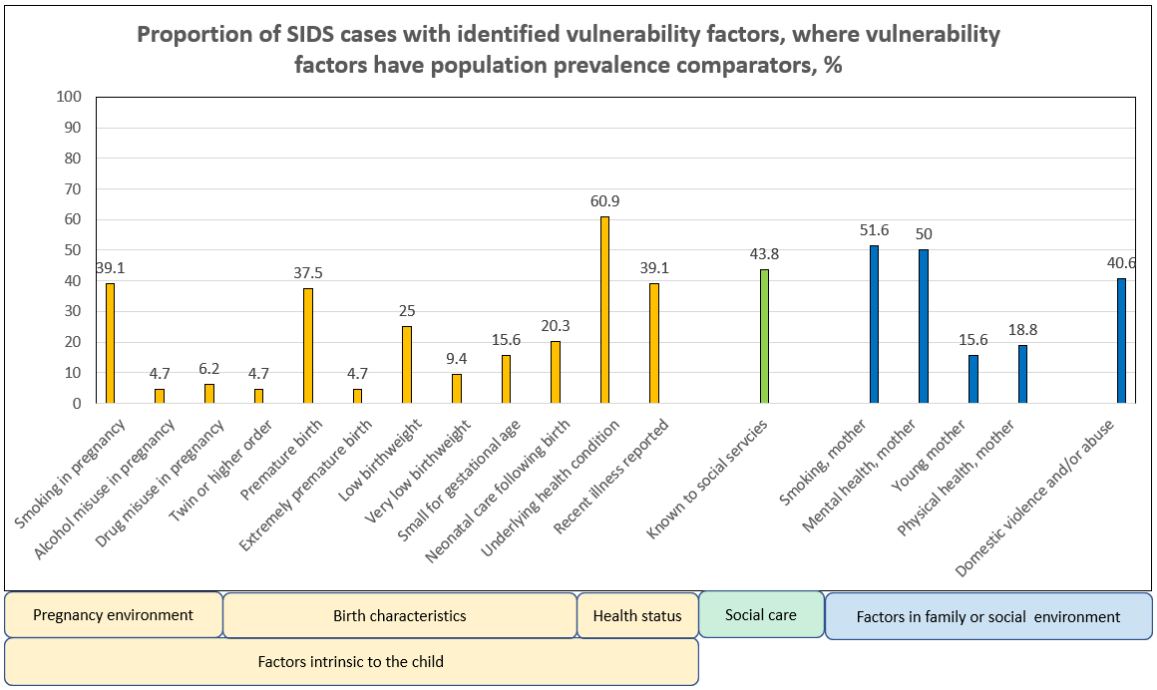
In the family or social domain, the most prevalent vulnerability factors, identified in over half of cases, are smoking in either parent (62.5%), mother smoking (51.6%), father smoking (51.6%), poor mental health in either parent (56.2%) and poor mental health in mother (50.0%). Over a third of cases identify domestic abuse (40.6%) and smoking in both parents (39.1%). Drug misuse and alcohol misuse have been identified as separate issues, recorded for either parent they are identified in over a quarter of cases (26.6% and 26.6% respectively). It is possible that the prevalence in cases would have been higher if the analysis had considered any household substance misuse, either drugs or alcohol. This ties in with evidence from serious case reviews where issues of domestic violence or abuse, problematic drug or alcohol use and poor mental health are frequently identified.

In the environmental domain, the most prevalent risk factors, identified in over three quarters of cases are not following advice and guidance on safe sleeping (78.1%) and identified in over half of cases co-sleeping (51.6%). Over a third of cases identify poor home environment (45.3%) and carer under the influence of alcohol or drugs (39.1%).

These vulnerability factors have all been previously identified in reports on SIDS. A thematic analysis including use of structured and free text information is time consuming but adds context and rich detail to the analysis as well as increasing the frequency at which some vulnerability factors are identified. This is especially true where reports have not been well codified, as the quality of information contained within the NCMD records is variable across the country.

Figure S summarises the proportion of cases, across domains, with individual vulnerability factors identified, where reasonable population prevalence comparators exist.

Figure S – Proportion of cases with identified vulnerability factors, across vulnerability domains



It is possible to start to estimate the relative risks of SIDS associated with the different vulnerability factors by comparing the prevalence of vulnerability factors identified in SIDS cases with their prevalence in the general infant, maternal or household/family population. This is important because it helps to prioritise areas for action. This is dependent upon the coverage and data quality of the national datasets originating from universal health services and the extent to which official statistics and reporting from national surveys addresses the target population of families with infants and young children.

Community services data from health visiting services includes records for most infants and identifies 3.3% of post-neonates as vulnerable in some way. There are many reasons why this is an underestimate, especially in the clinical domain, including transfer of information from one health setting to another and absence of current medical issues despite the infant having a poor start in terms of pregnancy environment or poor birth outcomes, which can have lifelong health impacts. Lack of data sharing from children's social services to health services (other than for CPP and LAC) can also result in underestimates of any contact with these services. Recording of family or social vulnerability relies in many cases on sensitive enquiry by professionals and disclosure by parents. Community services data is expected to improve over time.

Maternity services data is more complete than community services data and contains reasonable quality records for most pregnant women. This is a reasonable source of comparator data on pregnancy environment and some family or social risk factors which relate to the mother such as smoking, drug or alcohol misuse and pre-existing mental health diagnoses. More recent iterations of this dataset will provide more granular data on risk factors of interest.

Comparator statistics from ONS, official statistics produced by government departments and the NHS are reliable and provide robust comparators in many cases. Where there is no whole population match for a comparator the nearest known prevalence statistic can be utilised and opportunities for improving these data sources have been identified.

The highest relative risks of SIDS are associated with the family being known to social services (14.1) and experience of domestic violence or abuse (14.0). These are likely to be overestimates of relative risk as the comparators are based on children and adults respectively rather than on infants and their families. However, it is reassuring that similar levels of relative risk are identified for these two vulnerability factors as the cases overlap considerably.

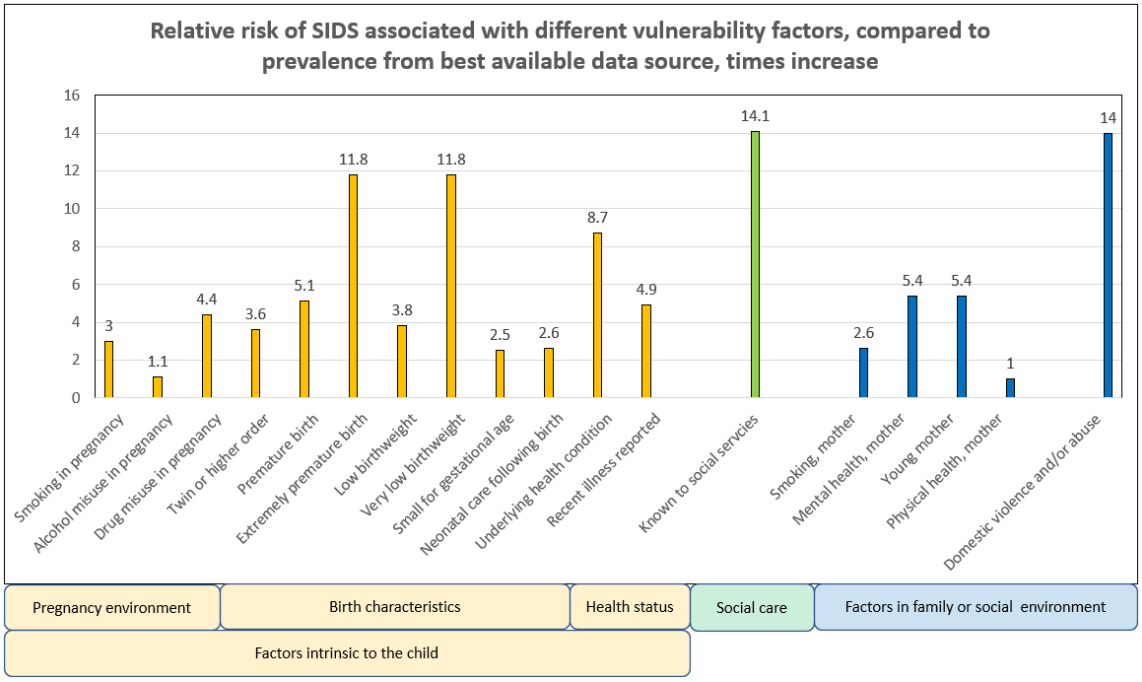
The next highest relative risks of SIDS are associated with vulnerability factors from the clinical domain. These include extreme prematurity (11.8) and very low birthweight (11.8). These are reliable estimates of relative risk with robust comparators from ONS. Again, it is reassuring that similar levels of relative risk are identified for these two vulnerability factors as the cases overlap with those born extremely premature also being very low birthweight because of their prematurity.

Also, from the clinical domain other vulnerability factors with high relative risk include infant's underlying health condition (8.7), prematurity (5.1), infant's recent illness (4.9) and mother's drug misuse during pregnancy (4.4). Estimates of relative risk for prematurity and drug misuse in pregnancy are reliable as the comparators are derived from relevant population health data and are reasonably robust. The estimates for relative risk associated with the infant's underlying health condition or recent illness are less reliable as the comparators are derived from sample-based survey data for a slightly different age grouping.

Other vulnerability factors with a high relative risk are from the family or social domain including mother's poor mental health (5.4) and a young mother, aged under 20 years (5.4). Estimates for relative risk associated with a young mother are reliable as the comparator derived from relevant population health data is reasonably robust. The relative risk associated with mother's mental health can only be an overestimate as the comparator is based on prenatal mental health diagnosis rather than postnatal, which would be higher.

Figure T summarises the relative risks of sudden infant death syndrome, over 3 months old, when compared to the general population and where reasonable comparators exist.

Figure T - Relative risk of SIDS associated with vulnerability factors, when compared to the general population.



Recommendations

Health Services and patient records

- Enhance the scope of safeguarding vulnerability factors recorded by community services (NHS England/OHID/Local Authorities).
- Standardise and improve the way maternity services enquire about and record information on:
  - maternal and household alcohol consumption
  - maternal and household drug use
  - maternal physical and mental health
  - maternal experience of domestic violence or abuse, current and historic (NHS England/OHID).

Interagency data sharing

- Consider options for expanding the scope of the Child Protection- Information System (CP-IS) to cover all children in need, that is all children in contact with social services at any point in their journey through referral, assessment, social services support, escalation and de-escalation or discharge. (NHS England)
- Agree a common set of safeguarding vulnerability factors to be recorded in a standardised format by all agencies. (NHS England/DfE/OHID/Local Authorities)
- Agreed a common framework for interagency data sharing and data linkage to enable further research. (NHS England/DfE/OHID/Local Authorities)

Data collection

Community services data (CSDS)

- Enhance the scope of safeguarding vulnerability factors recorded and coded by community services. (NHS England/OHID/Local Authorities/General Practices)
- Revise the information standard for community services data to mandate collection of the expanded list of safeguarding vulnerabilities. (NHS England (formerly NHS Digital))
- Improve the coverage and data quality of community services data. (NHS England, formerly NHS Digital)

Maternity services data (MSDS)

- Provide facility for disaggregation of complex social factors in pregnancy. (NHS England, including the former NHS Digital)
- Enhance the scope of safeguarding vulnerability factors recorded and coded by maternity services. (NHS England/OHID/Local Authorities/General Practices)

- Revise the information standard for maternity services data to mandate collection of improved information on drinking, drug use, mental and physical health and experience of domestic violence or abuse. (NHS England, including the former NHS Digital)

- Improve the coverage and data quality of maternity services data. (NHS England, including the former NHS Digital)

National Child Mortality Database (NCMD)

- Identify steps to improve the quality of data provided to the NCMD by local CDOP teams.

- Identify steps to increase the conversion of free text information in NCMD into structured information formats which aid analysis.

- Explore the use of natural language processing to support the analysis of free text information.

Statistical publications

- Develop and publish prevalence estimates for alcohol misuse in pregnancy. (OHID)

- Develop and publish prevalence estimates for perinatal mental health. (NHS England/OHID)

- Develop and publish prevalence estimates for postnatal mental health. (NHS England/OHID)

- Develop and publish prevalence estimates for smoking in households with infants and children. (NHS England, formerly NHS Digital/OHID)

- Develop and publish prevalence estimates for general health and illness, both longstanding and acute, in infants. (NHS England, formerly NHS Digital/OHID)

- Investigate the options for constructing prevalence estimates of infants exposed to second-hand smoke from family members and other carers in the home. (OHID)

Glossary of terms

A&E	Accident and Emergency or Emergency Department
ADHD	Attention Deficit Hyperactivity Disorder
BMI	Body mass index – a measure that uses your height and weight to work out if your weight is healthy
Category of death	Category of death is assigned in each child death review during the CDOP meeting. The classification of categories is hierarchical where the uppermost selected category will be recorded as the primary category should more than one category be selected
CDOP	Child Death Overview Panel
CDR	Child Death Review
Child	A young person aged from 0 up to their 18th birthday, excluding stillbirths and planned terminations of pregnancy carried out within the law
Child in need (CIN)	Defined under the Children Act 1989 as a child who is unlikely to achieve or maintain a reasonable level of health or development, or whose health and development is likely to be significantly or further impaired, without the provision of services; or a child who is disabled
Child protection plan (CPP)	A child protection plan is made when a child is judged to be at risk of significant harm, significant harm being a level of harm that affects the health, welfare, and development of the child
Complex social factors	Complex social factors for pregnant women include alcohol or drug misuse, recent migrant or asylum seeker status, difficulty reading or speaking English, aged under 20 and domestic abuse and are defined in NICE guidance
CSDS	Community Services Dataset
Domain A: Characteristics of the child	Factors in the child (and in neonatal deaths, in the pregnancy). Includes factors relating to the child's age, gender and ethnicity, any pre-existing medical conditions, developmental or behavioural issues or disability, and for neonatal deaths, the mother's health and wellbeing
Domain B: Social environment including family and parenting capacity	Factors relating to family structure and functioning and any wider family health issues; provision of basic care (safety, emotional warmth; stimulation; guidance and boundaries; stability); engagement with health services (including antenatal care where relevant); employment and income; social integration and support; nursery/preschool or school environment

Domain C: Physical environment	Factors relating to the physical environment the child was in at the time of the event leading to death, and for neonatal deaths, the mother's environment during pregnancy. Includes poor quality housing; overcrowding; environmental conditions; home or neighbourhood safety; as well as known hazards contributing to common childhood injuries (e.g., burns, falls, road traffic collisions)
Domain D: Service provision	Issues in relation to service provision or uptake for any agency. Includes any issues relating to identification of illness, assessment, investigations, and diagnosis; treatment or healthcare management; communication or teamwork within or between agencies; and organisational or systemic issues. Consider underlying staff factors, task factors, equipment, and work environment, education and training, and team factors
DVPN	Domestic Violence Protection Notice
Extremely preterm birth	A baby born before 28 weeks of pregnancy
GOR	Gastro-oesophageal reflux
HSE	Health Survey for England
HES	Hospital Episode Statistics
IUGR	Inter-Uterine Growth Restriction
Infant	A child under 1 year of age
Looked after child (LAC)	A child who has been in the care of their local authority for more than 24 hours is known as a looked after child. Looked after children can be: • Living with foster parents; • Living in a residential children's home; or • Living in residential settings like schools or secure units
Low birthweight	A baby born with a weight of less than 2,500g
Maternal obesity	BMI of 30 or above for a pregnant woman, measured during the early part of pregnancy
MARAC	Multi-Agency Risk Assessment Conference
MHMDS	Mental Health Minimum Dataset
MSDS	Maternity Services Dataset
Modifiable factor	Factors which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths
NCMD	National Child Mortality Database
Neonatal death	A neonatal death happens in the first 28 days after birth
Neonatal Unit	An intensive care unit specialising in the care for babies with the highest need for support. Includes Neonatal Intensive Care Units, Local Neonatal Units, Special Care Baby Units
NICE	National Institute for Health and Care Excellence

Odds Ratios (OR)	The odds (or likelihood) that an outcome will occur following an exposure to a risk factor compared to where there is no exposure to that risk factor
OHID	The Office for Health Improvement and Disparities, part of the Department of Health and Social Care
ONS	Office for National Statistics
Post neonatal death	A postnatal death which happens between 28 and 365 days after birth, between 1 month and 1 year
Preterm birth	A baby born before 37 weeks of pregnancy
PTSD	Post-Traumatic Stress Disorder
Relative Risk (RR)	The relative risk (RR) or risk ratio is the ratio of the probability (or chance) an outcome (in this case SUDI) in an exposed group (in the case exposed to a vulnerability factor) to the probability (or chance) of an outcome (in this case SUDI) in an unexposed group. Assuming the causal effect between the exposure and the outcome, values of relative risk can be interpreted as follows: RR = 1 means that exposure does not affect the outcome RR < 1 means that the risk of the outcome is decreased by the exposure, which is a “protective factor” RR > 1 means that the risk of the outcome is increased by the exposure, which is a “risk factor”
Review	A child death review is the responsibility of the child death review partners, and the purpose is to identify any matters relating to the death, that are relevant to the welfare of children in the area or to public health and safety, and to consider whether action should be taken in relation to any matters identified. A child death review is a statutory requirement
Safeguarding	Protecting a person’s health, wellbeing, and human rights; enabling them to live free from harm, abuse and neglect
SGA	Small for gestational age

SUDI	**Sudden unexpected death in infancy** Sudden unexpected death in infancy (SUDI): is a descriptive term used at the point of presentation for the death of an infant (under 1 year) whose death 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. SUDI is not a causal classification of death and does not have an International Classification of Diseases (ICD) code. Once all investigations are complete, SUDI deaths will divide into those for which there is a clear diagnosis (explained) and those for which there is no diagnosis (unexplained, also known as SIDS (Sudden Infant Death Syndrome).
SIDS	**Sudden Infant Death Syndrome** Sudden unexpected, unexplained death in infancy: are deaths that remained unexplained at the end of the CDOP review. These deaths were assigned the category of "Sudden unexpected, unexplained death" by the CDOP on the statutory analysis form. The definition of this category is: "Where the pathological diagnosis is either 'SIDS' or 'unascertained'. For ease of reading, the term SIDS is used for the whole category including all sudden unexpected, unexplained death in infancy."
SUDIC	Sudden unexpected death in infancy and childhood
Very low birthweight	A baby born with a weight of less than 1,500g
Very low birthweight at term	A baby born after 37 weeks of pregnancy with a weight of less than 2,500g
Vulnerability factor	A factor which increases the risk of poor outcomes or harm
Vulnerability framework, clinical domain	Clinical vulnerability - underlying diagnosed health conditions and disability or limited access to health services – NHS lead
Vulnerability framework, family or social domain	Social and family vulnerability - higher risk due to being negatively impacted through wider determinants of health and/or family stressors and social circumstances and may not be known to services – public health lead
Vulnerability framework, statutory domain	Statutory entitlement for care and support - increased risk due to family and social circumstances (education, health, and care plan and those with a social worker) – social services lead

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