

# NCMD

National Child Mortality Database

Knowledge, understanding and  
learning to improve young lives

# Child deaths due to Asthma or Anaphylaxis

**National Child Mortality Database  
Programme Thematic Report**

**Data from April 2019 to March 2023**

Published December 2024



## Authors

- Sylvia Stoianova<sup>1</sup>
- Tom Williams<sup>1</sup>
- David Odd<sup>1,2</sup>
- Vicky Sleep<sup>1</sup>
- James Fraser<sup>1,3</sup>
- Joanna Garstang<sup>1,4</sup>
- Jonathan Grigg<sup>5</sup>
- Mark L Levy<sup>6</sup>
- Vibha Sharma<sup>7</sup>
- Jennifer Townshend<sup>8</sup>
- Karen Luyt<sup>1</sup>

## Advisory working group members

- John Coveney<sup>3</sup>
- Andrew Cumella<sup>9</sup>
- Stephen Goldring<sup>10</sup>
- Lin Graham-Ray<sup>11</sup>
- Simon Langton-Hewer<sup>12</sup>
- Ian Sinha<sup>13</sup>
- Amena Warner<sup>14</sup>
- Emilia Wawrzkowicz<sup>15</sup>

1. National Child Mortality Database, University of Bristol
2. School of Medicine, Division of Population Medicine, Cardiff University
3. University Hospitals Bristol and Weston NHS Foundation Trust
4. School of Nursing and Midwifery, College of Medicine and Health, University of Birmingham
5. Queen Mary University of London
6. Locum GP, London
7. Royal Manchester Children's Hospital, Manchester University NHS Foundation Trust; Lydia Becker Institute of Immunology and Inflammation, University of Manchester
8. Children and Young People's Transformation Programme, NHS England; Newcastle Upon Tyne Hospitals NHS Foundation Trust
9. Asthma + Lung UK
10. The Hillingdon Hospitals NHS Foundation Trust
11. NHS South West London; South West London ICS
12. British Paediatric Respiratory Society
13. Alder Hey Children's NHS Foundation Trust; National Respiratory Audit Programme, Royal College of Physicians
14. Allergy UK
15. North West Anglia NHS Foundation Trust; Cambridgeshire and Peterborough ICS



## Partners



## Contact us

### National Child Mortality Database Programme

Level D, St Michael's Hospital,  
Southwell Street, Bristol BS2 8EG

**Email:** [ncmd-programme@bristol.ac.uk](mailto:ncmd-programme@bristol.ac.uk)

**Website:** [www.ncmd.info](http://www.ncmd.info)

**X** [@NCMD\\_England](https://twitter.com/NCMD_England)

**🦋** [@ncmd.bsky.social](https://www.instagram.com/ncmd.bsky.social)

© 2024 Healthcare Quality Improvement Partnership (HQIP)

## Acknowledgements

The National Child Mortality Database (NCMD) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, and the Royal College of Nursing. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations, and crown dependencies. [www.hqip.org.uk/national-programmes](http://www.hqip.org.uk/national-programmes).

### Supported by:

Nick Cook, Brian Hoy, Kate Hayter, James Harle, Ghazala Jones, and Gaja Wright from the NCMD team.

### With thanks to:

All Child Death Overview Panels (CDOPs) and Child Death Review Professionals who submitted data for the purposes of this report and for their continued support with information to NCMD for the national analysis and learning from child deaths in England.

Deborah Perriment (National Clinical Safeguarding Lead for Maternity, Babies, Children and Young People, NHS England) for the review and advice on the recommendations.

Vicky Gilroy and Georgina Mayes (Institute of Health Visiting) for reviewing the final draft and their advice on the role of health visitors.

Julie Critcher and Sallyann Sutton (School and Public Health Nurses Association (SAPHNA)) for review and advice on the recommendations.

Robert J. Boyle (Clinical Reader in Paediatric Allergy, Imperial College London) for reviewing the draft and input into the recommendations.

Sean Beevers (School of Public Health, Imperial College) for modelling exposure for the section on air pollution.

NHS England for providing linked data from Hospital Episodes Statistics and data from the Medicines dispensed in Primary Care datasets.

# Contents


|  |           |
|--|-----------|
| <b>Introduction .....</b>  | <b>2</b>  |
| <b>Child deaths due to asthma – key findings .....</b>                               | <b>3</b>  |
| <b>Child deaths due to anaphylaxis – key findings .....</b>                          | <b>14</b> |
| <b>Recommendations .....</b>   | <b>21</b> |
| <b>Additional key improvements needed in professional practice .....</b>             | <b>23</b> |
| <b>Existing guidance and recommendations requiring improved implementation .....</b> | <b>24</b> |
| <b>Next steps and future priorities.....</b>   | <b>25</b> |

# Introduction

Every child who dies is a precious individual and their deaths represent a devastating loss for parents, siblings, grandparents, carers, guardians, extended family and friends. With all child deaths there is a strong need to understand what happened, and why. We must ensure that anything that can be learned to prevent future deaths from happening is identified and acted upon.

This report analyses the deaths of children in England who died due to asthma or anaphylaxis. The data include children

who have died between 1 April 2019 to 31 March 2023. In addition, children who died before 1 April 2019, for whom the Child Death Overview Panel (CDOP) review was completed after 1 April 2019, are also included as reported to the National Child Mortality Database. This report does not include deaths where asthma contributed to the death but was not the underlying cause. More information about the background, methodology and limitations used for this report is available in [the Supporting Material](#).



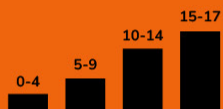
**“The majority of child deaths from asthma and allergies are preventable - each death is a heartbreaking tragedy. Preventing another child dying is the responsibility of us all – this responsibility sits across our multi-agency services, within our communities and our society – it is everyone’s business.”**

North Central London CDOP

# Child deaths due to asthma – key findings

There were 54 child deaths due to asthma between April 2019 and March 2023

## Child deaths due to asthma



15-17 year olds were the age group with the highest death rate due to asthma



The death rate was 4x higher for children from more deprived areas than less deprived



87% of the cardiac arrests occurred outside of hospital (at home or in a public place)



65% had attended an emergency department or had an emergency admission in the year before death



87% had three or more reliever inhalers dispensed in the year before death



All the children who died had been exposed to air pollution above WHO guidelines

## Themes from CDOP reviews



Smoking by family members



Poor communication between and within services



Concerns about abuse or neglect



No asthma action plan in place



27% were born before 37 weeks gestation or with a birthweight under 2500g



Poor indoor air quality



Pets in the house



Allergies

Full findings from the report, including recommendations, can be found at [ncmd.info/asthma](http://ncmd.info/asthma)

## Characteristics of children who died due to asthma

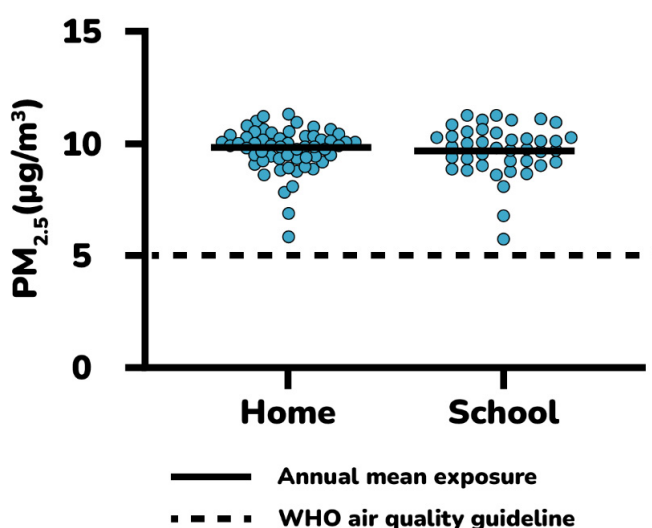
- There were 54 child deaths due to asthma in the 4 year period between 1 April 2019 and 31 March 2023; approximately 1 death every 4 weeks.
- Deaths occurred across all age groups (age range 2 to 17 years), but death rates were highest in 15 – 17-year-olds (2.07 per 1 million children), followed by 10 – 14-year-olds (1.61 per 1 million children).
- The death rate of boys (1.53 per 1 million children) was more than double that of girls (0.74 per 1 million children), which may reflect higher prevalence of asthma in boys than girls in the population<sup>1</sup>.
- There were 18 (34%) deaths of children from Asian, black, mixed or other ethnic backgrounds (an estimated 1.39 per 1 million children) and 35 (66%) deaths of children from a white ethnic background (an estimated 1.02 per 1 million children).
- The death rate was higher for children living in urban areas (1.18 per 1 million children) than rural areas (0.95 per 1 million children), and regional death rates ranged from 0.46 per 1 million children in the South West, to 1.93 per 1 million children in the West Midlands.
- The death rate was four times higher for children living in the most deprived neighbourhoods of England (2.66 per 1 million children) compared to the least deprived (0.68 per 1 million children). Poorer outcomes for children with asthma living in the most deprived areas have previously been shown<sup>2</sup>, with children living in the poorest 10% of areas four times more likely to have an emergency hospital admission than those in the least deprived 10%<sup>3</sup>. Asthma is one of the 5 clinical areas of focus in the [NHS England CORE20Plus5 approach on reducing health inequalities for children and young people](#).
- Deaths occurred throughout the year, with 19 (35%) occurring in winter months (Dec-Feb), 15 (28%) in spring (Mar-May), 13 (24%) in autumn (Sep-Nov), and 7 (13%) in summer (Jun-Aug).
- Where it was recorded (n=30), 27% (n=8) of children were born before 37 weeks gestation or with a birthweight under 2500g; higher than the proportion of overall live births (8% and 7%, respectively)<sup>4</sup>. Premature birth and associated low birthweight is a recognised risk factor for asthma<sup>5</sup>.

## Outdoor air pollution

See [Supporting Material](#) for full analysis and methodology.

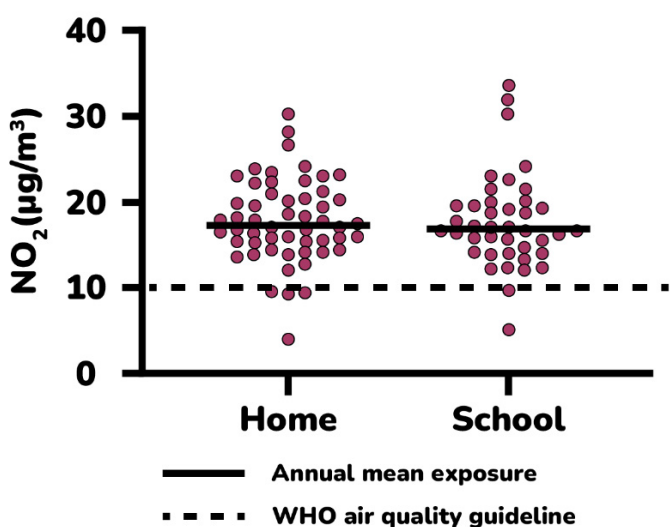
- The two main components of traffic-generated pollution, the most common source of outdoor exposure in the UK, are nitrogen dioxide (NO<sub>2</sub>) and particulate matter (PM<sub>2.5</sub>).
- The mean value of PM<sub>2.5</sub> at the home address of the children who died due to asthma was 9.6 (range: 5.8 to 11.24) µg/m<sup>3</sup>, and 9.6 (range: 5.5 to 11.2) µg/m<sup>3</sup> at school. All children were therefore likely exposed to PM<sub>2.5</sub> levels, at both home and school, above the [World Health Organisation \(WHO\) guideline](#) (5 µg/m<sup>3</sup>) (Figure 1), but below the current UK guideline value (20 µg/m<sup>3</sup>).
- For NO<sub>2</sub> the mean annual value at home was 17.5 (range: 3.9 to 30.2) µg/m<sup>3</sup>, and 17.6 (range: 5.1 to 33.4) µg/m<sup>3</sup> at school. At home, 92% (n=51/55) of children were exposed to NO<sub>2</sub> concentrations above the WHO limit (10 µg/m<sup>3</sup>) and 95% (n=39/41) were above the WHO guideline at school (Figure 2). Exposure of children was below the current UK guideline value for NO<sub>2</sub> (40 µg/m<sup>3</sup>) at both the home and school address.

**Figure 1: Distribution of the annual mean exposure to PM<sub>2.5</sub> at the home and school address of the children who died due to asthma between 1 April 2019 and 31 March 2023**



1 NHS England (2019)  
 2 Royal College of Paediatrics and Child Health (2020)  
 3 Asthma and Lung UK (2023)  
 4 ONS (2024)  
 5 NICE (2024)

**Figure 2: Distribution of the annual mean exposure to NO<sub>2</sub> at the home and school address of the children who died due to asthma between 1 April 2019 and 31 March 2023**



### Emergency hospital attendances and admissions

- There were 34 (63%) children who had attended the emergency department (ED) at least once in the year prior to their death (excluding the day the child died), with 7 attending over 5 times. Similarly, 27 (50%) children had at least one emergency hospital inpatient admission in the year prior to their death (excluding the day the child died), with 15 having asthma coded as the primary reason for the admission. There were 3 (6%) children who had over 5 admissions in the year prior to their death (excluding the day the child died). In total, 35 (65%) children attended ED or had an emergency admission to hospital in the year prior to their death.
- The ED attendances and emergency hospital admissions may reflect the severity of the asthma and/or be due to how well the asthma was managed and controlled, or the patient compliance with therapy, e.g., inhaled corticosteroids (ICS) treatment.
- One asthma attack is a risk factor for another, which may be more severe, and should therefore be treated as a significant event, and maximum effort is needed to identify any preventable factors and optimise care by someone trained to do so<sup>6,7,8</sup>.

### Increased use of emergency medicine

- 47 (87%) children had 3 or more dispensed SABA (short-acting beta agonist) inhalers (e.g., a salbutamol inhaler), or relievers, in the year preceding their death (range: 0 – 48), with 27 (50%) having 12 or more.
- 35 (65%) children had fewer than 9 dispensed inhaled corticosteroid (ICS) inhalers, or preventers, in the year preceding their death (range: 0 – 21), with 23 (43%) children having 4 or fewer.
- An excess number of SABA inhalers is an indication that asthma is poorly controlled, and SABA overuse is associated with increased risks of severe asthma attacks and deaths due to asthma<sup>9</sup>.
- Good asthma control is usually achieved with the regular use of preventer medication as per the NICE/BTS guidelines. SABAs should not be prescribed without a concomitant prescription of an ICS<sup>10</sup>.

See [Further Guidance and Resources](#) document for more information

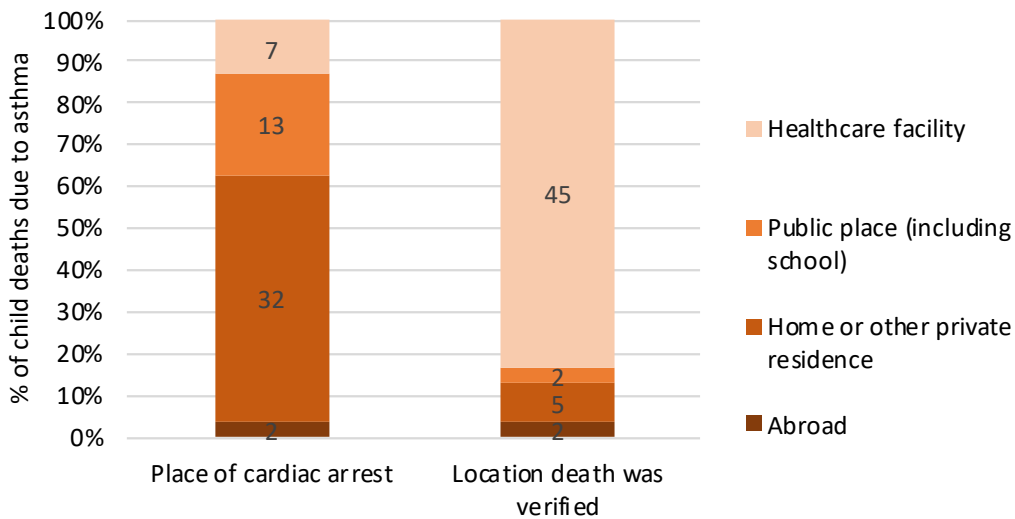
### Place of cardiac arrest, location the death was verified, and mode of death

- Of the 54 children who died, 32 (59%) had a cardiac arrest at home, 13 (24%) had a cardiac arrest in a public place (including 3 in a vehicle being driven to hospital by a family member, 2 at school, and 1 on an aeroplane) and 7 (13%) had a cardiac arrest in a healthcare facility (including 2 on a hospital ward, 2 in ED, 1 in theatre, 1 in an ambulance, and 1 at a GP surgery). 2 (4%) occurred abroad with the precise location of the cardiac arrest unclear (Figure 3).
- Therefore, where it was known (n=52), 45 (87%) of the cardiac arrests occurred out of hospital (in a home or public place) (Figure 3). In the 2 cases where the cardiac arrest occurred in ED, both children arrived in a moribund condition and arrested before intubation. The cardiac arrest in the 2 children on a hospital ward occurred in the context of a pneumothorax (see the [Supporting Material](#) for additional analysis on pneumothorax). Insufficient information was available relating to the circumstances of the cardiac arrest in theatre, ambulance or the GP surgery to draw conclusions around service delivery.

6 Levy et al. (2018)  
 7 Primary Care Respiratory Society (2023)  
 8 GINA (2024)  
 9 Nwaru et al. (2020)  
 10 Levy et al. (2024)

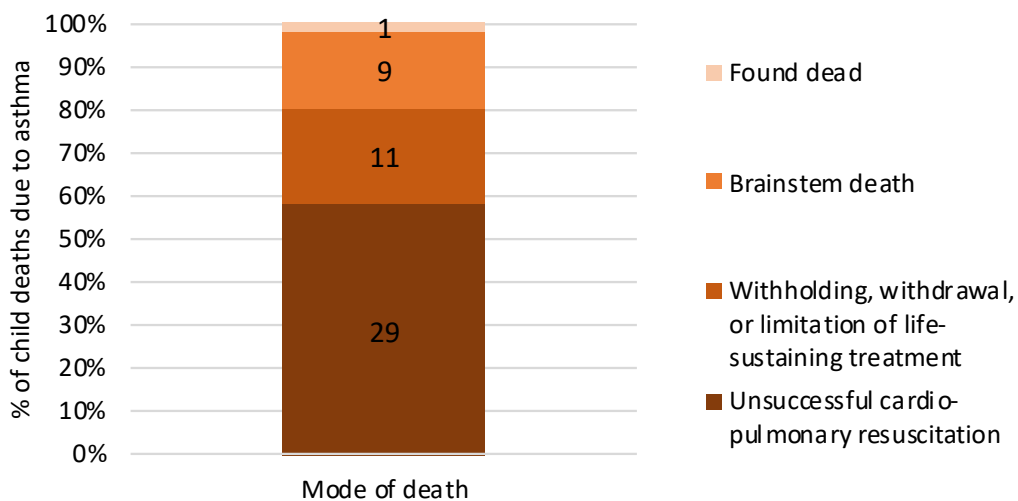
- The outcome following out of hospital cardiac arrest in children with asthma is very poor and likely results in death or severe brain damage. Prognosis following out of hospital cardiac arrest of any aetiology in children is poor<sup>11</sup>. The limitation is that no control data exists for children with asthma who may survive cardiac arrest. Prompt pre-hospital attendance by paramedics and advanced resuscitation of children with acute severe asthma, including intramuscular adrenalin, are important. Prevention of asthma attacks should remain the primary means by which asthma deaths in children are reduced.
- In 45 (83%) cases the death was certified in a hospital, including 23 (43%) in ED, 19 (35%) in a Paediatric or Adult Intensive Care Unit (PICU/AICU), and 3 (6%) on a hospital ward or in theatre. For deaths certified in a PICU or AICU, all occurred in the context of devastating brain injury and treatment withdrawal. A further 7 (13%) deaths were certified at home or in a public place, and 2 (4%) abroad (with the exact location unknown) (Figure 3).

**Figure 3: Number of deaths due to asthma between 1 April 2019 and 31 March 2023 (4 years), by place of cardiac arrest and the location where the death was verified**



- Where the mode of death was known (n=50), 29 (58%) children had unsuccessful cardiopulmonary resuscitation, 11 (22%) had withdrawal or limitation of life sustaining treatment, 9 (18%) were certified brain stem dead using neurological criteria, and 1 (2%) child was found dead (Figure 4).

**Figure 4: Number of deaths due to asthma between 1 April 2019 and 31 March 2023 (4 years), by mode of death**



In 4 cases the mode of death was not recorded.

11 Albarqi et al. (2022)



## Completed reviews of child deaths due to asthma

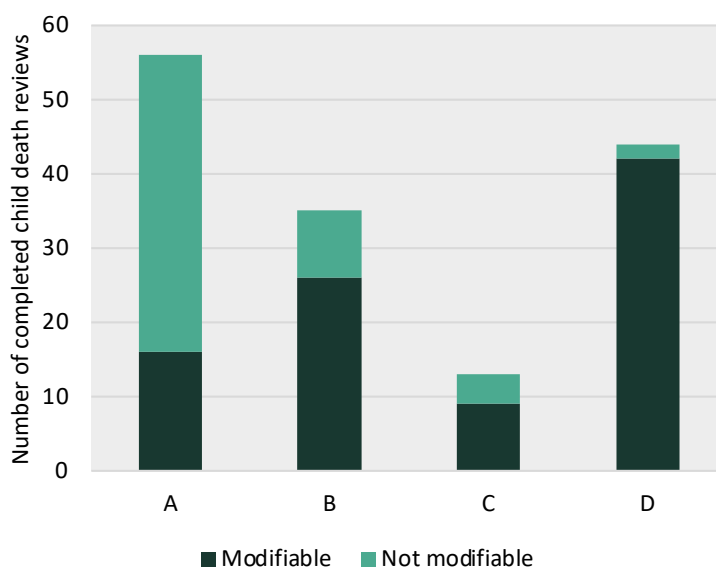
There were 67 asthma deaths reviewed by a CDOP and reported to NCMD. This includes 48 completed reviews where the death occurred between 1 April 2019 and 31 March 2023, and a further 19 completed reviews where the death occurred before 1 April 2019 (earliest death occurred in the year beginning 1 April 2016). See [Supporting Material](#) for more information.

## Contributory and modifiable factors and learning from CDOPs

As part of the child death review process, CDOPs are required to record any contributory factors identified during the review and decide which may be modifiable. Definitions of these terms can be found in the [child death analysis form](#). The interaction of multiple factors can increase the impact of these factors and vulnerability to death, compared with what the impact might have been if there was only one factor present.

The most common contributory factors reported were in the domain of factors intrinsic to the child (84%, n=56) (Figure 5).

**Figure 5: Factors recorded by the CDOP that may have contributed to the vulnerability, ill health or death of the child, for completed child death reviews where the child died due to asthma**



A = Characteristics of the child, B = Social Environment, C = Physical Environment, D = Service Provision

The main factors identified were related to the child's health history/medical condition (84%, n=56), followed by issues related to following guidelines, pathways and policies (51%, n=34) and challenges for parents with access to services (39%, n=26).

Modifiable factors were identified by CDOPs in 81% (n=54/67) of deaths.

### **Factors intrinsic to the child or young person**

#### **Underlying health conditions**

There were 6 (9%) reviews that recorded that the child had other underlying health conditions (excluding asthma and allergies) as a contributory factor. In addition, there were 5 (7%) reviews which recorded an infection as contributory.

#### **Body mass index**

In 2 reviews, childhood obesity or the child being underweight was recorded as a contributory factor by CDOPs. Obesity is a known risk factor for asthma<sup>12</sup>.

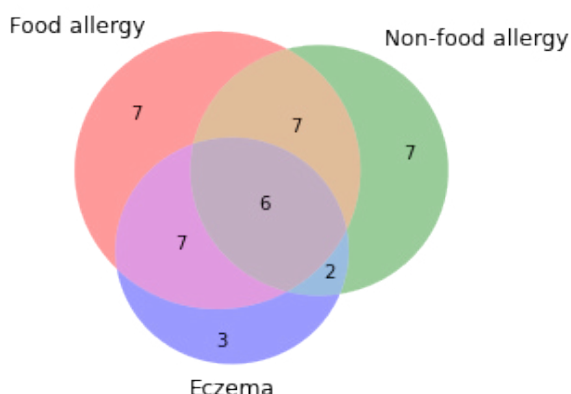
#### **Known allergies and eczema**

There was a total of 36 (54%) children who were reported to have allergies, and 15 of these children also had eczema. From the remaining 31 reviews, 3 reported eczema only, 9 reported "no known allergies" and 19 reported no information on allergies.

27 children had allergies to food items and 22 children were allergic to non-food items (including hay fever); 13 children had allergies to both food and non-food items (Figure 6).

12 NICE (2024)

**Figure 6: The number of children who died of asthma with reported eczema and allergies, by type of allergy**



Allergies reported included: nuts, egg, milk, pets, dust, and hay fever.

Allergies or eczema were recorded as a contributory factor in 15 of the reviews.

The triggers were identified and communicated to the parents, carers or child in 16 cases where this information was available in the child death review supplementary reporting form (n=17). There was limited information from the reviews on whether the children had long term allergy care plans in place.

[NICE guideline \[NG245\]](#) provides guidance on including questions on personal or family history of allergies at the initial clinical assessment, and on testing.

### Smoking and vaping by the child

The child was known to smoke or use a vaping device in 2 reviews. In 22 reviews, the child was not known to be a smoker. The information on whether the child was known to smoke or not was not available for most of the reviews.

Emerging research evidence is showing an association between vaping or smoking of electronic cigarettes and lung injury and predisposition to pneumothoraxes in the general population<sup>13,14</sup>.

See [Further Guidance and Resources](#) document for more information

### Substance misuse by the child

Cannabis use by the child was recorded in 4 reviews. CDOPs highlighted the need for raising awareness of the dangers of cannabis use by people with asthma.

[NICE guideline \[NG245\]](#) recommends that adolescents should be asked if they smoke or vape and be encouraged to stop. This should include the smoking of any substances, not only tobacco. If they smoke, they should be provided with advice and signposted to local NHS stop smoking services.

### Factors in the social environment

In 26 (39%) reviews the CDOPs recorded factors related to the child not being brought to appointments (n=12), parental non-compliance or disguised compliance with medication, treatment or professionals' advice (n=12), delays in seeking medical attention (n=8) or parental non-engagement with services (n=6). There is evidence from some of the reviews that the voice and needs of children were not recognised.

### Abuse and neglect concerns and social care involvement

Abuse and neglect concerns were recorded by the CDOPs in 9 reviews (13%). There was evidence of household violence in the child's or child's family life recorded in 19 (28%) reviews. Where it was known (n=57), 23 (34%) of the children were known or previously known to social care services, and 9 children had ever been subject to a statutory Child Protection or Child in Need plan.

Reviews documented that there were multiple missed appointments for asthma reviews over many years, with primary, secondary and tertiary care, and with children discharged from services. Poor compliance with preventer medication was also documented. There were examples of children who were managing their asthma without adult oversight. There were also examples of services failing to follow up and escalate appropriately. For example, reliever medication was frequently prescribed by GPs despite children not being brought for reviews or collecting prescriptions for preventer inhalers.

In some cases, parents continued to smoke cigarettes inside the home and keep several different animals inside despite advice given to them on asthma triggers. In some cases, the living conditions were only apparent when the ambulance attended when the child collapsed, and this led to safeguarding referrals. Parental drug misuse was also a factor in some reviews.

A common theme from these reviews was that health services did not follow their 'Was Not Brought (WNB)' policies and children were discharged without consideration of safeguarding concerns or the potential impact on the child.

In some cases, it was recorded that healthcare professionals repeatedly referred children to social care due to missed appointments and non-compliance with treatment, stating their concerns about risk of significant harm and death due to poor asthma management. These referrals were not considered as needing a statutory response and were passed to [Early Help](#) services. In the few cases where social workers were directly supporting families, there was poor communication with health services. As a result, the risk of severe and fatal asthma was not recognised by social care, and asthma normalised as a common condition of childhood.

CDOPs' learning raised the importance of all multi-agency frontline staff to search for, recognise and analyse patterns and repeat behaviours when evaluating how well children are safeguarded and their wellbeing is promoted. Multi-agency

<sup>13</sup> Chuang et al. (2023)

<sup>14</sup> Adhikari et al. (2021)



safeguarding hubs (MASH) should always request contextual, historical and repeat behaviours information when discussing referrals, moving from an incident-focused to a context-focused approach to assessing the risk of harm. MASH should develop ways to ensure multi-agency information is properly distributed and accessible to other agencies when decisions have been made.

CDOPs highlighted the importance for pharmacists to have specific safeguarding training that makes links between parental drug misuse, prescription medical equipment and childhood asthma. Communication between GPs and pharmacists in these types of cases is essential.

#### Smoking by parents and/or carers

There were 32 (48%) reviews that recorded smoking by family members, with 29 (43%) reviews reporting parental smoking. This is significantly higher than the proportion of adults who smoke cigarettes in the UK (13%)<sup>15</sup>.

Cannabis smoking in the child's house by the child's carers (parents and grandparents looking after the child) was recorded in 5 reviews. The information mentions "strong smell" of cannabis in the house as well as in the child's bedroom.

Smoke exposure is a significant risk factor for asthma<sup>16</sup>.

National standards of care for professionals on raising awareness of the risks of smoking/vaping in the child's living environment and on supporting and referring parents into smoking/vaping cessation services are included in the National Bundle of Care for Children and Young People with Asthma.

#### Factors in the physical environment

##### Poor home safety/conditions

There were 7 reviews where the CDOPs recorded contributory factors in relation to poor home conditions. These included instances of excessive mould and dust, and dirty, overcrowded and tobacco smoke-filled houses. Factors related to poverty and deprivation were also present including living environment deprivation, homelessness, property in poor repair, and cold houses.

Where this information was recorded, 3 of the children lived in social/council/housing association housing and for 2 of them, mould or damp was recorded as a contributory factor. Indoor air quality can have a significant impact on children and young people's health. Poor housing quality is strongly associated with asthma<sup>17,18</sup>. Housing conditions, e.g., mould, damp or parental smoking can all be potential triggers for asthma.

<sup>15</sup> ONS (2023)

<sup>16</sup> Kanoh et al. (2012)

<sup>17</sup> Tiotiu et al. (2020)

<sup>18</sup> Royal College of Paediatrics and Child Health (2020)

The National Bundle of Care for Children and Young People with Asthma sets national standards of care for professionals and integrated care systems to follow, to minimise the risks associated with indoor air pollution. These include understanding and discussing the risks with children, young people and their families as part of the personalised asthma action plan, and to discuss these risks with housing providers to encourage timely repairs or for rehousing to be considered as per government guidance and legislation.

### **Pets in the household**

There were 15 (22%) reviews where there were pets in the household and in 6 (9%) reviews CDOPs recorded this as a contributory factor.

Allergens found in the animal's skin flakes (dander), saliva, or urine can all trigger asthma symptoms, and animal allergies can develop at any stage of life. Asthma and Lung UK provide further information on how pets can trigger asthma symptoms, and advice on how to lower the risks for children.

### **Factors relating to service provision**

#### **Following guidelines, pathways and policies**

CDOPs recorded contributory factors related to following guidelines, pathways and policies in 34 (52%) reviews, which included 32 deaths where this was recorded as a modifiable factor.

Examples included:

- primary care not referring the child to a respiratory paediatric specialist when the threshold was reached for secondary care referral<sup>19</sup>
- hospital discharge without a planned review by the paediatricians following the discharge
- communication issues between hospitals and GPs where the hospital did not communicate with the GP on discharge from hospital
- issues with appropriate referrals made to social care by the school where there were concerns of neglect

Information on whether the child had an asthma action plan was available in 36 (54%) reviews. In 26 reviews the child had an action plan, and in 10 reviews the child had no asthma action plan in place.

There were examples in the reviews where it was not clear to families that their child's school needed to have an asthma care plan in place as their understanding was that care plans were only for severe cases. CDOPs highlighted that parents and carers should be made aware that all asthma, no matter how mild or severe, requires regular reviews and up-to-date care plans. The care plan should be an up-to-date working document for the patient and carers which is shared with the GP, nurses and the school. Independent schools should follow the same guidance.

School nurses play an important role in providing additional support for children and families as defined in the Healthy child programme: health visitor and school nurses commissioning.

They are specialist community public health nurses who work with school-aged children and young people and their families to improve health and wellbeing outcomes and reduce inequalities and vulnerabilities<sup>20</sup>.

Where it was known and applicable (n=17, 25%), there was no follow up by a GP or a hospital within 2 days following the most recent hospital admission in 11 reviews.

CDOPs highlighted the importance for GPs to monitor the number of prescriptions to ensure that medication is being taken regularly and that there is no overreliance on reliever inhalers as opposed to preventer medicine. Providers of GP systems' software can consider developing automated alerts to help practices monitor this and promptly respond. Regular monitoring using a peak flow meter would give parents an objective measure to monitor asthma severity and give an early warning of poor control. Parents would need training on when to use the monitor and clinicians would need to ask to review what the readings were.

See Further Guidance and Resources document for more information

#### **Communication between or within agencies**

Factors related to communication issues within or between agencies were recorded as contributory in 24 (36%) reviews, and 21 of those were recorded as modifiable.

- The main factors identified were poor information sharing between primary and secondary care providers and between the multi-agency professionals e.g., between health, mental health and education and social care providers (n=17), and poor documentation and record keeping (n=9).

Examples included:

- » history of non-attendance of secondary care appointments

Issues related to a discharge from secondary care because of missed appointments have been previously highlighted by a coroner in a Regulation 28 Prevention of Future Deaths Report

- » health professionals not knowing the child was known to social care
- » the severity of the child's asthma not shared with social care and Child and Adolescent Mental Health Services (CAMHS)
- » previous recent ED admissions with life-threatening asthma attacks not clearly stated in the medical records

<sup>19</sup> Royal College of Physicians (2014)

<sup>20</sup> Local Government Association (2022)

- » no record of discussions between urgent care doctors and on-call paediatricians
- » poor documentation of asthma management in hospital
- » no asthma discharge list completed by the hospital
- » suspected asthma diagnosis not recorded on the primary care system

CDOPs highlighted the importance of improving communication between NHS specialisms and services and that practice should move from information exchange to communication and discussion-based practice.

CDOPs also stressed the important role of professional curiosity, assertive practice and challenging parents who are displaying disguised compliance or resistance to expectations and advice.

#### Communication with families

CDOPs recorded poor communication between professionals and families as a contributory factor in 17 (25%) reviews.

Parental and carers' concerns were recorded where parents expressed concerns about the care provided, including lack of clear guidance on how to recognise and what to do if their child's condition worsens, and information not made available in the parent's/carer's native language.

The need for better guidance and support in asthma management for parents/carers and the child was a recurring theme in many of the reviews. CDOPs have recorded that parents may feel that their child's asthma is mild or is well controlled but are not aware of what to do in the event of a sudden deterioration.

CDOPs highlighted the importance of better communication with parents and carers to help them understand that asthma is a chronic condition that needs treatment, and that asthma can also lead to acute exacerbations and how those should be managed. Some children and parents, but also health professions, view asthma as only an acute condition and fail to recognise the progressive lung damage that under-treated asthma can cause. The chronic nature of asthma and the need for adequate treatment, even in the absence of exacerbations, needs to be recognised.



CDOPs also highlighted that education for families needs to be reinforced at every contact with professionals. This should include correct asthma inhaler technique and use of a spacer device, how to recognise asthma deterioration, what action to take with a sudden deterioration, and when to call for emergency help.

Parents had also raised concerns about the ambulance services response time and them “not being listened to”.

Parents/carers should be instructed to state clearly that the child is having an asthma attack, breathing difficulty, is short of breath, or not responding to their blue reliever when calling emergency services, as these words trigger priority response.

See [Further Guidance and Resources](#) document for more information

### **Initiation of treatment and/or identification of illness**

CDOPs recorded issues with identification of illness or initiation of treatment in 21 (31%) reviews, which included 20 deaths where this was recorded as a modifiable factor.

The main factors identified were:

- **No formal diagnosis of asthma** was recorded in 5 deaths. The recorded reasons for this included the child being too young for a formal diagnosis, which was inconsistent with existing guidance, and not wanting to cause alarm to parents.

The explanations provided to parents varied:

- » children under the age of 3 with breathing difficulties were often described as having ‘likely asthma’
- » parents were told that children under the age of 3 years are difficult to diagnose with asthma as symptoms can disappear
- » that a child needs to be able to use a peak flow meter (device used to measure lung function, which the child needs to be able to blow into correctly) before a precise diagnosis can be made

Children were prescribed reliever and preventer asthma inhalers, or reliever inhaler only, but were diagnosed with viral induced or nocturnal wheeze.

The diagnosis of asthma or suspected asthma was not discussed with the parents, and the child was not provided with a personalised asthma action plan.

This may mean that parents may not understand the serious nature of their child’s illness, nor know how to recognise or know what to do in the case of an asthma attack. This also means that professionals may not do a follow up for further investigations and management of the condition.

[NICE guideline \[NG254\]](#) recommends that children under the age of 5 years are diagnosed with asthma or suspected asthma based on observation and clinical judgement and reviewed and treated on a regular basis.

The [National Bundle of Care for Children and Young People with Asthma](#) includes clear guidance on early, accurate diagnosis of asthma and the diagnostic pathways. It states that “suspected” should be clearly stated and only a temporary classification while further investigations are carried out and information gathered. It also states that children with pre-school wheeze (between the ages of 1 and 5) in whom there is not a clear diagnosis of asthma should be classified and coded as either ‘episodic viral wheeze’ or as ‘suspected asthma’ depending on the presence of certain red flag features, and managed according to agreed pathways. Children with pre-school wheeze should be reviewed periodically as their classification may change with time<sup>21</sup>.

- **The child’s deterioration was not recognised** in 6 deaths, and this was recorded as modifiable by the CDOP for all of them.

Examples included:

- » instances with professionals not recognising and therefore not managing severe life-threatening asthma
- » emergency care service not understanding the significance of severe asthma (e.g., the importance of the patient having blue lips)
- » professionals not recognising and planning for appropriate management of the fluctuating course of the disease, which subsequently may lead to failure in medical escalation and/or appropriate specialist referrals (e.g., significant use of salbutamol not recognised as a sign of a deteriorating child)

- **Issues with treatment including delays** were recorded in 13 deaths.

Examples included:

- » issue with the NHS 111 call assessment where a serious incident investigation identified that at the time the child died there was not a specific deteriorating asthma pathway to support the triage of asthma patients. Contributory factors identified a lack of probing during the remote assessment, not speaking directly to the patient, and the clinical triage process not being followed
- » the initial 999 call categorised incorrectly
- » lack of appropriate equipment at the scene of collapse
- » incorrect and therefore ineffective positioning of cannulas to chest/pleural cavities, failure to maintain airway, and wrong dose of adrenaline

Recently, significant changes were made in the [NHS Pathways](#) and deployed to all NHS 111 and 999 providers to improve the assessment of asthma for all patients over the age of 5 years. The changes include an improved specific asthma assessment in the ‘Breathing Problems, Breathlessness or Wheeze’, ‘Cough’ and ‘Chest and Upper Back Pain’ pathways. Specifically for children

21 Beat Asthma (2024)

with asthma, those short of breath at rest, functionally impaired, and either confused, drowsy or agitated, should receive a Category 1 Ambulance response. NHS Pathways has changed the supporting information to support health advisors to better identify those who are using increasing or excessive amounts of their inhalers to control their symptoms.

Speaking directly to the patient is a fundamental part of the core competencies within the training for all staff using NHS Pathways, and this now includes all children over the age of 5 years. When triaging young children, a health advisor is encouraged to speak to the child (even if for a short time), which helps to improve the assessment.

#### Use of nebulisers without appropriate medical supervision

CDOPs have highlighted instances where nebulisers have been prescribed for home use by GPs. The British National Formulary for Children (BNFC) includes guidance on the appropriate use of nebulisers and the requirements for their use should only be initiated and managed by asthma specialists.

#### The importance of appropriate management of severe acute asthma

CDOPs highlighted that after a severe acute asthma attack, a child should be admitted for at least 24 hours observation even if the asthma symptoms resolved rapidly. With such severe acute asthma, best practice would be to refer the case to a specialist multidisciplinary asthma team, including a psychologist, within a tertiary hospital. Free training for professionals is available.

#### Empty inhalers/lack of dosage counters on the inhaler devices

There were 8 (12%) cases where a lack of dose counter on the salbutamol pressurised metered-dose inhaler (pMDI) was implicated as a contributor to the fatal outcome at the CDOP review.

Previous research highlights that up to 40% of patients use an empty inhaler<sup>22</sup>. 25% found the inhaler to be empty when needed acutely and 8% of these went on to require emergency assistance as a result<sup>23</sup>.

The British National Formulary (BNF) and the BNF for Children have included information to alert health care professionals to the dangers of a lack of dose counter, and on what advice professionals should be giving to children and their families and carers about this<sup>24</sup>. Training on the dangers of the lack of dose counter on salbutamol pMDIs is also provided as part of the e-learning developed to complement the National Capabilities Framework for professionals who care for children and young people with asthma.

Whilst updates to the BNF, specific training and national guidance are helpful to raise awareness of the dangers associated with pMDIs that do not have a dose counter, there is a clear need to explore potential options to eliminate this identified issue. NHS England and MHRA have prioritised this significant safety issue and are working proactively with partners in the pharmaceutical industry to seek to ensure that all pMDIs supplied in the UK have an integral dose counter.

See Further Guidance and Resources document for more information



22 Conner and Buck (2013)

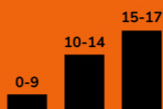
23 Saunder et al. (2006)

24 BNFC (2024)

# Child deaths due to anaphylaxis – key findings

## Child deaths due to anaphylaxis

There were 19 child deaths due to anaphylaxis between April 2019 and March 2023



15-17 year olds were the age group with the highest death rate due to anaphylaxis



53% of the anaphylactic events occurred at home, or at the house of a friend or relative



47% had attended an emergency department in the year before death



All children who died of anaphylaxis and had known allergies were also known to have asthma

## Themes from CDOP reviews

Most common food allergies



Nuts



Milk



Eggs



Public safety was the most commonly recorded factor in child deaths due to anaphylaxis (eg. unclear labelling)



The most common allergen that triggered fatal anaphylaxis was milk



There is a need for standardised allergy plans at schools and hospitals

**NCMD**  
National Child Mortality Database

Full findings from the report, including recommendations, can be found at [ncmd.info/asthma](https://ncmd.info/asthma)





### Characteristics of children who died due to anaphylaxis

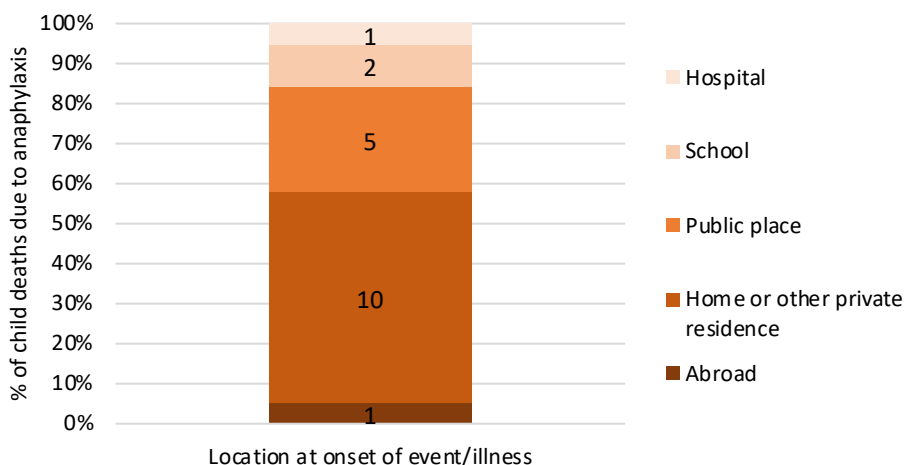
- There were 19 deaths due to anaphylaxis in the 4 year period between 1 April 2019 and 31 March 2023; on average 5 deaths each year.
- Deaths occurred across all ages; 2 (11%) were of children aged under 10, 7 (37%) aged 10-14 years, and 10 (53%) aged 15-17 years. The highest death rate was seen for children aged 15-17 years (1.29 per 1 million children) followed by those aged 10-14 years (0.51 per 1 million children).
- There were similar numbers of deaths of females (n=8, 42%) and males (n=11, 58%).
- There were 9 children who were from an Asian, black, mixed, or other ethnic background (an estimated 0.70 per 1 million children). A further 9 deaths were of children from a white ethnic background (an estimated 0.26 per 1 million children).

- Deaths occurred throughout the year, with 7 (37%) occurring during autumn months (Sep-Nov), and 4 (21%) in each of the other seasons – in spring (Mar-May), summer (Jun-Aug), and winter (Dec-Feb).
- All children who died of anaphylaxis and had known allergies (n=18), were also known to have asthma.

### Location at the onset of the event, and location the death was verified

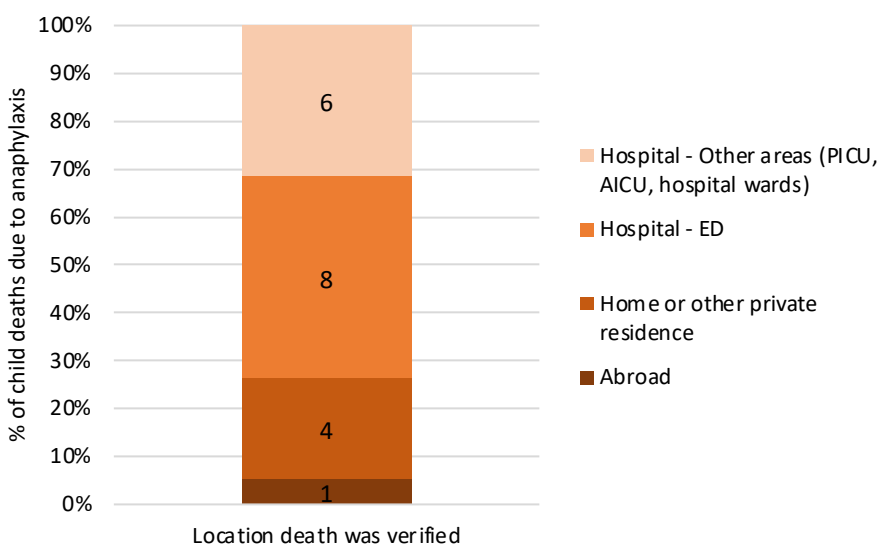
- The anaphylactic event occurred within the home or another private residence in 10 (53%) deaths, including 5 deaths where the child was at another family member or friend's house. A further 5 (26%) occurred in a public place (e.g., a restaurant or place of worship), and 4 (21%) occurred elsewhere including a school, hospital, or abroad (Figure 7).

**Figure 7: Number of deaths due to anaphylaxis between 1 April 2019 and 31 March 2023 (4 years), by the location of the anaphylactic event**



- Duration from exposure to the allergen and time of death varied, which influenced where the death was certified. 4 (21%) deaths were certified at home or in a public place. In 14 (74%) cases the death was certified in a hospital, including 8 (42%) in the Emergency Department and 6 (32%) on PICU, AICU, or other hospital wards. 1 case (5%) occurred abroad (with the exact location unknown) (Figure 8).

**Figure 8: Number of deaths due to anaphylaxis between 1 April 2019 and 31 March 2023 (4 years), by the location of where the death was verified**



### Emergency hospital attendances and admissions

- There were 9 (47%) children who attended the emergency department (ED) at least once in the year prior to their death (excluding the day the child died).
- 4 (21%) children also had at least one hospital emergency inpatient admission in the year prior to their death (excluding the day the child died). In 3 of these 4 cases asthma was the primary reason for admission.

### Completed reviews of child deaths due to anaphylaxis

There were 21 deaths due to anaphylaxis reviewed by a CDOP and reported to NCMD. This includes 13 where the death occurred between 1 April 2019 and 31 March 2023, and a further 8 where the deaths occurred before 1 April 2019 (earliest death occurred in the year beginning 1 April 2016). See the Methodology and limitations section in the [Supporting Material](#) document for more information.

### Contributory and modifiable factors and learning from CDOPs

As part of the child death review process, CDOPs are required to record any contributory factors identified during the review and decide which may be modifiable. Definitions of these terms can be found in the [child death analysis form](#). The interaction of multiple factors can increase the impact of these factors and vulnerability to death, compared with what the impact might have been if there was only one factor present.

The most common contributory factors recorded were related to the child's health history/medical conditions (n=14/21). Almost all of them were related to the child's history of having allergies and asthma, including also previous episodes of asthma attacks and anaphylaxis.

Modifiable factors were identified by CDOPs in 16 (76%) child death reviews.

### Known allergies and the allergens that triggered the fatal anaphylaxis

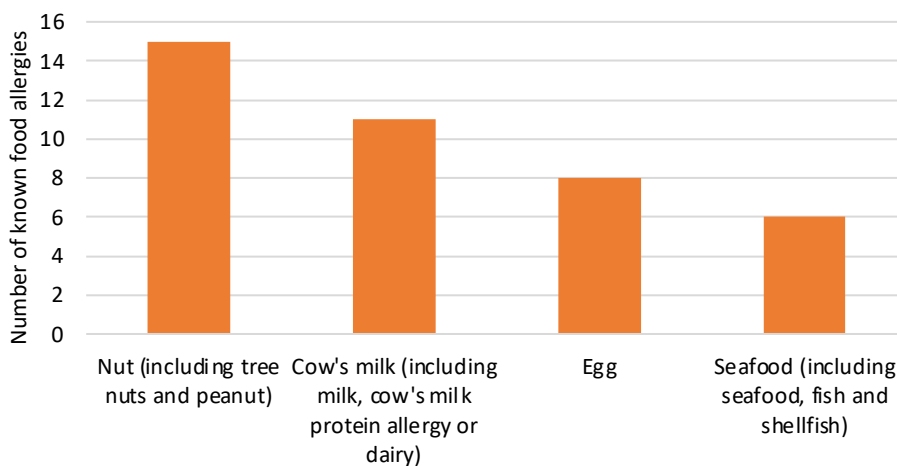
All children barring one had known allergies and they all had food related allergies (95%, n=20) (Figures 9 and 10).

There was one case related to a peri-anaesthetic anaphylaxis in a child with no known allergies.

Most of the children with known allergies had multiple food or non-food related allergies.

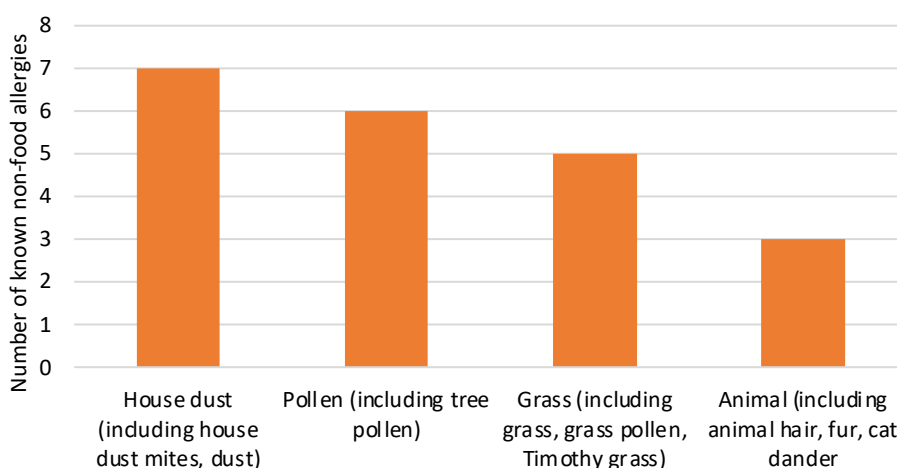
Of the children who had milk allergy (n=11), 3 were recorded to have had severe reactions prior to death.

**Figure 9: Most common food allergies recorded in the reviews of child deaths due to anaphylaxis**



Please note each child may have had multiple allergies, and therefore the numbers will not sum to the total number of child death reviews.

**Figure 10: Most common non-food allergies recorded in the reviews of child deaths due to anaphylaxis**



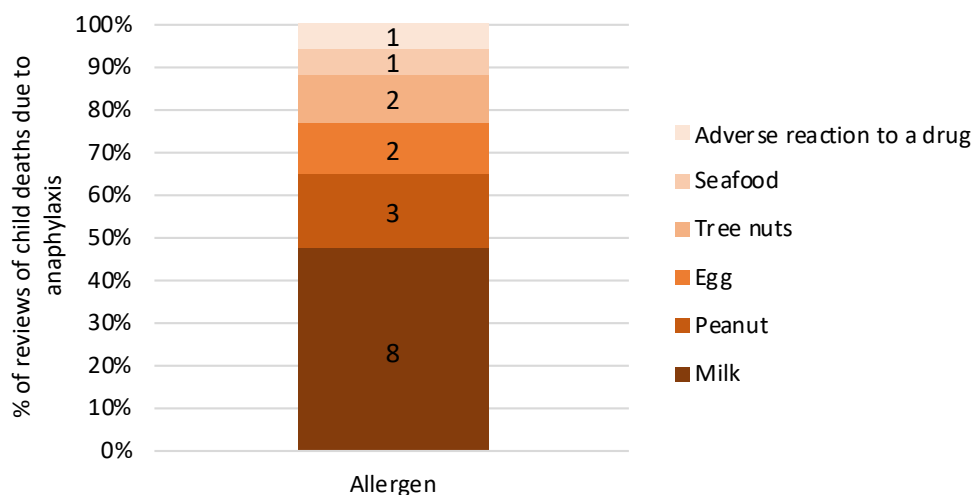
Please note each child may have had multiple allergies, and therefore the numbers will not sum to the total number of child death reviews.

There were 3 cases where the child was also recorded as known to have rhinitis (including allergic rhinitis).

In 10 cases, it was recorded that the child had previous episodes of anaphylaxis or severe reactions.

The allergen that triggered the fatal anaphylaxis was identified in 17 reviews; milk was the most common allergen recorded (47%, n=8/17) (Figure 11).

**Figure 11: Allergen that triggered the fatal anaphylaxis recorded in the reviews of child deaths due to anaphylaxis**



In 4 cases the allergen was not known or not recorded.

Previous studies had shown that milk is the most common food trigger for fatal anaphylaxis in children in the UK, followed by peanut and tree nuts<sup>25</sup>. There is also evidence that milk allergy that continues into school age is often associated with asthma and more severe reactions, particularly in children who are unable to tolerate milk in well-baked food such as biscuits or cakes<sup>26</sup>. These exposures to hidden allergens often result in reactions which mimic asthma. The nature of the allergen may not be obvious. It is therefore important to always consider anaphylaxis in someone with a known food allergy who has sudden breathing difficulty<sup>27</sup>, particularly in children with asthma.

### Asthma and eczema

All children who had known allergies (95%, n=20) were also known to have an asthma diagnosis and 11 (52%) children were also recorded to have eczema. In 3 cases it was recorded that the child's asthma was poorly controlled.

The following were recorded as indicators related to the increased risk of poorly controlled asthma:

- reduced use of inhaled preventer (inhaled steroid) and increased use of reliever (salbutamol) inhaler
- multiple admissions to emergency departments and to hospital due to asthma in the previous year
- lack of recognition of faltering asthma control

In one case, information was inconsistent where it was recorded that there was no evidence of asthma as a long-term condition/known condition, but that the child had attended all their appointments related to their allergies, asthma and eczema. This indicates that the child may not have had a formal asthma diagnosis, which may have had implications on how this was documented in the child's medical records, and on how well the associated risks were managed and communicated to the child and the child's parents or carers.

It is known that children with poorly controlled asthma may be at a higher risk of breathing difficulties if they have a serious allergic reaction<sup>28</sup>. For people with both asthma and allergies there is a higher risk of more severe allergic reaction<sup>29</sup>.

25 Turner et al. (2015)

26 Turner et al. (2016)

27 Anagnostou and Turner (2019)

28 Olabbari et al. (2020)

29 Allergy UK (2021)

Multiple specialties and hospitals or clinics can be involved in the management of children and young people who have eczema as well as asthma and rhinitis. These conditions are persistent and require ongoing management and control, with clear documentation and communication between the different specialties.

CDOPs learning indicated that allergy symptoms were not always communicated to healthcare professionals but should be asked about at asthma review and food-allergies-specific questions incorporated into asthma reviews. Children who have both asthma and allergies should have an emergency plan in consultation with a specialist.

CDOPs identified issues with sharing information between agencies. They highlighted the importance of referrals to secondary care in the event of poor asthma control in children with food allergies, either due to disease severity or to poor treatment compliance. Personal asthma action plans should include details on how and when to take medication, how to recognise the dangers and how and when to call for medical help. Professionals should also be raising awareness with children and their parents/carers of the risk of life-threatening anaphylaxis in children and young people with food allergy and asthma.

See [Further Guidance and Resources](#) document for more information

### **Emergency medicine use**

Where this information was available in the record (n=16), the emergency adrenaline autoinjector (AAI) medicine was administered at the time of incident in 8 (50%, n=8/16) of the cases. Information is limited for most of the cases on whether the AAI was administered appropriately and if all the required doses were given, and the timeliness of the administration.

In 5 cases (30%, n=5/16) the AAI was recorded to be out of date; this also included cases where the AAI available at the school was out of date or the AAI device was of sub-optimal strength.

In 4 cases the child had a prescribed AAI but was not carrying it at the time of the incident.

The recorded reasons for this include:

- the child not carrying an AAI as the family forgot to carry the emergency kit
- the child never needed to use or did not use it in the recent past, giving a false sense of security; the risk was hence felt to be reduced on the basis of the recent experience
- the child and the family had observed symptoms of anaphylaxis but had noted them to improve on previous accidental exposure to the allergen, without the use of adrenaline, so the recommended treatment was felt not to be important to carry with them

- the child or family were not intending to eat on that occasion and therefore felt it was unnecessary to carry the emergency kit with them

In 3 of the cases, the child was not prescribed an AAI. The reasons listed included that the child was known to only have mild allergic reactions previously.

In some cases, the healthcare professionals had not recognised that the allergic reactions were anaphylactic based on the history that had been provided.

This indicates issues related to the lack of understanding of the risks and the importance of the emergency medicine to be in-date, always be accessible, and knowing when and how to use it correctly.

The amount of allergen which is needed to evoke an allergic reaction can vary. A smaller amount of allergen than has been required on previous events may lead to a reaction if there was ill-health, lack of asthma symptom control, lack of sleep, and co-medications. Severity of the reaction may worsen with change in posture or exertion during anaphylaxis.

CDOPs have raised the importance of reinforcing the message for children, young people and their parents or carers that the prescribed AAIs should be within their shelf life and replaced if past the expiry date, and carried in person with the patient at all times. They should have a clear understanding of when and how to use the AAIs.

Learning also highlighted the need for safety plans when there are disruptions to routines e.g., festive periods or parties, which may contribute to lapses in checks and precautions normally taken with checking ingredients in any new foods. There should also be greater awareness and training in the use of AAI devices among friends and acquaintances of allergy sufferers.

See [Further Guidance and Resources](#) document for more information

### **Mast cell tryptase test**

There was limited information in the CDOP reviews on whether a mast cell tryptase blood test was carried out and on the timing of the test. From the available information there were instances where the test was not taken at all, checked only at the time of the post-mortem examination, or it was taken but there was no information on the timing of sample collection.

Mast cell tryptase is an enzyme that is stored in mast cells throughout the body. When the mast cells are activated, they release histamine, tryptase, and other chemicals, which leads to symptoms of allergies such as itching, redness, or difficulty breathing. Measuring the mast cell tryptase in the blood can help determine if a severe reaction has occurred. If anaphylactic reaction is suspected, the blood sample should be taken as soon as possible after the emergency treatment has started. This sample should be taken ideally within 1 to 2 hours and no more than 4 hours from the onset of the first symptoms, and a further paired sample must be collected 12 hours or later to see the tryptase return to its baseline levels<sup>30</sup>.

---

30 NICE (2011)

[NICE clinical guideline CG134](#) covers assessment and referral for anaphylaxis including a set of recommendations for the steps that healthcare professionals should take after an anaphylactic or suspected anaphylactic reaction in children and young people.

### **Emergency services response**

Issues with identification of the place of incident or accessing the building where the incident happened have been identified in the reviews. Suggested solutions by the CDOPs included the need for patients and families to be more aware of the [What3Words App](#) to convey exact geolocation to emergency services, and for improvements to be made to street signs to make locations more accessible.

### **Public safety**

CDOPs recorded factors related to public safety in 33% (n=7) of the reviews. Of those, the most common factor was related to unclear, misleading or inaccurate labelling of food, either packaged or cooked, purchased from supermarkets or takeaway shops. There was one case of cross-contamination of packaged food served at a public venue, where the issue identified was related to the manufacturing process and the appropriate testing for allergens potentially not being fully carried out.

Ingredients in recipes may change, so an assumption must not be made that a previously eaten food at a restaurant or outlet may be safe for consumption again. There should be clear signage in the takeaway shops advising customers to ask about allergens even if they have eaten there before and because suppliers may change. [Natasha's Law](#), introduced in 2021, calls for clear allergen labelling for prepacked food for direct sale and [guidance for businesses](#) provided by the Foods Standards Agency.

## **Schools**

Factors related to the delay in recognition of anaphylaxis and use of emergency medication at schools were recorded.

A [Regulation 28 Prevention of Future Deaths Report](#) was issued by the coroner highlighting the need for targeted education at schools, to include raising awareness of allergies and the risks of exposure to allergen to all pupils, that instructions of when and how to use AAls should be part of the staff's first aid training, and the importance of standardised allergy action plans across hospitals and schools.

CDOPs highlighted that school policies' focus should be on avoiding allergens rather than depending on emergency medicines. Schools should review their medicines in school guidance to ensure this is being adhered to. Deaths can occur despite the use of adrenaline auto-injectors. It is important to avoid allergen exposure, rather than relying on successful reversal of symptoms of anaphylaxis by use of emergency medicines.

The importance of the role of school nurses is also highlighted. School nurses can ensure schools have up to date anaphylaxis/allergy action plans, and available and in-date AAI emergency medicine. School nurses can help with awareness raising, training and education for staff on the symptoms and what to do in an emergency, and in reiterating the message of allergen avoidance. School nurses can also provide support and guidance for older adolescents who are becoming more independent in decision making and are at greater risk.

In 2017, a legislative amendment was made to the UK Human Medicines Regulation under Schedule 17 that allows schools as defined in the Education Act to obtain AAls without a prescription. AAls supplied in this way are to be kept on school premises for use in an emergency to treat anaphylaxis, in a pupil known to be at risk. The AAls held by a school are intended as a back-up and not to replace a pupil's own AAls. The accompanying [guidance issued by the Department of Health](#) specifies that the back-up AAls are intended for use in children who are medically authorised, and where parental/guardian consent is in place, to receive the back-up AAls. A consideration should be made on whether the cost of the emergency medicines that schools need to purchase (and renew stocks annually) without prescription could be a barrier for them to follow the guidance, and on what the possible solutions could be.



## Recommendations

### Policy

1. Recognise asthma as an important and significant public health issue. As such, the government should oversee a systematic reform in the delivery of asthma care, to ensure that adherence to current asthma guidelines and standards of care is integrated into routine care, with a particular emphasis on the improved delivery of asthma care in primary care.

This may be achieved by:

- » Mandating competency assured asthma training for all professionals who may care for a child with asthma as per [The National Capabilities Framework for Professionals who care for Children and Young People with Asthma](#). Only professionals who have been adequately trained and their competences accredited should care for a child or young person with asthma. This has also been previously highlighted by a coroner in a [Regulation 28 Prevention of Future Deaths Report](#).
- » Making preventable child deaths due to asthma that can be linked to a failure of one or more of the elements of the integrated care and public health system a never event.

**Action: Department of Health and Social Care**

### Outdoor and indoor air pollution

2. Ensure that there is a government plan to reduce air pollution levels to meet [the World Health Organisation \(WHO\) air quality guidelines](#).

**Action: Department of Health and Social Care, Department for Environment, Food & Rural Affairs**

3. Adopt the [Asthma Friendly Homes initiative](#) to ensure that all children with asthma who are living in homes with damp or mould are prioritised for housing repairs following the introduction of the new [Tenancy Consumer Standards](#). Consider adding targets on reducing smoking in households in the [Joint Strategic Needs Assessments](#) and [Joint Forward Plans](#).

**Action: Ministry of Housing, Communities & Local Government, Local Authorities, Integrated Care Boards**

### Commissioning

4. Include a requirement within acute or community paediatric service specifications, for asthma nurses to offer home visits to any child who has had a paediatric intensive care or high dependency unit hospital admission with asthma and/or anaphylaxis. In the home environment asthma nurses can: a) provide a holistic understanding of family and home circumstances, b) support and guide families on asthma and allergy management and inhaler technique, c) advise about smoking and drug use, d) signpost to smoking cessation services, and e) help identify those families for whom further support from other agencies such as social care, housing, smoking cessation and mental health, may be required. In addition, all children admitted to a High Dependency Unit or PICU with asthma or anaphylaxis should be seen by/discussed with an asthma or allergy clinician during the admission in order for appropriate discharge planning steps to take place.

**Action: Integrated Care Boards, Paediatric Critical Care Operational Delivery Networks**

5. Maintain inhaler technique checks in the Respiratory domain of the [Pharmacy Quality Scheme](#) and expand this criterion to require pharmacists to discuss the dangers of inhalers with no dosage counters with children and their carers; this should include an explanation of how they can ensure their inhaler does not become empty. The [Community Pharmacy Contractual Framework](#) should be updated to include a requirement for pharmacists to alert primary care of any patients where there has either been an increased number of prescriptions requested for reliever inhalers or a failure to collect prescribed inhaled corticosteroids. This event can be an early indicator for poorly controlled asthma and would strengthen the role of community pharmacies in supporting delivery of the [NHS Long Term Plan](#). Explore the technology solutions for this e.g., for an automated alert to primary care in the cases where there is an increased number of prescriptions for reliever inhalers or failure to collect the preventer inhalers.

**Action: NHS England**

### Education

6. Fund school nursing provision in every school in recognition of the important role school nurses play in supporting children at school with asthma and/or allergies in line with the [School and Public Health Nurses Association \(SAPHNA\) vision document](#) and the [Healthy child programme: health visitor and school nurse commissioning](#).

**Action: Department for Education, Office for Health Improvement and Disparities, Independent Schools Council**

7. Update the [RSE and Health Education statutory guidance](#) to include asthma education in order to raise awareness among children and young people on what asthma is, how it is treated, what the symptoms are of an asthma attack and when to seek help, and how children with asthma can be supported by their peers to feel accepted and safe in using their inhaler medication.

**Action: Department for Education**

### Medicines

8. Ensure that all asthma inhalers that are licensed and supplied in the UK have dose counters. In the interim, a warning on the risks of devices without dose counters should be included in [the revised NICE asthma guidelines](#).

**Action: Medicines and Healthcare products Regulatory Agency (MHRA), NHS England, Department of Health and Social Care**

### Healthcare practice

9. Recognise [asthma attacks](#) as significant events and ensure the correct pathways are in place for a detailed 'post attack review' to be conducted within 48 hours. This should be undertaken by an appropriately trained professional to identify and deal with modifiable risk factors to prevent future attacks. This is in line with the [British Thoracic Society \(BTS\) guidelines on the management of asthma](#) and part of the [Quality Outcome Framework \(QOF\)](#) for General Practitioners.

**Action: Integrated Care Boards, Primary Care Networks, Royal College of Paediatrics and Child Health, Royal College of General Practitioners**

### Research

10. Commission research into the use and effectiveness of peak flow monitors before they can be used more widely.

**Action: National Institute for Health and Care Excellence**





# Additional key improvements needed in professional practice

**All professionals** should refer to children's social care all children and young people whose parents/carers persistently fail to adhere to medication or health advice (including also advice on smoking cessation) or fail to bring them in for medical appointments. Referrals should be made in line with Local Safeguarding Children Partnership thresholds for Children in Need or Child Protection including when escalation is required due to interagency disagreement. Referrals should be made immediately if there is a concern that the child is suffering or is likely to suffer significant harm as per the [Working together to safeguard children statutory guidance](#).

**All social workers** working with children who have asthma should complete the free online tier 1 training as part of [The National Capabilities Framework for Professionals who care for Children and Young People with Asthma](#), and their competence accredited. Social workers must be aware that asthma is a potentially dangerous condition that can result in severe asthma attacks and death.

**All schools** should:

- adopt the [Asthma Friendly Schools](#) initiative so that children and young people with asthma in primary and secondary school are better supported.
- ensure regular support and training is provided to school staff and that emergency medicines for children with asthma and those with allergies are available and regularly verified as in-date as per the Department of Health and Social Care [Guidance for schools in England on using emergency inhalers](#) and [Guidance on the use of adrenaline auto-injectors in schools](#).

**All healthcare professionals** should:

- ensure that every child prescribed 2 or more reliever inhalers in 12 months must be referred to be reviewed by an appropriately trained clinician. Excess prescription of short-acting  $\beta_2$ -agonists (SABA) particularly without inhaled corticosteroids is recognised in the [BTS](#) and [NICE](#) guidelines. This is also supported by recent research<sup>31</sup>. This should be endorsed by the relevant royal colleges – the Royal College of Paediatrics and Child Health, the Royal College of Emergency Medicine, and the Royal College of General Practitioners.
- ensure that an asthma inhaler is only prescribed when there is a clear clinical indication and/or a formal diagnosis of asthma or suspected asthma and a referral made to an appropriately trained clinician. This should be endorsed by the relevant royal colleges – the Royal College of Paediatrics and Child Health, the Royal College of Emergency Medicine, and the Royal College of General Practitioners.

- ensure training is provided to families and children and young people on the correct and appropriate use of the emergency adrenaline autoinjector (AAI) medicine. Awareness should be raised and messaging reinforced at every contact with services related to the child's and young person's asthma or allergies, of the risks and the importance of the emergency medicine to be in-date, always be accessible, and technique checked on its correct and appropriate use.

**All pharmacists** should:

- check good inhaler technique at every opportunity and recognise that 2 or more prescriptions a year of reliever inhalers may be a red flag for poorly controlled asthma. Pharmacists should also recognise the risks associated with inhalers with no dosage counters and advise on measures to help prevent the use of an empty inhaler. Resources to support learning needs and knowledge are available at the [Centre for Pharmacy Postgraduate Education \(CPPE\)](#). Such expectations should form part of the [NHS New Medicine Service](#). This should be endorsed by the Royal Pharmaceutical Society and the Association of Pharmacy Technicians UK.
- check good emergency adrenaline autoinjector (AAI) medicine technique at every opportunity and raise awareness of the risks and the importance of the emergency medicine to be in-date and always accessible.

**All school nurses and health visitors** should complete relevant speciality tier training as per [The National Capabilities Framework for Professionals who care for Children and Young People with Asthma](#). School nurses can raise awareness of asthma triggers for school staff and support children and young people with asthma and allergies and their families. Health visitors can also help raise awareness of the triggers for asthma with parents through their universal reach. The uptake of training should be promoted by the relevant professional bodies - the Institute of Health Visiting and the School and Public Health Nurses Association and by the Office for Health Improvement and Disparities and NHS England.

**All food suppliers** must ensure food ingredients are easily available to consumers. This should include cooked foods by caterers for private consumption, food available at restaurants and take-aways and food suppliers to schools.

31 Bloom et al. (2020)

## Existing guidance and recommendations requiring improved implementation

- All children with newly diagnosed asthma or suspected asthma should be followed up by a healthcare professional with appropriate training as per the [British Thoracic Society \(BTS\)/SIGN guidelines on the management of asthma](#).
- Health care professionals should refer any child or young person who had 2 or more asthma attacks in 12 months to an asthma specialist as per the [National Review of Asthma Deaths \(NRAD\): Confidential enquiry report 2014](#). NRAD recommended that follow-up arrangements must be made after every attendance at an emergency department or out-of-hours service for an asthma attack.
- Every child diagnosed with asthma has an up-to-date written asthma plan that is shared with the GP, school and everyone who is involved with the care of the child as per the [British Thoracic Society \(BTS\)/SIGN guidelines on the management of asthma](#) and the [Global Initiative for Asthma - GINA guidelines](#). The percentage of patients with asthma who have had an asthma review in the preceding 12 months is a Quality and Outcomes Framework (QOF) indicator for asthma in the General Medical Services (GMS) contract.
- Any child with asthma who has not been prescribed an inhaled corticosteroid must be reviewed by an appropriately trained clinician per the [Global Initiative for Asthma - GINA guidelines](#).
- Any child and young person with asthma attending and/or admitted to emergency department and hospital with issues related to their asthma has their inhaler technique checked, action plan administered, and both documented in the medical notes. A follow-up with their GP should be organised with someone with the appropriate training. This is a national quality improvement priority as identified by the [Royal College of Physicians' Children and Young People Asthma Audit 2019/2020](#) and a [NICE Quality Statement 2013](#). The attendance and admission to hospital should be automatically considered as part of the child's asthma monitoring control.
- All children and young people who present to primary care, walk-in centres, ambulance, or emergency departments with acute symptoms are reviewed by a healthcare professional who has been trained to the appropriate level according to [The National Capabilities Framework for Professionals who care for Children and Young People with Asthma](#) and their competence accredited. Those delegating this care should, in accordance with the 2024 GMC Guidance, ensure that those delegated to have the appropriate competence for the roles assigned. The rationale for clinical decisions must be documented in the discharge correspondence for the General Practitioner (GP).





## Next steps and future priorities

### Child death review process

Work by NCMD is ongoing to continuously improve data quality by further developing the child death review (CDR) data collection forms. This aims to better support the CDR process and provide more granular and comprehensive data for deeper understanding of child deaths.

Analysis of this report has identified the need for improvements including:

1. The [CDR Asthma and Anaphylaxis Supplementary Reporting Form](#) should be updated. For instance, additional questions should be considered to improve data collection on vaping and smoking of tobacco and other substances; NHS prescriptions data for the 12 months before the death of the child should be gained from the GP practice and recorded in the form.
2. CDOPs should hold themed annual asthma/fatal anaphylaxis meetings with appropriate expertise to inform, discuss and better identify learning.
3. CDR professionals should follow the [Joint Agency Response \(JAR\) to Suspected Child Death from Anaphylaxis or Asthma guidance](#) which supplements standard JAR guidance. This includes:
  - » Mast cell tryptase testing in the cases of suspected anaphylaxis
  - » Forensic collection of potential sources of allergen for testing and collection of food packaging in the event of potential food allergy

4. Pre-hospital data should be collected and reviewed during the child death review process. The [CDR Care Pathway Supplementary Reporting Form](#) should be completed to allow better analysis and learning on the pre-hospital care, to include:
  - » 999 call logs
  - » Ambulance service documentation
  - » Helicopter Emergency Medical Service (HEMS) documentation

### Future priorities

Key areas where further research is needed include:

- Further examination of the impact of environmental factors related to air pollution and climate change on child mortality.
- Further work to achieve better data collection and improve understanding of anaphylaxis, as also highlighted in [Regulation 28 Prevention of Future Death reports](#) issued by the coroner.
- CDOPs and the [UK Fatal Anaphylaxis Registry \(UKFAR\)](#) should share data, with the appropriate legal basis in place, to improve the understanding and learning from deaths due to anaphylaxis. UKFAR can assist the child death review process with further relevant investigations to be undertaken and help ascertain the cause of death with greater degree of certainty.



**Cover image: Breathe, Jasmine Pradissitto**

This sculpture in NOXORB™ ceramic by Dr Jasmine Pradissitto (recipient of The Pioneering Arts in Environment award in 2021) on one of London's Busiest roads, cleans the air of the brown toxic nitrogen dioxide gas, a by-product of combustion. NO<sub>2</sub> is one of the contributory factors in respiratory disease such as asthma. Commissioned in 2016 by The Mayor of London and Euston Town, it was installed in 2020 above Camden People's Theatre.

With thanks to Haroon Ihsan, founder of Mantis Innovation, who continues to create and research into this incredible geopolymers.

Images courtesy of photographer Jeff Moore for Gillian Jason Gallery.

# NCMD

National Child Mortality Database

Knowledge, understanding and  
learning to improve young lives

## National Child Mortality Database (NCMD)

Level D, St Michael's Hospital  
Southwell Street  
Bristol, BS2 8EG

**Email:** [ncmd-programme@bristol.ac.uk](mailto:ncmd-programme@bristol.ac.uk)

**Website:** [www.ncmd.info](http://www.ncmd.info)

**X:** @NCMD\_England

**Bluesky:** [ncmd.bsky.social](https://bsky.app/profile/ncmd.bsky.social)