



HEALTHCARE SAFETY  
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## Interim bulletin

# Management of chronic asthma in children aged 16 years and under

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This interim bulletin contains facts which have been determined up to the time of issue. It is published to inform the NHS and the public of the general circumstances of events and incidents and should be regarded as tentative and subject to alteration and correction if additional evidence becomes available.



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INVESTIGATION BRANCH

## Introduction

The Healthcare Safety Investigation Branch (HSIB) was notified by the Department of Health and Social Care of a safety risk identified in three reports to 'Prevent Future Deaths' (PFD) by coroners. These related to the deaths of children occurring between 2014 and 2017. The reports highlighted missed opportunities to recognise asthma as a chronic and life-threatening condition. Issues were identified around how the condition was managed across both primary and secondary care. In addition, it was observed that care did not meet the relevant National Institute for Health and Care Excellence (2017) Quality Standard, in a number of areas.

Asthma is a long-term condition that is characterised by chronic airway inflammation (swelling). Symptoms include breathlessness, wheezing, coughing and tightness of the chest. Acute asthma attacks can be fatal; analysis of official figures from the Office for National Statistics (Asthma UK, 2019) shows that more than 1,400 adults and children died from asthma attacks in 2018, an 8% increase since 2017.

An investigation was launched after HSIB identified an incident involving a child aged five years who suffered a near-fatal asthma attack. The investigation will explore the implementation of safety improvements for managing chronic asthma in children aged 16 years and under.

The investigation will lead to the development of recommendations to improve current and future management of asthma in children in this age group.

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## National context

Asthma is the most common lung disease in the UK, and there are around 1.1 million children currently receiving treatment for the condition (Asthma UK, 2020).

The causes of asthma are not well-understood and there is currently no cure for the condition. Treatment focuses on patient awareness and the management of symptoms.

Evidence-based asthma guidelines were first published almost 30 years ago. However, studies repeatedly demonstrate that these guidelines were not implemented in clinical practice (Levy, 2015).

The National Review of Asthma Deaths (NRAD) (Royal College of Physicians, 2014) reviewed asthma deaths that occurred in the UK between 1 February 2012 and 31 January 2013. It identified potentially avoidable factors related to non-implementation of asthma guidelines in about half of these deaths. The NRAD report contained 19 recommendations that clinicians responsible for the care of people with asthma should observe to reduce the number of preventable asthma attacks, improve care and highlight basic minimum standards. Six years on, only one of the recommendations – a national asthma audit – has been implemented.



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INVESTIGATION BRANCH

## Decision to investigate

HSIB conducted a preliminary investigation, following which the Chief Investigator authorised a full investigation as the risk met the following criteria:

### **Outcome Impact - what was, or is, the impact of the safety issue on people and services across the healthcare system?**

- The missed opportunity to recognise asthma as a chronic and life-threatening condition.
- The issues related to how the condition is managed in accordance with national guidance.
- How asthma attacks can be treated in isolation and without consideration of their link to the underlying chronic condition.
- How patient harm and death may result from delayed or absent clinical treatment.

### **Systemic Risk - how widespread and how common a safety issue is this across the healthcare system?**

- 'The Global Asthma Report 2018' found the UK's asthma mortality rate for the period 2011 to 2015 was in the top 10 of high-income countries where asthma is separately coded as a cause of death (British Medical Association, 2019).
- Asthma deaths in England and Wales have increased by 32.7% from 2008 to 2018 (Office for National Statistics, 2020).



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INVESTIGATION BRANCH

- Asthma is the most common lung condition in children, affecting around 1 in 11 children in the UK (Asthma UK, 2020).
- PFD reports covering different care sectors highlight issues recurring across the system, including a lack of co-ordination of records and care across primary and secondary care and a potential lack of understanding of how to manage the condition.

**Learning Potential - what is the potential for an HSIB investigation to lead to positive changes and improvements to patient safety across the healthcare system?**

- A focus on children aged 16 years and under would highlight issues in an under-investigated cohort.
- Potential for an HSIB investigation to offer a new approach to those previously taken, involving a wider group of stakeholders, including patients and charities.
- Opportunity to highlight and improve potential gaps in current processes and influence the design of future processes.
- New thinking is needed to enable substantial improvements in diagnosis and management (Lenney et al., 2018).

## The reference event

The investigation focuses on the case of a child who was born prematurely and, as a consequence, suffered from a number of health issues, one of which was



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INVESTIGATION BRANCH

chronic lung disease. Secondary to this, the child had a wheeze (whistling sound made during breathing) and a 'wet cough' (producing mucus). He was reviewed as an outpatient by paediatric respiratory medicine following discharge from neonatal services. The child also had numerous planned inpatient and outpatient attendances for his other health conditions. Additionally, there were eight unplanned (emergency) hospital attendances over a time period of two and a half years, all relating to respiratory symptoms.

Because the child was in an at-risk group, each winter, he received an influenza vaccination by injection at the GP group practice. During the child's first term at school, a nasal influenza vaccine was offered as part of the school vaccination programme. However, the child's mother was concerned that the nasal vaccine may not be the most effective form of treatment for her son given that he was at higher risk. She was also aware that the vaccine contained pork gelatine, and the family does not eat pork for religious reasons.

The child's mother attended the GP practice to find out what alternative was available for him, thinking that he would be given the injection as on previous occasions. However, she was advised that her son was in the school-age cohort of children covered by the school vaccination scheme and her concerns were not explored further. Therefore, the child did not receive a vaccine that winter, as schools only offer the nasal vaccine and there is currently no alternative which does not contain pork gelatine (Public Health England, 2019).

During his first year at school, the child remained generally well and was discharged from several specialty hospital services. However, his respiratory



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INVESTIGATION BRANCH

symptoms persisted, and different treatment regimens were tried in an attempt to control the 'wet cough' and intermittent wheeze.

At the end of the summer term, the child suddenly became ill with a high temperature and persistent cough. On day four of the child's illness, a GP diagnosed a viral illness. By the evening of day five the child's symptoms had not improved, so his mother rang NHS 111. She described his symptoms, including his rapid breathing rate and chest recessions (when the soft tissue of the chest is drawn inwards due to breathing problems). She was advised that her child needed to be seen face to face at the nearest hospital, and an hour later they arrived there by taxi. The child was noted to be suffering from **'shortness of breath in children, increased work of breathing'**. Several hours later, he was admitted to a paediatric intensive care unit with respiratory failure, where he needed extracorporeal membrane oxygenation (ECMO) [1], to support his breathing. He was diagnosed with an acute exacerbation of asthma, secondary to type A influenza.

The child made a gradual recovery and was discharged home just over six weeks later, with an ongoing plan for community therapy support.

Prior to the event, the child had no formal diagnosis of asthma and issues had been identified (but not resolved) regarding adherence to prescribed medicines. The child was being given salbutamol inhalers to relieve his symptoms, but a corticosteroid 'preventer' treatment was not being regularly administered to prevent symptoms. Additionally, the outpatient follow-up appointments were delayed.



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INVESTIGATION BRANCH

## Identified safety issues

Formal diagnosis of asthma in children under the age of five can be challenging. The symptoms can be confused with those of other respiratory diseases and young children are usually unable to perform lung function tests. Diagnosis relies on closely monitoring how a patient's symptoms respond to treatment.

In the reference event, the effectiveness of asthma management was particularly challenging because:

- 1 The suspected or possible asthma diagnosis was not formally discussed.
- 2 The care fell between hospital and general practice, where responsibility for monitoring the condition was not clearly defined.
- 3 There were inconsistent and unreliable mechanisms for sharing clinical information.
- 4 There was minimal information and training provided to the mother about asthma to enable the appropriate management of her son's condition.

## Next steps

HSIB is engaging with subject matter advisors to advise the investigation team on elements of the investigation, and with key stakeholders.

The investigation will continue to explore the identified safety issues and welcomes further information that may be relevant from any source.

HSIB will report any significant developments as the investigation progresses.



HEALTHCARE SAFETY  
INVESTIGATION BRANCH

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## Endnotes

[1] ECMO is a technique that uses a machine to pump and oxygenate a patient's blood, providing prolonged cardiac and respiratory support to patients whose heart and lungs are not functioning well enough to sustain life.