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Preventing further deaths from fatal anaphylaxis

The UK Fatal Anaphylaxis Registry collects data on fatal anaphylaxis reactions.

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This article explores how the UK Fatal Anaphylaxis Registry is investigating reports on anaphylactic reactions to identify how care can be improved and fatal reactions prevented. Key themes include communication, patient awareness and unrecognised symptoms.

The *Coroners and Justice Act 2009* allows a coroner to issue a Regulation 28 report (also known as a Prevention of Future Deaths report) to an individual, organisations, local authorities or government departments and their agencies, where the coroner believes that action should be taken to prevent further deaths.[1]

Reviewing fatal anaphylaxis reports

The UK Fatal Anaphylaxis Registry (UKFAR) undertook a review of the Prevention of Future Deaths reports by hand-searching the relevant categories of 'Other related deaths' and 'Hospital death (clinical procedures and medical management)-related deaths' on the repository of Prevention of Future Deaths reports on the Courts and Tribunals Judiciary website.

From this, 56 potentially relevant reports related to anaphylaxis were identified. After review of the contents, 43 reports were included. The review identified 161 individual recommendations made by coroners and extracted them from the reports for comparison. Following this, the data was synthesised into the following broad themes (Table 1).

Table 1. Themes identified in the Prevention of Future Deaths reports.

Theme		Number of recommendations identified	
Poor documentation	Poor allergy documentation in health records	13	34
	Poor clinical documentation	8	
	Inability to access relevant records	8	
	Allergy action plans	5	
Poor clinical practice	Failure to follow clinical guidelines	12	32
	Lack of suitable equipment	5	
	Patients not receiving regular allergy reviews	5	
	Fitness to practice	3	
	Inadequate patient observation	3	
	Delayed care	2	
	Insufficient support to escalate concerns	1	
	Insufficient senior medical involvement	1	

Training and learning	Poor training provision	9	22
	Lack of learning following fatalities	5	
	Insufficient staff knowledge	4	
	Ambulance algorithm not fit for purpose	3	
	Unclear clinical guidelines	1	
Poor communication	Poor communication between different services	8	19
	Poor communication with patient/family	7	
	Poor handover of patient care	2	
	Inadequate referral processes	1	
	Failure to escalate care	1	

Adrenaline auto-injectors	Not enough adrenaline auto-injectors provided to patients	5	15
	Adrenaline auto-injectors should be available in the same manner as defibrillators	3	
	Adrenaline auto-injector training for patients	3	
	Concerns regarding needle length and/or adrenaline dose	2	
	Shortage of adrenaline auto-injectors	1	
	Out-of-date adrenaline auto-injector	1	
National registry and leadership required	UK Fatal Anaphylaxis Registry	7	14
	Better assistance investigating anaphylaxis cases	3	
	Mandatory reporting of anaphylaxis	2	
	National leadership required	2	
Patient and public awareness	Knowledge of anaphylaxis	7	11
	Allergy awareness	3	
	Food labelling	1	

Unsafe staffing	Hospital staffing	7	8
	Community staffing	1	
Post-mortem	Updated guidance required	1	3
	Failure to retain samples	1	
	Poor-quality post-mortem examination	1	
Industry concerns	Beauty industry	2	3
	Food industry	1	

Analysing the key themes

Documentation and communication

Several concerns were repeatedly raised regarding documentation. Coroners made several recommendations relating to the need to improve allergy documentation in records. Poor clinical documentation was also raised as a concern. Even where there were no concerns with the standard of documentation, the review repeatedly found that relevant documentation was inaccessible when required.

This was particularly pertinent when patients were seen across different parts of the health service – hospitals struggled to access GP and ambulance records (including records of known allergies), and vice versa. The implementation of a unified patient record would help to mitigate this, by ensuring that all healthcare professionals involved in a person's care are able to access all relevant information about an individual and, therefore, provide higher-quality care.[2]

Additionally, the review often noted poor communication between healthcare services and patients and their families; referral processes were repeatedly found to be inadequate. Fragmented care and poor communication between different services have been identified as key factors leading to suboptimal allergy care.[3] Samantha Singh attended her GP with concerns that she had a peanut allergy.[4] Radioallergosorbent testing was undertaken and it was confirmed that Samantha had a peanut allergy. However, the results were originally miscategorised as 'normal' and it was only because Samantha arranged an appointment with her GP to discuss the results that they realised that a mistake had been made. Additionally, following this appointment, Samantha was not referred to any kind of allergy clinic for follow-up.

Inadequate review

UKFAR has reviewed many cases where patients were not receiving adequate clinical review for their allergies, including the high-profile cases of Shanté Turay-Thomas[5] and James Atkinson,[6] neither of whom had appropriate follow-up and review for their allergies. There has recently been recognition that not all allergy care can be provided in secondary care, and needs to be provided in primary care.[7]

Patient and public awareness

Many coroners raised concerns and recommendations relating to a need to improve patient and public awareness of allergy and anaphylaxis. Poor recognition of anaphylaxis was a recurring theme for both healthcare professionals and people with allergies. The recent high-profile case of Hannah Jacobs, which resulted in her preventable death, illustrates this.[8]

Hannah and her mother bought hot chocolates on their way to the dentist, both of which were supposed to be made with soya milk. However, they were incorrectly served hot chocolates made with cows' milk. Hannah had a sip of her drink while at the dentist and immediately felt unwell. She began to salivate excessively, but this was not recognised as a manifestation of her inability to swallow and, thus, a sign of anaphylaxis. Hannah and her mother then left the dentist to go to a nearby pharmacy. Hannah had swollen lips, which was identified as a mild-to-moderate symptom of allergy on her allergy plan, which the Prevention of Future Deaths report noted provided a false sense of reassurance.

Unrecognised symptoms

UKFAR has also reviewed multiple cases where anaphylaxis had not been recognised because there was no urticaria. Wang *et al*. (2014) found that only 55% of health professionals correctly identified cases of anaphylaxis without skin symptoms.[9] However, it is known that 10–20% of anaphylaxis cases have no skin involvement,[10] so it is important that anaphylaxis is still considered as a differential diagnosis in cases where there is no obvious rash.

For example, UKFAR analysed the case of a 73-year-old woman who quickly developed hypotension and oxygen desaturation following induction of anaesthesia. But, as she did not immediately present with an erythematous rash, the initial working diagnosis was fast atrial fibrillation causing hypotension. It was only when she developed an erythematous rash that anaphylaxis was considered as the cause of her deterioration.

UKFAR also reviewed a case of a young girl who died from an anaphylactic reaction to milk, but the death was recorded as an asthma death, partially owing to the lack of classic skin symptoms for anaphylaxis.

Coroners' recommendations

Several recommendations were made by coroners relating to the need for a national registry and national leadership for allergies. The need for a national registry and the need to support UKFAR were highlighted several times. UKFAR was set up in 1992 and exists to collect information pertaining to fatal anaphylactic reactions, with the aim of analysing the data and sharing the findings to improve clinical outcomes.[11]

The recommendations also highlighted the need for better assistance for those investigating suspected cases of anaphylaxis. UKFAR often faces significant barriers and delays in accessing patient records and details of fatalities. This makes it harder to capture important details of the suspected fatal anaphylaxis; important evidence can be lost or discarded before it can be included in the registry. More consistent and timely contact with UKFAR would enable better learning from fatalities and help to ensure that they could be prevented in the future. UKFAR is also able to assist with death review processes, which can help to ascertain the cause of death with a greater degree of certainty.[12]

Following the death of Alexandra Briess, who had a fatal anaphylactic reaction to rocuronium used during anaesthesia for surgery to repair post-operative bleeding following a tonsillectomy, a recommendation was made that the RCPath guidelines on autopsy in suspected anaphylaxis should be updated.[13] UKFAR has contributed to updating the autopsy guideline in cases of suspected anaphylaxis, which is due to be published soon. UKFAR has also contributed to the revised Resuscitation Council guidelines for peri-operative anaphylaxis; the recommendation to contact UKFAR is included in the algorithm in case of a fatal outcome.[14] Additionally, UKFAR has contributed to the National Child Mortality Database report of child deaths due to asthma or anaphylaxis,[12] which found that anaphylactic episodes were frequently under-recognised in children. This has led to collaboration and the development of a childhood death review process protocol.

In conclusion, coroners have made multiple recommendations in efforts to prevent future deaths from anaphylaxis, and there has been a mixed response to this. While progress has been made in some areas (particularly in relation to the maintenance of a UK Fatal Anaphylaxis Registry), there remain several areas of significant concern that do not appear to have been addressed, despite repeated reporting and recommendations in Prevention of Future Deaths reports. There is significant scope for more work to be done to improve patient care and reduce future fatalities from anaphylaxis.

References available on our website.

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