UK Anaphylaxis Registry: Paper version for Case Report Form

This **Paper version of the UK Anaphylaxis Registry Case Report Form** can be used to collect de-identified data relating to a recent unintended allergic reaction to food or non-food trigger in the last 12 months. We are collecting all such events in adults and children, irrespective of whether the reaction was anaphylaxis.

Only ONE reaction should be documented per form. ALL fields are mandatory. Once completed, the data should be entered on to the Registry platform (anaphylaxie.net).

Please ask the patient (or parent/guardian) for verbal consent and to provide their email address: this is needed in order for them to receive a patient consent form and survey by email.

Patient Information	**Healthcare Professional Information- Internal use**
Date of reaction	Name and Surname
Patient age (years / months)	Occupation
Sex at birth	Person entering data online
Verbal consent agreed (Yes/ No)	
Patient's email address	

Section 1. Information about the allergic reaction

1.1 What symptoms occurred? *Please circle all that apply*

Skin and mucosal	None	Angioedema (incl. swollen lips/ face) Erythema/ flush		Pruritus/ itch Conjunctivitis	Urticaria Unknown
Gastrointestinal	None	Abdominal pain/ cramps Abdominal distension	Diarrhoea Dysphagia	Nausea Faecal incontinence	Vomiting Unknown
Respiratory	None	Rhinitis Dyspnoea/SOB Cough	Throat tightness Chest tightness Wheezing (expiratory)	Stridor Vocal hoarseness Laryngeal oedema	Respiratory arrest Unknown
Cardiovascular	None	Dizziness Palpitations/ arrhythmia, Less alert (floppy in babies)	Loss of consciousness Hypotension (collapse) Chest pain/angina	Tachycardia Bradycardia Cardiac arrest	Unknown
Other	Dysarthria Paraesthesia	Hotness Sight disorder	Sweating Feeling of impending doom	Trembling Cyanosis	Tingling/burning of the hands/feet Pallor

1.2 What was the approximate time between allergen exposure and first symptoms?

1.3 Did a biphasic reaction occur? ○ Yes ○ No ○ Unknown

If yes, *please describe, using symptoms above:*

How long after initial symptoms did further symptoms occur with biphasic reactions? (hours)

1.4 For fatal reactions only

Time from exposure to death:

Was treatment commenced prior to arrest? ○ Yes ○ No ○ Unknown

Was adrenaline used prior to arrest? ○ Yes ○ No ○ Unknown

1.5 Where was the patient at the time of the exposure?

In which country the reaction occurred: ○ UK ○ Abroad ○ Unknown

Location where exposure occurred *please describe (e.g. school, restaurant):*

1.6 Has the patient reacted to this allergen before? ○ Yes ○ No ○ Unknown

How many times has this allergen caused a reaction? ☐

Was this reaction more or less severe than before? ○ Less ○ Same ○ More ○ Unknown

Which systems were affected? *Please circle all that apply*: Gastrointestinal tract, Skin, Cardiovascular system, Lower respiratory

How long did the patient previously react to this allergen? ○ In the last 6 months ○ 6-12 months ago ○ 1-2 years ago ○ More than 2 years ago

1.7 Has the patient ever had anaphylaxis before (to *any* allergen)? ○ Yes ○ No ○ Unknown

Section 2. Diagnostic testing

Has the patient had any diagnostic testing to the eliciting allergen?
○ Yes, before this reaction happened ○ Yes, but only since this reaction ○ No ○ Unknown

What diagnostic tests have been done? *Choose one answer for each row*	*Not done*	*Test done: +ve*	*-ve*	*Not known*
Skin prick test (SPT)	○	○	○	○
Challenge test (e.g. food, drug provocation)	○	○	○	○
Specific IgE: whole allergen extract	○	○	○	○
Specific IgE: recombinant allergen/component	○	○	○	○
CAST (cellular antigen stimulation test)	○	○	○	○
IgG4 (venom exposition marker)	○	○	○	○
Intradermal test	○	○	○	○
Basophil activation test	○	○	○	○
Other	○	○	○	○

Has the patient ever had a baseline tryptase measured?
specify value (ng/mL) ☐

Did the patient know that they were allergic to the eliciting allergen prior to this reaction?
○ Yes ○ No ○ Unknown

Section 3. The eliciting factors

3.1 Is the suspected allergen known? ○ Yes ○ No ○ Reasonable suspicion

3.10 Is the elicitor known to be an occupational allergen for this patient? ○ Yes ○ No ○ Unknown

For food allergens only

3.2 Which food caused the reaction, *describe:*

If non-prepacked, where was it bought? *(e.g. Bakery, School, Supermarket)*

If prepacked product, was the brand known?
If yes, which brand:

Did the patient or person providing the food read the label (or other relevant information) before the food was eaten?
○ Yes ○ No ○ Unknown

If prepacked, was the food listed on the packaging?
○ Allergen listed as ingredient ○ No
○ Allergen listed as "may contain" ○ Unknown

Who read the label? *Please circle one choice*:
Patient / family member / friend / catering staff / unknown

Estimated amount eaten, *please describe (e.g. teaspoon, cup, plate, contact only):* ☐

For drug allergens only

3.3 Which drug caused the reaction?

For other eliciting factors only

3.4 Which other eliciting factor caused the reaction, *please choose one:*
○ Insect Venom, *please specify* ☐
○ Latex, *please specify how (e.g., wearing latex gloves, etc)* ☐
○ Specific immunotherapy (SIT), *please specify* ☐
○ Exercise as the cause for anaphylaxis, in the absence of any other factor
○ Temperature e.g. heat/ cold-induced symptoms
○ Other eliciting factors not specified above: ☐

Section 4. Exacerbating factors and diseases

4.1 Does the patient have any concomitant diseases (including allergic diseases)? ○Yes ○No ○Unknown

Which of the following concomitant diseases does the patient have and which occurred in the past?
Please circle <u>one</u> for each. Legend: Yes Ongoing ($Y^{ongoing}$), Yes in the past (Y^{past}), No (N), Unknown (UNK)

- Allergic rhinitis	$Y^{ongoing}$	Y^{past}	N	UNK	- Malignant diseases	$Y^{ongoing}$	Y^{past}	N	UNK
- Asthma/ COPD	$Y^{ongoing}$	Y^{past}	N	UNK	- Mastocytosis	$Y^{ongoing}$	Y^{past}	N	UNK
- Atopic dermatitis/eczema	$Y^{ongoing}$	Y^{past}	N	UNK	- (other) food allergies	$Y^{ongoing}$	Y^{past}	N	UNK
- Diabetes mellitus	$Y^{ongoing}$	Y^{past}	N	UNK	- Nasal polyps	$Y^{ongoing}$	Y^{past}	N	UNK
- Cardiovascular diseases	$Y^{ongoing}$	Y^{past}	N	UNK	- Thyroid disease	$Y^{ongoing}$	Y^{past}	N	UNK
- Chronic infection (e.g. HIV, HP-gastritis, TB, hep B/C)	$Y^{ongoing}$	Y^{past}	N	UNK	- Chronic urticaria	$Y^{ongoing}$	Y^{past}	N	UNK

Which cardiovascular disease are known/ has been diagnosed by the patient? *Please choose <u>one</u> for each:*

- Hypertension	○Yes	○No	○Unknown	- Congestive heart failure	○Yes	○No ○Unknown
- Coronary artery disease	○Yes	○No	○Unknown	- Arrhythmia:	○Yes	○No ○Unknown
- Prev myocardial infarction	○Yes	○No	○Unknown	- Other:	○Yes	○No ○Unknown

Was the patient on antihistamines around the time of reaction? ○Yes ○No ○Unknown

4.2 Might the following conditions have contributed to reaction severity? *Tick <u>all</u> that apply:*

- ☐ An acute infection (e.g. common cold, flu)
- ☐ Physical exercise as co-factor/ exacerbating factor, *please circle:* mild/ moderate/ vigorous/ unknown
- ☐ Psychological stress
- ☐ Drugs, *please specify* _____
- ☐ Menstruation
- ☐ Hormone-based contraception / HRT
- ☐ Alcohol
- ☐ Sleep deprivation
- ☐ Other cofactors, *please describe* _____
- ☐ None identified/ unknown

Section 5. Treatment

Were emergency medical services contacted? ○ 999 ○ 111/NHS direct ○ No ○ Unknown

5.1 What treatment(s) were used for initial management, and by whom? *Please choose <u>one</u>:*

- ○ Non health professional
- ○ Health professional
- ○ First lay person followed by health professional
- ○ No treatment
- ○ Unknown

If given by a non health professional, which person?
Please choose <u>one</u>:
- ○ Self-administered
- ○ Family member
- ○ Unknown

Drugs given by lay person or self-administered. *Tick <u>all</u> that apply:*

- ☐ Patient's own adrenaline auto-injector
- ☐ Auto-injector belonging to someone else
- ☐ Beta2-mimetics, e.g. Salbutamol
- ☐ Antihistamine
- ☐ Corticosteroids
- ☐ Other
- ☐ Unknown

If health professional, which person? *Please choose <u>one</u>:*

- ○ Allergy specialist (Dr/nurse)
- ○ General practitioner
- ○ Pre-hospital
- ○ In clinic / A&E department
- ○ Other health professional

Drugs given by health professional. *Tick <u>all</u> that apply and specify:*

- ☐ Adrenaline: *which route* _____
- ☐ Antihistamines: *which route* _____
- ☐ Beta2-mimetics: *which route* _____
- ☐ Corticosteroids: *which route* _____
- ☐ iv Fluids
- ☐ O_2
- ☐ Other: *circle* Dopamine, Glucagon, Methylene blue, Theophylline iv / oral
- ☐ Unknown

5.3 Was a second dose of adrenaline administered?
Please choose one:
○ Yes, just one further dose
○ Yes, more than two doses: *how many in total?* ☐
○ No
○ Unknown

Who administered the second dose?
Please choose one:
○ Self/ lay (using auto-injector)
○ Emergency paramedic
○ Healthcare professional
○ Unknown

5.5 Was further treatment needed following stabilisation of initial symptoms? ○Yes ○No ○Unknown

If yes, who performed the SECOND LINE treatment?
○ Allergy specialist (Dr/nurse)
○ General practitioner
○ Pre-hospital (Doctor/paramedic)
○ In clinic/ ED
○ Other health professional

Drugs given by health professional. *Tick all that apply and specify:*
☐ Adrenaline: *which route* ☐
☐ Antihistamines: *which route* ☐
☐ Beta2-mimetics: *which route* ☐
☐ Corticosteroids: *which route* ☐
☐ iv Fluids
☐ O_2
☐ Other: *circle* Dopamine, Glucagon, Methylene blue, Theophylline iv / oral

5.6.1 Was the patient admitted to the hospital because of the anaphylaxis reaction?
○ Yes ○ No ○ Unknown ○ Not applicable

Where was the patient admitted to? *Please choose one:*
○ To normal patient ward
○ To short-stay ward/ observation unit
○ Unknown

5.6.2 Was the patient treated in intensive care because of the anaphylactic reaction?
○ Yes ○ No ○ Unknown

Where was the patient treated? *Please choose one:*
○ Intensive care
○ High dependency unit or equivalent
○ Unknown

6 Discharge/ post-acute management

6.1 What advice/ follow-up management was provided following the episode? ○ Known ○ Unknown
If known, *please tick all applicable boxes, at least one per row.* *AAI=adrenaline autoinjector*

	Pt already has	Provided pre-discharge	GP requested to provide	Provided at F/U clinic	Not given
- Advice about potential triggers	☐	☐	☐	☐	☐
- Advice about avoidance	☐	☐	☐	☐	☐
- Emergency Allergy Plan	☐	☐	☐	☐	☐
- Prescription for emergency medication*	☐	☐	☐	☐	☐
- How to use AAI (with "trainer device")	☐	☐	☐	☐	☐
- How to use AAI (no trainer device used)	☐	☐	☐	☐	☐
- Referral for allergen immunotherapy	☐	☐	☐	☐	☐

***6.2 If emergency medication provided, which ones?**	Pt already has	Provided pre-discharge	GP requested to provide	Provided at F/U clinic	Not given
- Adrenaline auto-injector (AAI)**	☐	☐	☐	☐	☐
- Adrenaline inhaler (not licensed in UK)	☐	☐	☐	☐	☐
- Antihistamines	☐	☐	☐	☐	☐
- Reliever inhaler e.g. Salbutamol	☐	☐	☐	☐	☐
- Corticosteroids	☐	☐	☐	☐	☐

****6.3.1 Which AAI device was prescribed?**
○ Emerade®
○ Epipen®
○ Anapen® ○ Other
○ Jext® ○ Unknown

How many AAI devices were prescribed?
○ One
○ Two
○ More than 2
○ Unknown

What dosage of AAI was prescribed?
○ 150 mcg (0.15 mg)
○ 300 mcg (0.3 mg)
○ 500 mcg (0.5 mg)
○ Unknown