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## ORIGINAL ARTICLE

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# Risk taking and self-care behaviours amongst adolescents and young adults with food allergies

Hannah Keohane<sup>a</sup>, Caoimhe Cronin<sup>a</sup>, Juan Trujillo<sup>a,b\*</sup>

<sup>a</sup>Department of Paediatrics and Child Health, University College Cork, Cork, Ireland

<sup>b</sup>Cork University Hospital, Irish Centre for Maternal and Child Health Research (INFANT), HRB Clinical Research Facility Cork (CRF-C), Cork, Ireland

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## KEYWORDS

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## Abstract

**Background:** Anaphylaxis is a systemic, life-threatening reaction and its prevalence is rising amongst adolescents and young adults (AYA) with food allergies. The likelihood of fatal anaphylaxis is disproportionately high in this population. The effective management of anaphylaxis can be done by adhering to various food allergy-related self-care behaviours, namely avoidance of allergens, carriage and use of adrenaline auto-injectors (AAI). Unfortunately, compliance of AYA to these behaviours is believed to be suboptimal and the likely reason behind their increased rates of fatal anaphylaxis.

**Methodology:** To evaluate the adherence to food allergy-related self-care behaviours amongst adolescents and young adults with anaphylaxis an electronic search was conducted utilizing PubMed, MEDLINE, and CINAHL plus to identify relevant studies. 175 article abstracts were screened, and 26 remained which were read in full to determine which best satisfied the inclusion and exclusion criteria. Ultimately, 10 articles were selected for this review.

**Results:** The compliance to food allergy-related self-care behaviours amongst AYA founded to be suboptimal. AAI design, peer influence, and emotional attitudes of AYA were found to be the most significant factors influencing AYA compliance to self-care behaviours.

**Conclusions:** The adherence of AYA to food allergy-related self-care behaviours is suboptimal and evidence on the factors affecting AYA compliance has been largely contradictory. AAI design, peer influence, and emotional attitudes are significant factors influencing AYA adherence. Therefore, further research directed at these factors is imperative in facilitating the design of guidelines to maximize the adherence of AYA to food allergy-related self-care behaviours.

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\*Corresponding author: Juan Trujillo, MD, MSc, Department of Paediatrics and Child Health, University College Cork, Cork, Ireland. Email address: [juan.trujillo@ucc.ie](mailto:juan.trujillo@ucc.ie)

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## Introduction

Anaphylaxis can be defined as an acute, life-threatening systemic allergic reaction with different mechanisms, triggers, clinical presentations, and severity.<sup>1</sup> Studies suggest it is increasing in prevalence worldwide, particularly in developed countries and amongst children and adolescents.

Importantly, the management of anaphylaxis is well established. Adrenaline administered intramuscularly into the anterolateral thigh is the cornerstone of treatment.<sup>2</sup> However, adrenaline auto-injectors (AAI) are consistently underutilized by patients, with one study finding only 36.3% of anaphylaxis cases had an AAI administered before Emergency Department (ED) arrival.<sup>3</sup> Failure to use AAI appropriately increases the likelihood of hospital admission and fatal outcomes.<sup>3,4</sup> Fatal anaphylaxis is disproportionately common amongst adolescents and young adults (AYA), yet little work is done to ascertain exactly why they are so vulnerable.<sup>4,5</sup> This is a significant issue given the rising prevalence of anaphylaxis and food allergies in this population.

Optimal management of food allergy involves adhering to many food allergy-related self-care behaviours such as avoidance of known allergens, carriage of AAI, and use of AAI. It has been speculated that the higher rates of fatal anaphylaxis amongst AYA are linked to failure to comply with these behaviours.

The aim of this study is to systematically review and appraise the published literature on the adherence of AYA to food allergy-related self-care behaviours and the relevant factors influencing this.

## Objectives

1. To evaluate the adherence to food allergy-related self-care behaviours amongst adolescents and young adults with anaphylaxis; namely, avoidance of allergens, AAI carriage, and use of AAI.
2. To identify the factors affecting adherence to food allergy-related self-care behaviours in this population.
3. To examine the subsequently proposed strategies to improve AYA adherence to food allergy-related self-care behaviours.

## Methodology

### Literature search strategy

An electronic search was conducted on PubMed and EBSCOhost databases, to identify relevant existing literature on this topic and to address the aim and objectives of this review.

### Inclusion and exclusion criteria

Due to the relatively limited body of research in this area, articles dating as far back as 2005 were included. Additionally, the location was not limited to Ireland as

**Table 1** List of filters applied to PubMed, MEDLINE, and CINAHLplus.

No.	Filter	Specifications
1	Language	English
2	Date of Publication	2005-2020
3	Species	Humans
4	Subject Age	Child, Adolescent, Young Adult
5	Text Availability	Full Text

primary searches found no applicable articles from Ireland (see Table 1).

### Study selection process

On PubMed, the initial search yielded 152 results and was reduced to 93 after the application of filters (Table 1). On EBSCO, the initial search yielded 263 results but was subsequently reduced to 96 after filters were applied (Table 1). After the removal of duplicates, 175 articles remained. Of the 175 abstracts screened, 149 were found to not fulfil the inclusion criteria (Table 2). 26 articles remained which were read in full to determine which articles best satisfied the inclusion and exclusion criteria. Reasons for exclusion of articles is shown in Table 3. Ultimately, 10 articles were selected for the review.<sup>6-15</sup> A flow chart summarizing the search strategy is shown in Figure 1.

### Data extraction and management

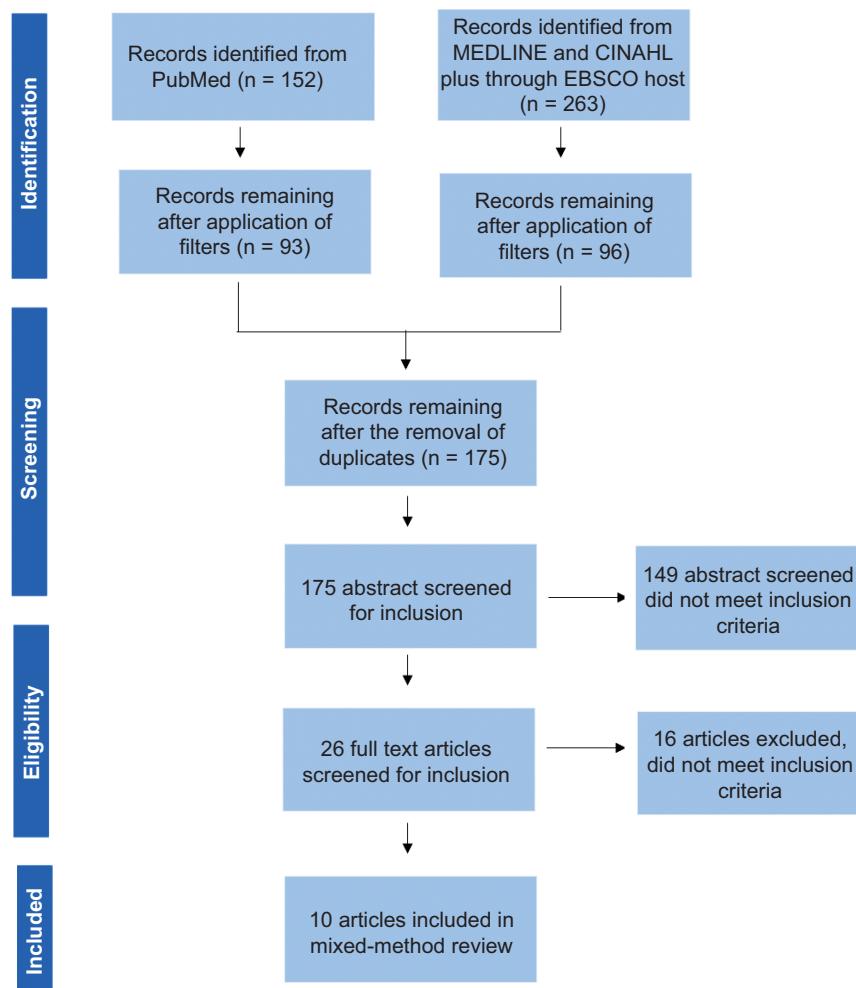
The data extracted from the included studies include the authors, year of publication, location, study title, objectives, study population, sample size, selection criteria, study design, methods, key findings, and the strengths and limitations of each study. Mendeley Reference Management Software was used to manage references.

### Article validity and quality

This literature review included 10 studies. Seven of the studies were quantitative and included five cross-sectional studies, one prospective questionnaire-based study and one observational, retrospective cohort study. Three qualitative studies with a semi-structured interview design were also included. The included studies were conducted across several countries, five in the UK, four in the USA, and one in Spain. The sample size ranged from 18 to 1885. The results are shown in Tables 6 and 7 of the “Results” section. Critical appraisal was conducted on each study using the EBL and CASP critical appraisal tools. The quantitative studies with the highest validities were proved to be cross-sectional and prospective questionnaire-based studies.<sup>6,7</sup> Each of the qualitative studies was proved to be robust with one study found to be less valid.<sup>14</sup>

**Table 2** Inclusion and exclusion criteria for studies to be included in this literature review.

Inclusion criteria	Exclusion criteria
Articles available in English	Articles in languages other than English
Studies that were published between 2005 and 2020	Studies that were published prior to 2005
Studies on humans	Articles without full text availability
Studies on children, adolescents, and young adults	Articles that are systematic reviews, editorials, periodicals, case reports, series, or meta-analyses
Articles with full text availability online or through the UCC library online loans	Studies involving venom and drug-induced anaphylaxis
Studies that evaluated risk-taking behaviours related to and adherence to allergen avoidance, AAI carriage, and use	Studies that did not address AAI in any regard, be it carriage or use
Studies that explored factors affecting adherence in this population	Studies addressing adherence of healthcare workers to anaphylaxis protocol, adrenaline use, or prescription
Articles that are either quantitative or qualitative peer-reviewed, original research studies	Studies examining the clinical relevance of immunotherapy in treating food allergies
Studies exploring food allergies or food-induced anaphylaxis	Studies that were not include children, adolescents, or young adults in the study sample

**Figure 1** Search strategy for selecting relevant articles for inclusion in this review.

**Table 3** Reasons for exclusion of articles from review during the screening process.

Reason for exclusion	Number of articles
Studies predominately on children/adolescents with non-food allergies or asthma	37
Systematic reviews or meta-analyse	33
Studies focusing on adults, e.g. parents, school staff	26
Articles addressing adherence of healthcare workers to anaphylaxis protocol, adrenaline use, or prescription	22
Studies that did not address AAI in any regard, be it carriage or us	17
Studies addressing risk-taking and self-care behaviours with regards to another disease, i.e. not related to food allergy	14
Articles focused on pharmacological factors associated with allergy treatment/ immunotherapy	11
Editorial or periodical	3
Case reports or series	2
<b>Total</b>	<b>165</b>

## Results

### **Adherence to food allergy-related self-care behaviours amongst AYA**

#### *Avoidance of allergens and carriage of AAI*

Six studies probed AYA avoidance of allergens.<sup>6,8,10,12,14,15</sup> Rates of AYA always avoiding their allergens ranged from 39.5% to 85%.<sup>6,12</sup> Sampson et al.<sup>8</sup> reported that 42% of AYA were willing to eat a food labelled “may contain” an allergen. Rates of AYA “always” carrying AAI varied between 9.6% and 61%.<sup>6,8,12</sup>

#### *Knowledge of when and how to use AAI*

Six studies investigated AYA recognition when AAI use as indicated.<sup>6,7,11,13-15</sup> Respondents generally had a suboptimal knowledge of anaphylaxis symptoms and when to use AAI which was shown by Noimark et al.<sup>7</sup> found 83% of participants experiencing anaphylaxis symptoms did not use AAI; 54.4% of these stated this was because they did not think it was necessary. Knowledge was shown to be similarly suboptimal by Monks et al.<sup>15</sup> who found that 41% of participants said they were somewhat confident (35%) or not very confident (6%) in recognizing symptoms of a reaction. Contrary to this, several studies found that knowledge of the AAI technique was good with 77% of respondents in one study stating they were confident in using their AAI.<sup>6,14</sup>

#### *The factors affecting adherence to self-care behaviours amongst AYA*

##### *Contextual factors*

Four studies revealed that AYA decide to carry AAI depending on whether they felt they were “at risk” of a

reaction.<sup>8,10,14,15</sup> Sampson et al.<sup>8</sup> identified that 94% of AYA carried an AAI while travelling but only 43% carried an AAI to sporting events. Several of the studies linked this to issues with AAI design, which most AYA described as “bulky”, “inconvenient” and a deterrent to the carriage.<sup>10,14</sup>

##### *Attitudes of others*

Peer influence on AYA compliance to self-care behaviours was described by five studies.<sup>6,8,9,14,15</sup> In some studies, AYA reported being teased about their allergies.<sup>8,9,14,15</sup> Warren et al.<sup>9</sup> found that being bullied about FA led to increased compliance [Odds Ratio (OR), 0.22; 95% Confidence Interval (CI), 0.09-0.51;  $p = 0.09$ ]. However, Sampson et al.<sup>8</sup> found that AYA who were teased were less likely to adhere to self-care behaviours ( $p = 0.01$ ). Jones et al.<sup>6,8</sup> found that adherence strongly correlated with a membership in a peer support group [OR = 2.54, (1.04, 6.20) 95% CI;  $p = 0.001$ ], yet Sampson found no association between the two ( $p > 0.05$ ).

The impact of parental attitudes was investigated by three studies.<sup>10,14,15</sup> Two indicated that the majority of AYA was still heavily reliant on their parents to ask about allergens in restaurants and carry AAI.<sup>14,15</sup> They noted that the level of dependence was not related to age. It was also found that there were differences in perceptions between parents and adolescents regarding the degree to which adolescents were in control of their anaphylaxis management, with some parents perceiving a lack of risk-awareness in their teenage children. However, contrary to common stereotypes, most adolescents carried their auto-injectors at least some of the time.<sup>10</sup>

##### *Patient factors*

Age and gender were investigated by four studies.<sup>8,9,13,14</sup> Only one study reported an association between age and adherence, that increased age of AYA was associated with increased risk-taking behaviours, namely failure to carry AAI ( $p < 0.05$ ).<sup>8</sup> No association was described between self-care behaviour adherence and gender ( $p > 0.05$ ).

Eight studies examined the relationship between medical factors and adherence.<sup>6-9,11,12,14,15</sup> Two found a history of severe reactions increased AYA avoidance of potentially allergenic foods,<sup>9,12</sup> in Greenhawt et al.<sup>12</sup> for example, a significantly higher number of students who had not reported symptoms consistent with anaphylaxis reported they did not avoid potentially allergenic foods versus those reporting symptoms consistent with anaphylaxis (56.6% vs. 41.5%,  $p = .026$ ). However, four studies found no association.<sup>6,8,14,15</sup> The presence of co-morbidities such as asthma had no correlation with compliance.<sup>6,7,9,11</sup>

The AYA knowledge of self-care behaviours was widely studied.<sup>6-8,10,11,14,15</sup> Poor understanding of anaphylaxis symptoms correlated with failure to use AAI in four studies.<sup>7,8,10,11</sup> However, two studies found no association between knowledge of anaphylaxis and adherence.<sup>6,13</sup> Personalized anaphylaxis management plans were strongly linked to lower rates of risk-taking behaviour among AYA [OR = 3.22, (1.18, 8.81) 95% CI] ( $p < 0.05$ ).<sup>6</sup>

The emotional attitudes of AYA had a substantial influence on their adherence according to three qualitative studies.<sup>10,14,15</sup> Two linked feelings of invincibility, denial, and embarrassment to the reduced carriage of AAI.<sup>10,14</sup>

Three studies identified prominent levels of needle phobia amongst AYA, this was found to negatively affect their likelihood of using AAI but not AAI carriage.<sup>10,14,15</sup>

### **Proposed strategies to improve AYA adherence to self-care behaviours**

Several qualitative studies suggested AYA should be empowered to make safe risk assessments rather than instructed to always carry AAI.<sup>10,14,15</sup> Studies found that AYA need support in transitioning to self-management of their allergies and felt online support would be beneficial.<sup>8,10</sup>

One study found that AYA were interested in learning from peers who have experienced anaphylaxis rather than healthcare personnel.<sup>15</sup> Four studies detailed AYAs' desire for their peers to be educated about FA, to facilitate them in managing their allergies.<sup>8,9,10,15</sup> AYA also widely expressed the desire for the design of AAI to be less bulky.<sup>10,14,15</sup>

Evidently, poor allergy management bears a significant life-threatening risk to AYA with food allergies. However, there is little evidence explaining the particular vulnerability of AYA to noncompliance with food allergy-related self-care behaviours and the factors affecting this. Additionally, there is a lack of published guidelines establishing strategies and interventions to best improve their adherence.

Table 5 gives an overall summary of the articles in this review and their strengths and limitations, with abbreviations used in the Table 5 defined in Table 4.

## **Discussion**

### **The adherence to food allergy-related self-care behaviours amongst AYA**

Despite the overarching consensus that AYA adherence is suboptimal, rates of compliance differed widely between studies.<sup>6-12,14,15</sup> Two studies with high validity cited low rates of "always" carrying an AAI, at 9.6% and 41% of participants.<sup>6,12</sup> One study contradicted this, finding a much higher rate of "always" carrying an AAI at 61%, however, this was found to have lower validity.<sup>8</sup> The majority of studies reported underuse of AAI.<sup>7,11,13</sup> Of concern is the underuse of AAI among AYA despite the presence of life-threatening symptoms.<sup>7</sup> Despite the lower validity of Simons et al.'s study, its findings concurred with studies of higher relevance.<sup>6,7,11,13-15</sup> Such findings highlight the importance of clinicians educating AYA about the important signs and symptoms of anaphylaxis and discussing the possible barriers they may perceive themselves to have in real-life situations in the use of an AAI, so that clinicians may offer solutions to alleviate barriers to AAI use both for the young person and their families.

One study citing high rates of AAI carriage may have been influenced by selection bias as participants were recruited through FAAN social media and thus may be more conscientious than average AYA.<sup>8</sup> However, the findings of this review concur with current literature reporting high levels of FA-related risk-taking behaviour amongst AYA.<sup>16,17</sup> It would be important for future research to strive

**Table 4** The list of abbreviations used in Table 5.

Abbreviation	Meaning
AYA	Adolescents and Young Adults
FA	Food Allergy
AAI/EAI	Adrenaline/Epinephrine Auto-injector
SIA/SIE	Self-injectable Adrenaline/Epinephrine
AIE	Auto-injectable Epinephrine
LCA	Latent Class Analysis
FAAN	Food Allergy & Anaphylaxis Network
HBM	Health Belief Model
HUFA	Hospital Universitario Fundación Alcorcón
QOL	Quality Of Life

to achieve a more representative study sample as selection bias proved to be an issue in a number of studies.

### **The factors affecting adherence to self-care behaviours amongst AYA**

There was an agreement amongst the high-quality studies that AYA engage in complex risk assessments when deciding to eat potential allergens and carry their AAI.<sup>8,10,14,15</sup> However, the aforementioned selection bias may be an important factor here. If participants included in these studies are more motivated and knowledgeable about their allergies yet still take frequent risks, it is likely the real picture is one of even poorer AYA adherence.

Significantly, poor AAI design reduced the likelihood of carriage by AYA.<sup>10,14,15</sup> Studies have identified this as a problem with parents of food-allergic children amongst whom it negatively affects their confidence in using AAI.<sup>17</sup> The size of the AAI was identified as a significant barrier to the carriage, and AYA themselves suggested preferred methods of administration, such as an oral medication.<sup>14</sup> Quantitative research may be useful in identifying the magnitude of this issue and its potential implications for manufacturers, as the studies examining it in this review were small sample size qualitative studies.

There was contradicting evidence on the impact of AYA peers on their adherence. Peer influence and AYA "embarrassment around friends" was associated with reduced AAI carriage.<sup>6,8,9,10,14,15</sup> Bullying had a contradictory effect on the carriage of AYA in two studies.<sup>7,8</sup> Although this negatively impacts the quality of life of AYA, only one valid study cited this as adversely affecting AAI carriage.<sup>8</sup> As AYA transition from children to young adults, they spend less time with their parents and more time with peers, it is more likely that an anaphylactic reaction may occur when in the company of their peers.<sup>15</sup> Therefore, there is a need for guidelines to be established to educate AYA in schools regarding the seriousness of anaphylaxis and the use of an AAI, in order to reduce the experience of bullying among those with food allergies and improve the knowledge of peers. This in turn would improve the quality of life of AYA as they would feel less embarrassed around friends regarding their food allergy and would feel greater support from friends in managing their allergy.

**Table 5** Summary of included studies.

Author, (Year), Location, Title	Objectives	Study population, Sample size, Selection criteria	Study design, Methods	Key findings	Strengths and limitations
Jones CJ. et al. (2015) Brighton, UK “Factors associated with good adherence to self-care behaviours amongst adolescents with food allergy” <sup>6</sup>	<ul style="list-style-type: none"> <li>To use the Health Belief Model (Appendix B) to explore the relationship between food-allergic adolescents’ health beliefs, demographic, structural and social psychological factors with adherence to self-care behaviours, including allergen avoidance and carrying emergency medication.</li> </ul>	<p>N = 118 (558 surveys sent)</p> <p><i>Inclusion criteria:</i></p> <ul style="list-style-type: none"> <li>Age 13 to 19 years</li> <li>FA diagnosis</li> <li>Hospital-prescribed AIE for FA</li> <li>Informed consent obtained from subject or caregiver if &lt;18 years of age.</li> </ul> <p><i>Exclusion criteria:</i></p> <ul style="list-style-type: none"> <li>Unable to read, write, or speak English.</li> </ul>	<p><i>Cross-sectional study</i></p> <ul style="list-style-type: none"> <li>Participants were recruited from two pediatric allergy outpatient clinics in the southeast of England.</li> <li>Participants under 16 years of age had an invitation, information sheet, consent form, and questionnaire sent to guardians.</li> <li>Participants over 16 years were sent this pack directly.</li> <li>Questionnaire was returned to the research team by Freepost.</li> <li>The HBM psychological model informed the questionnaire design, measuring five constructs.</li> <li>Participants were asked about adherence to four key self-care behaviours: avoidance of allergens, enquiring about ingredients at restaurants and friends’ houses, and carrying AIE at all times.</li> </ul>	<ul style="list-style-type: none"> <li>Knowledge of how to use AIE high with a mean of 7.78/9 correct steps of administration identified.</li> <li>Participants reported high confidence in their ability to use AIE, 40% feel “sure” and 37% feel “absolutely sure” of their ability to correctly use AIE.</li> <li>Full adherence to the four self-care behaviours assessed was reported in only 16% of participants.</li> <li>41% of respondents reported carrying an AIE at all times.</li> <li>85% reported generally trying to avoid foods they were allergic to.</li> <li>Adherence to self-care behaviour correlated with being a member of a support group, having an anaphylaxis management plan, having greater confidence in using AIE, perceiving FA to be more serious and perceiving fewer barriers to management.</li> <li>Demographic factors (age, sex, ethnicity), structural factors (age at FA diagnosis, number of anaphylactic reactions, previous AIE use, knowledge of AIE use, co-morbid asthma), and social psychological factors (optimism) and knowledge of AIE were found to have no correlation with adherence to self-care behaviours.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>Use of a validated questionnaire.</li> <li>First study to quantify adolescent adherence to self-care behaviours related to FA.</li> <li>Respondents were representative of the ethnic diversity found in the city of London, where the survey was conducted.</li> <li>Anonymized survey returned to the researcher not the clinician may help counteract issues with self-reporting.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>Poor response rate of 34% (118/558) raises concerns about responder bias.</li> <li>Selection bias may persist, particularly in regards to other demographics which were not known for non-respondents such as ethnicity.</li> <li>As this is a cross-sectional study, data is supportive but cannot suggest causality, e.g. in the case of support group association with better self-care adherence</li> <li>Using self-reporting to measure adherence to self-care behaviours risks overinflated estimates due to social desirability bias.</li> <li>Generalizability of these findings may be limited due to participating adolescents being recruited from specialist allergy clinics and thus their disease characteristics may be more severe than those with FA managed in primary care.</li> </ul> <p>SPSS version 15 for Windows was used for statistical analysis of the results.</p>

	<ul style="list-style-type: none"> <li>• Logistic regression analysis was used to analyse multivariate associations.</li> </ul>		
Noimark L. <i>et al.</i> (2012) London, UK “The use of adrenaline autoinjectors by children and teenagers” <sup>7</sup>	<ul style="list-style-type: none"> <li>• To see how many AAI were used during anaphylactic reactions.</li> <li>• To determine why they were not used in situations where they were clinically indicated.</li> </ul> <p><b>Inclusion criteria:</b></p> <ul style="list-style-type: none"> <li>• Children and teenagers aged up to 18 years</li> <li>• Had been prescribed an AAI for at least 1 year.</li> <li>• Informed consent obtained from subject or caregiver if &lt;18 years of age.</li> </ul> <p><b>Exclusion criteria:</b></p> <ul style="list-style-type: none"> <li>• Refusal to participate.</li> </ul> <p><b>Prospective, questionnaire-based study:</b></p> <ul style="list-style-type: none"> <li>• Participants were recruited prospectively at 14 pediatric allergy clinics in the UK.</li> <li>• Participants completed a single page anonymized questionnaire covering demographic data, atopic status, and details of allergic reactions in the year following.</li> <li>• STATA version 9.2 was used for analysis and to account for any clustering by centre.</li> <li>• Associations between symptoms and the use of an AAI or between potential risk factors and anaphylaxis were assessed using logistic regression analysis.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Utilizing a short questionnaire may help maximize participation.</li> <li>• Large sample size, thus generalizability to the population is likely strong.</li> <li>• Participants recruited from 14 locations improves generalizability of results.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>• Short questionnaire limited the ability to describe the population.</li> <li>• Did not collect socio-economic data thus could not exclude the possibility that non-White ethnicity is acting as a marker of relative economic deprivation rather than differences in allergen exposure.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• First study of its type to find potentially rectifiable aspects of risk-taking in a group of AYA with FA.</li> <li>• Both sexes and all ages were well represented.</li> <li>• Questionnaire was meticulously designed.</li> </ul>
Sampson MA. <i>et al.</i> (2006) New York and Fairfax, USA “Risk-taking and coping strategies of adolescents and young adults with food allergy” <sup>8</sup>	<ul style="list-style-type: none"> <li>• To gain insight towards devising interventions by querying risk-taking behaviours and coping strategies of persons aged 13 to 21 years with FA.</li> </ul> <p><b>Inclusion criteria:</b></p> <ul style="list-style-type: none"> <li>• Age 13 to 21 years</li> </ul> <p><b>Exclusion criteria:</b></p> <ul style="list-style-type: none"> <li>• Did not indicate a FA</li> <li>• Outside age group 13-21</li> </ul> <p><b>Cross-sectional survey:</b></p> <ul style="list-style-type: none"> <li>• Questionnaire devised on the basis of four 90-minute focus groups with AYA 13-21 years of age with FA conducted to identify areas of importance.</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of consciousness, difficulty in swallowing, feeling of impending doom, difficulty in breathing, and swelling were all found to be independent predictors of using an autoinjector.</li> <li>• 83% of participants who experienced an episode of anaphylaxis in the year did not use their AAI, despite experiencing severe symptoms such as loss of consciousness, difficulty in swallowing, difficulty in breathing, throat tightness, and wheezing. 54.4% of these said they did not use an AAI because they thought it was unnecessary and 19% because they were not sure if it was necessary.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• 37% of respondents with severe symptoms did not receive SIE.</li> <li>• 38% of respondents did not have an SIE with them during a severe reaction.</li> <li>• Many respondents had a misperception of anaphylaxis. Up to 58% of respondents who</li> </ul>

(continues)

Table 5 Continued

Author, (Year), Location, Title	Objectives	Study population, Sample size, Selection criteria	Study design, Methods	Key findings	Strengths and limitations
			<ul style="list-style-type: none"> <li>Internet-based anonymous survey was advertised in a FAAN newsletter, on the FAAN website and Canadian food allergies organizations websites.</li> <li>Participation was voluntary and anonymous.</li> <li>Descriptive statistics were used to evaluate the results of the survey.</li> </ul>	<p>self-reported “anaphylaxis” experienced typical severe symptoms. 61% of respondents who did not self-report “anaphylaxis” had experienced at least one of the typical severe symptoms.</p> <p>61% indicated they “always” carried an SIE but frequencies varied with social circumstances, convenience, and perceived risks.</p> <p>Carriage was increased when travelling (94%) and eating at restaurants (81%) and decreased when wearing tight clothes (53%), and at sports (43%).</p> <p>The group of respondents designated “high-risk” (n=29) felt more “different” because of their allergy.</p>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>Self-reporting of own risk-taking behaviour and medication adherence may lead to underrepresentation of risk-taking due to social desirability bias.</li> <li>Participants may be more educated about FA than average due to being recruited through an allergy website/newsletter, thus selection bias is probable.</li> <li>Could not verify FA, although answers to the questionnaire were consistent with true FA.</li> </ul>
Warren CM. et al. (2017) Chicago, USA	To characterize FA-related risk-taking and self-management behaviours of AYA with FA.	N = 200	<ul style="list-style-type: none"> <li><i>Inclusion criteria:</i> <ul style="list-style-type: none"> <li>English-speaking.</li> <li>Age 14 to 22 years.</li> <li>1 or more concurrent FA.</li> </ul> </li> </ul>	<p><i>Cross-sectional survey</i></p> <ul style="list-style-type: none"> <li>Participants older than 18 years of age were recruited via email and social media messages posted by groups including “Food Allergy Research and Education”.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>First study to identify patterns of FA-related risk-taking behaviours among AYA that can be predicted by multiple clinical, demographic, and social risk factors.</li> <li>Questionnaire meticulously designed with expert panel review and cognitive interviews of adolescents (n = 5).</li> </ul>

<p><b>"Food-allergy related risk-taking and management behaviours among adolescents and young adults"</b></p> <ul style="list-style-type: none"> <li>Informed consent obtained from subject or caregiver if &lt;18 years of age.</li> <li>Exclusion criteria:           <ul style="list-style-type: none"> <li>None.</li> </ul> </li> </ul>	<p><b>• In-person recruitment at teen FA conferences.</b></p> <ul style="list-style-type: none"> <li>• Electronically administered survey.</li> <li>• LCA was used to identify distinct patterns of FA-related risk-taking and management.</li> </ul> <p><b>• 43% reported FA-related bullying at school and in social activities.</b></p> <ul style="list-style-type: none"> <li>• 61%, 45%, and 89% of respondents were not confident their male friends, female friends, and classmates respectively, would know what to do in a FA emergency.</li> <li>• Two distinct FA behavioural risk classes were identified, representing less (<math>n=120</math>, Class 2) and more (<math>n=80</math>, Class 1) risky behaviours. Members of Class 2 were significantly more likely to carry an EAI.</li> <li>• Odds of more risky class membership were significantly reduced for AYA with peanut allergy, supportive female friends, an established management plan, a history of being bullied, and overprotective mothers.</li> <li>• Older participants were more likely to be in Class 1.</li> <li>• AYA with support from peers, parents, and teachers and an established management plan engage in fewer FA-related risk-taking behaviours.</li> <li>• Sex, race, age at first reaction, number of severe reactions, history of EAI use, and the presence of co-morbid chronic conditions were not found significantly associated with class membership.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>Data collected in the survey was all self-reported and thus may be subject to recall bias.</li> <li>Unable to confirm the diagnosis of IgE-mediated FA due to de-identification of data collected.</li> <li>Selection bias was highly probable as subjects volunteered and the survey was administered via advocacy groups and FA conferences.</li> <li>Study sample was not very racially or socio-economically diverse, e.g. 79% of respondents identified as White.</li> <li>Unlikely to be representative of the wider US population of AYA with FA.</li> </ul>
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**Table 5** Continued

Author, (Year), Location, Title	Objectives	Study population, Sample size, Selection criteria	Study design, Methods	Key findings	Strengths and limitations
Gallagher M. <i>et al.</i> (2011) Edinburgh, UK “Epinephrine auto-injector use in adolescents at risk of anaphylaxis: a qualitative study in Scotland, UK” <sup>10</sup>	<ul style="list-style-type: none"> <li>To gain knowledge of adolescents’ attitudes towards “Epi” and experience of EAs in order to inform improvements in patient education.</li> </ul>	<p>N = 26 adolescents and 28 parents</p> <p><b>Inclusion criteria:</b></p> <ul style="list-style-type: none"> <li>Adolescents at high risk of anaphylaxis, indicated by anaphylaxis in the last 5 years, or an earlier reaction/or testing indicating higher risk.</li> <li>Adolescents aged 13–19 years.</li> <li>Informed consent received.</li> </ul> <p><b>Exclusion Criteria:</b></p> <ul style="list-style-type: none"> <li>Those who only experienced mild reactions or reactions in early childhood.</li> </ul>	<p><b>Semi-structured interviews.</b></p> <ul style="list-style-type: none"> <li>Patients were recruited from locations across Scotland through school nurses, allergy specialists, primary care, a patient support group, and via a press release.</li> <li>Interviews lasted approximately 1 hour and all but one parent telephone interview were carried out face to face.</li> <li>Interview guides were devised around key areas in the literature for anaphylaxis management and key issues for adolescents with several professional and patient/ family contacts who had experience in this field.</li> </ul>	<ul style="list-style-type: none"> <li>Several barriers to EAI use were identified. In addition to the technical ability to use auto-injectors, patients must have the motivation and self-discipline to carry an EAI, ability to identify a reaction, and know when to use EAI and be prepared to manage the challenging emotions of a reaction.</li> <li>EAI carriage caused a significant amount of parent-adolescent conflict.</li> <li>Participants had issues with the “bulky” design of EAIs and said it deterred them from carrying them.</li> <li>Many adolescents expressed confusion about knowing when to use EAI.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>The sample size was adequate to achieve data saturation, indicated by no new information gathered in the last three interviews.</li> <li>First in-depth study of adolescent attitudes and behaviours regarding EAI use.</li> <li>Both adolescents and parents were interviewed at length, enabling the researcher to fully probe and discuss the relevant issues.</li> <li>Mix of focus groups and interviews.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>Small number of participants restricts the generalizability of the finding and the ability for subgroup analysis, such as age and gender.</li> </ul> <ul style="list-style-type: none"> <li>Interview topics relevant to EAI use included accounts of reactions, emergency management, and what might improve management.</li> <li>Following analysis of interview data, participants were</li> </ul>

<p>invited to participate in focus groups. 8 adolescents and 10 parents took part in these focus groups. These were recorded, transcribed verbatim, anonymized and analysed with NVivo.</p> <ul style="list-style-type: none"> <li>The focus groups were conducted to gauge the level of consensus and dissent amongst adolescents and parents about which interventions would be useful.</li> </ul>	<p><b>Simons FER. et al. (2009)</b> Winnipeg, Canada, Pittsburgh and Boston, USA “Anaphylaxis in the community: Learning from the survivors”<sup>11</sup></p> <p><b>Inclusion criteria:</b></p> <ul style="list-style-type: none"> <li>survivors of anaphylaxis in the community and their experiences using, or not using, an EAI for first-aid treatment.</li> <li>Someone they are responsible for (e.g. a child) experienced an anaphylactic reaction.</li> </ul> <p><b>Exclusion criteria:</b></p> <ul style="list-style-type: none"> <li>None.</li> </ul>	<p><b>Cross-sectional survey.</b></p> <p>Survey was emailed to visitors to the Centre for Anaphylactic Support (<a href="http://www.epipen.com">www.epipen.com</a>).</p> <p>Responses were anonymized.</p> <p>Participation was voluntary.</p> <p>Participants were divided into epinephrine users and nonusers.</p> <p>500 (27%) were users, meaning they had injected epinephrine into themselves or into someone else for whom they were responsible during the anaphylaxis episode.</p> <p>1385 (73%) were nonusers, meaning they had not injected epinephrine into</p> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>62% of epinephrine users and 64% of nonusers had no written anaphylaxis management plan.</li> <li>Nonusers reasons for not using an EAI included: an antihistamine was used (38%), did not receive a prescription for an EAI (28%), the allergic reaction was mild (13%), unsure when to give epinephrine injection (8%), and afraid to inject epinephrine (6%).</li> <li>73% of participants were nonusers, highlighting the underuse of EAIs.</li> <li>32% of users had difficulty deciding when to use EAI.</li> <li>Users were significantly more likely to have asthma.</li> <li>Most users (78%) reported using EAI within the first 30 minutes of noticing the first anaphylaxis symptom; however, 40% of them reported they took or gave antihistamines or an asthma puffer before using EAI.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>Study design does not provide a true denominator to assess the potential magnitude of selection bias. However, participants had access to a computer, did not report difficulty affording EAIs and were motivated to seek information regarding anaphylaxis.</li> <li>Therefore, it is likely this group representing the best-case scenario and there would likely be a higher number of nonusers in a more generalizable population.</li> <li>Could not verify FA status.</li> </ul>
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**Table 5** Continued

Author, (Year), Location, Title	Objectives	Study population, Sample size, Selection criteria	Study design, Methods	Key findings	Strengths and limitations
Greenhawt M.J. et al. (2009) Michigan and Tennessee, USA “Food allergy and food allergy attitudes among college students” <sup>12</sup>	<ul style="list-style-type: none"> <li>To assess food allergy trends and behavioural attitudes on a large college campus.</li> </ul>	<p>N = 513 (survey sent to 14,990)</p> <p><b>Inclusion criteria:</b></p> <ul style="list-style-type: none"> <li>Participants must be older than 18 years of age.</li> <li>Must be a student at the University of Michigan, Ann Arbor.</li> <li>Have an active student email account.</li> <li>Informed consent was obtained.</li> </ul> <p><b>Exclusion criteria:</b></p> <ul style="list-style-type: none"> <li>Respondents who did not indicate a specific FA.</li> </ul>	<p>themselves or into someone else for whom they were responsible during the anaphylaxis episode.</p> <ul style="list-style-type: none"> <li>Analysis was performed using STATA 10.0 software.</li> </ul> <p><b>Cross-sectional survey.</b></p> <p>Survey was designed and electronically distributed using SurveyMonkey.</p> <ul style="list-style-type: none"> <li>Respondents who did not indicate a specific FA were excluded by skip logic which redirected them during the survey.</li> <li>Data was analysed with SPSS version 16.</li> <li>Respondents with FA were stratified into two subgroups based on symptom severity as measured in the presence or absence of anaphylaxis.</li> </ul>	<ul style="list-style-type: none"> <li>Within the overall population who reported a reaction (<math>n=287</math>), only 6.6% of students reported maintaining emergency medication, and 21% of these reported maintaining SIE.</li> <li>Only 9.6% of students within the anaphylaxis subset carried an SIE at all times.</li> <li>Although, the number of respondents reporting SIE carriage varied by allergen, significantly more respondents with tree nut and peanut allergies reported carrying an SIE at all times.</li> <li>Only 39.7% of students with FA reported always avoiding foods to which they are allergic. However, within the anaphylaxis subset, this specific risk taking behaviour was lower.</li> <li>Within the group that reported consuming known allergens, there were significantly less number of individuals who reported carrying SIE.</li> <li>There was a significant relationship between prior anaphylaxis and having a reaction occur while at college.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>First study to examine food allergy on college campuses.</li> <li>Large sample size of <math>n=513</math> is sufficient to provide initial data on the scope of FA and FA-related risk-taking behaviour amongst college students.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>Poor response rate of 3.5% (513/14,990) raises concerns of responder bias.</li> <li>Self-reported data are subject to recall bias.</li> <li>Unable to confirm the diagnosis of IgE-mediated FA due to de-identification of data collected.</li> </ul>

Múgica-García M. V. et al. (2015) Alcorcón, Spain “Self- management of Anaphylaxis is Not Optimal” <sup>13</sup>	<ul style="list-style-type: none"> <li>To ascertain the degree of adherence to recommendations made to patients with anaphylaxis in an allergy outpatient clinic.</li> </ul>	<p>N = 887 (1512 surveys sent)</p> <p><i>Inclusion criteria:</i></p> <ul style="list-style-type: none"> <li>Patient diagnosed with anaphylaxis between 1998 and 2005.</li> <li>Within the catchment area of the Hospital Universitario Fundación Alcorcón (HUFA), Alcorcón, Spain.</li> </ul> <p><i>Exclusion criteria:</i></p> <ul style="list-style-type: none"> <li>None.</li> </ul>	<p><i>Observational, retrospective cohort study.</i></p> <ul style="list-style-type: none"> <li>All cases of anaphylaxis in HUFA were obtained from computerized clinical records.</li> <li>Questionnaire comprehensibility was tested twice among six experienced allergists.</li> <li>Survey sent by mail to 1512 patients of this cohort.</li> <li>Responses from patients &lt;18 years of age were obtained from parents or guardians.</li> </ul>	<p>No differences between the incidences of recurrence of anaphylaxis were detected between patients who were counselled on allergen avoidance measures and those who were not.</p> <ul style="list-style-type: none"> <li>Among patients who had recurrences of anaphylaxis, 30.74% reported using EAI and 31.8% had not used it.</li> <li>Age did not favour more frequent use of EAI.</li> <li>Intake of oral medication was more common than the use of EAI.</li> <li>93.5% of patients with food anaphylaxis avoided the allergen.</li> <li>Only 67% of patients prescribed an EAI bought one.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>Intermediate response rate of 58.7% (887/1512) for studies of this kind (online/email-based).</li> <li>Large sample size.</li> <li>Questionnaire comprehensibility was tested by allergists not members of the target population and thus may not have been appropriately designed for this group.</li> <li>Self-reported data are subject to recall bias.</li> <li>Results may be influenced by responder bias.</li> </ul>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>Questionnaire comprehensibility was tested by allergists not members of the target population and thus may not have been appropriately designed for this group.</li> <li>Self-reported data are subject to recall bias.</li> <li>Results may be influenced by responder bias.</li> </ul>
MacAdam C. et al. (2012) Southampton, UK	<ul style="list-style-type: none"> <li>To investigate the barriers to the carriage of EAIs.</li> </ul> <p>“What factors affect the carriage of epinephrine auto-injectors by teenagers?”<sup>14</sup></p>	<p>N = 20</p> <p><i>Inclusion criteria:</i></p> <ul style="list-style-type: none"> <li>Aged 12-18 years old.</li> <li>Previously been prescribed an EAI.</li> <li>Informed consent was obtained before the interview.</li> </ul> <p><i>Exclusion criteria:</i></p> <ul style="list-style-type: none"> <li>None.</li> </ul>	<p><i>Semi-structured interview.</i></p> <ul style="list-style-type: none"> <li>Participants were interviewed before their routine clinical appointment at Southampton University Hospital NHS Trust (SUHT).</li> </ul>	<p>Most teenagers made complex yet largely rational risk assessments to determine whether to carry the EAI.</p> <ul style="list-style-type: none"> <li>Factors affecting carriage included location, who else would be present, the attitudes of others (parents, friends), and physical features of the EAI.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>One interviewer reduces the likelihood of inter-observer variability/bias.</li> <li>Thematic saturation was reached as no significant development of themes occurred in the last three interviews.</li> <li>First study to investigate factors and feelings that may inhibit or improve the carriage of EAI by teenagers under the care at a specialist allergy clinic.</li> </ul>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>One interviewer reduces the likelihood of inter-observer variability/bias.</li> <li>Thematic saturation was reached as no significant development of themes occurred in the last three interviews.</li> <li>First study to investigate factors and feelings that may inhibit or improve the carriage of EAI by teenagers under the care at a specialist allergy clinic.</li> </ul>

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**Table 5** Continued

Author, (Year), Location, Title	Objectives	Study population, Sample size, Selection criteria	Study design, Methods	Key findings	Strengths and limitations
			<ul style="list-style-type: none"> <li>Demographic data and information about allergic history were collected on a short questionnaire before the interview.</li> <li>Interviews were conducted by one trained interviewer in a private, clinical setting.</li> <li>Interviews were semi-structured and conducted with a prompt sheet.</li> <li>Interviews were digitally recorded, anonymized, and transcribed by an experienced transcriber.</li> <li>Thematic coding was used to identify the main themes.</li> </ul>	<ul style="list-style-type: none"> <li>There were no notable differences in responses between patients who had previously suffered from severe reactions and those who had suffered mild/moderate reactions.</li> <li>Several of the teenagers reported fearing the needle/ injection aspect of EAI and this would impact its usage in reactions but not its carriage.</li> <li>Many teenagers relied on others being responsible for their EAI, especially their mothers. Independence did not increase with age. Boys were more reliant than girls.</li> <li>For some teenagers, emotions such as concern about reactions increased the carriage of EAI. But largely fear and anxiety about FA did not affect adherence to carrying EAI. Emotions such as embarrassment or "it won't happen to me" invincibility reduced EAI carriage.</li> </ul> <p><b>Semi-structured interview.</b></p> <ul style="list-style-type: none"> <li>N = 18</li> <li>Inclusion criteria:</li> <li>Aged 11–18 years.</li> <li>IgE-mediated FA diagnosis on basis of a food challenge, typical history with positive skin prick test, or serum-specific IgE.</li> </ul>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>Small number of participants restricts the generalizability of the finding and the ability for subgroup analysis, such as age and gender.</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>One interviewer reduces the likelihood of inter-observer variability/bias.</li> <li>Participants represented the breadth of socioeconomic status in terms of maternal education.</li> <li>In-depth analysis of barriers facing teenagers in managing FA.</li> </ul>
Monks H. et al. (2010)	"How do teenagers manage their food allergies?" <sup>15</sup>	To understand the practical challenges that teenagers with FA experience using a qualitative approach.	<ul style="list-style-type: none"> <li>• To understand the practical challenges that teenagers with FA experience using a qualitative approach.</li> <li>• To generate potential interventions for tackling these challenges.</li> </ul>	<ul style="list-style-type: none"> <li>Participants were recruited from the Children's Allergy Clinic at Southampton University Hospital Trust.</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>More than half admitted to trying food that might contain an allergen.</li> <li>In general, responses did not relate to whether or not participants had previously experienced an anaphylactic reaction.</li> </ul>

	<ul style="list-style-type: none"> <li>• Informed consent was received before the interview.</li> <li>• Participants whose QOL was impaired by other co-morbidities excluding asthma and allergic rhinitis.</li> </ul> <p><b>Exclusion criteria:</b></p> <ul style="list-style-type: none"> <li>• Purposeful sampling was used to ensure equal representation of both sexes and all ages.</li> <li>• Teenagers completed a questionnaire about their FA and underwent a focused, semi-structured interview (30-60 minutes) with open questions guided by <i>a priori</i> topic areas.</li> <li>• Interviews were recorded, transcribed, and analysed using a thematic approach.</li> <li>• All interviews were conducted by one investigator.</li> </ul>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>• Parents were more likely to ask about ingredients in restaurants and often carried the SIA.</li> <li>• Majority of participants did not carry their SIA all the time.</li> <li>• 41% of participants said they were somewhat confident (35%) or not very confident (6%) in recognizing symptoms of a reaction.</li> <li>• Teenagers say they would carry an SIA more if the devices were smaller.</li> <li>• A small number were worried about using an SIA because of fear of needles.</li> <li>• Half of the participants indicated their classmates were the group most in need of education regarding FA. Some participants had been teased because of their FA and some felt classmates did not appreciate how serious FA can be.</li> <li>• Majority thought it would make things easier for them if peers knew more about FA.</li> <li>• Teenagers believed it would be beneficial to be shown videos of people having allergic reactions and wished for frankness in discussing the consequences of risk-taking.</li> <li>• A minority felt that doctors and nurses were the best people to educate them about FA. They felt it would be helpful to learn from peers who have similar FA.</li> <li>• Teenagers were interested in practical SIA training including using real SIA in dummies rather than trainer pens.</li> </ul>
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**Table 6** Summary of EBL assessment of validity for quantitative studies.

Article	Population validity score (%)	Data collection validity score (%)	Study design validity score (%)	Results validity score (%)	Overall validity score (%)
Jones et al. (2015) <sup>6</sup>	100	83	100	100	96
Noimark et al. (2012) <sup>7</sup>	100	86	100	100	96
Sampson et al. (2006) <sup>8</sup>	50	83	100	83	78
Warren et al. (2017) <sup>9</sup>	50	80	100	83	77
Simons et al. (2009) <sup>11</sup>	50	67	80	100	74
Greenhawt et al. (2009) <sup>12</sup>	83	83	100	100	91
Múgica-García et al. (2015) <sup>13</sup>	67	83	100	100	83

Notably, few studies recognized parental effect on AYA adherence specifically, identifying another important area for future research. Two articles documented AYA relax their allergy management if parents are present, as they expect their parents to assume responsibility.<sup>14,15</sup> Findings related to parents of AYA with Type 1 Diabetes may be instructive. One cross-sectional study ( $n = 252$ ) suggested that a constructive parental relationship encouraging independence rather than behavioural direction was associated with improved adherence and less risk-taking behaviours.<sup>18</sup>

There were discrepancies regarding the effect of age and medical history on adherence. Only Warren et al.<sup>9</sup> associated increasing age with decreased carriage of AAI and this study had a lower validity score than those that did not identify any association. Studies included in this review could not link anaphylaxis history, co-morbidities, or time since the last reaction to adherence to self-care behaviours.<sup>6-8</sup> This contradicts a recent prospective cohort study that found the time since the previous reaction was inversely proportional to the likelihood of carrying an AAI amongst 400 AYA.<sup>19</sup> Prospective studies such as this, which minimize recall bias and self-reporting, would be of benefit in future research examining the multifactorial influences on AYA compliance.

One exclusive study reported no association between knowledge of AAI use and adherence to self-care behaviours, challenging the common belief that poor knowledge causes poor adherence.<sup>6</sup> Contrastingly, Noimark's study had a larger study sample and found that the majority of AYA did not use the AAI due to poor knowledge of anaphylaxis symptoms.<sup>7</sup> This raises questions about the common belief that poor knowledge is the root of poor adherence. Personalized management plans were the only educational tool investigated with a strong relationship to improved adherence.<sup>6</sup> Interestingly, one study established that the majority of AYA did not have management plans.<sup>11</sup> These findings highlight the need for randomized control trials to be conducted to investigate the benefits of management plans in this population.

Three highly valid qualitative studies investigated AYA emotional attitudes' effect on adherence.<sup>10,14,15</sup> Their in-depth, semi-structured interview design is extremely valuable in this regard. Needle phobia and its negative impact on AAI use were recognized, this is with respect

to studies that have highlighted the adverse psychological toll FA take on AYA and their families.<sup>20-22</sup> Interestingly, some literature acknowledges the difficulty in assessing the significance of AAI needle phobia, as anaphylaxis itself often induces significant fear. Indeed, Pumphrey<sup>23</sup> suggests fear may facilitate AAI use if clinicians encourage patients to treat this as a signal to inject AAI. These studies suggest that psychological and emotional aspects of anaphylaxis management should be explored and addressed when designing interventions and resources for AYA.

#### ***Proposed strategies to improve AYA adherence to self-care behaviours***

Many studies emphasized the need for AYA empowerment and support in managing their allergies rather than didactic educational interventions.<sup>6,10,13-15</sup> Indeed, despite adequate education, many AYA still engaged in significant levels of risk-taking behaviours.<sup>6,10,13-15</sup> Alternatively, empowering AYA to self-manage their allergies has been linked to improved adherence.<sup>6,10,14</sup> This corresponds with current understandings, as one systematic review of interventions to enhance compliance of AYA with chronic disease identified that a purely educational approach was sufficient in only two out of seven studies.<sup>24</sup> Contrastingly, behaviour-centric approaches improved self-management in four out of seven studies. More research into behavioural interventions is imperative, as it could have a significant impact on AYA adherence.

AYA expressed a desire for the education of their peers about the risks of allergies.<sup>6,8-10,14,15</sup> "Embarrassment around friends" was found to correlate with reduced AAI carriage, thus further research exploring whether peer education leads to reduced embarrassment amongst AYA, and subsequent adherence improvements maybe hugely important. Randomized controlled trials found that peer-inclusive asthma education programs positively impact the compliance of affected children and AYA.<sup>25,26</sup> Peer-led education interventions and support groups have also been found to be highly effective in the management of asthmatic AYA.<sup>27</sup> It would be of benefit to conduct trials similar to these for AYA with allergies.

Article	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Are the findings valuable?
Gallagher et al. (2011) <sup>10</sup>	Y	Y	Y	Y	Y	C	Y	Y	Y
MacAdam et al. (2012) <sup>14</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y
Monks et al. (2010) <sup>15</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y

Key: Y=Yes; N=No; C=Can't tell.

### Areas failed to be addressed by the included studies

Remarkably, few of the articles in this review addressed the impact of socio-economic factors and ethnicity on AYA behaviours. Many studies utilized online surveys thus their participants, at a minimum, had access to a computer. This may be indicative of a higher socio-economic status, or at least fails to include AYA that may not have access to technology. Socio-economic factors may play a significant role in AYA compliance, as it is true with regard to other illnesses and lifestyle prescriptions.<sup>28-30</sup> This challenges the generalizability of the findings. Exploring this may be of clinical benefit in improving adherence and thus this is a significant gap in FA literature.

Similarly, these articles did not investigate the potential effects of social media on AYA self-care attitudes and compliance. Mobile phone applications and social media-based interventions have been identified as new routes for improving treatment compliance amongst AYA with asthma, among other conditions.<sup>31,32</sup> Most of the studies included in this review reported that AYA were interested in online education programs, supplementing this with self-care positive social media sites could be beneficial in improving AYA compliance. If studied by future researchers, this would likely yield interesting results.

### Limitations

There are several limitations to the findings in this review. This study only included articles that were available as full free text in English on relevant databases, which could potentially alter the results. Word count restrictions limited a more detailed analysis. The study samples were from the UK, USA, and Spain only; this may limit the generalizability of the articles. Furthermore, the work of a single researcher in this review may also have introduced systemic bias.

### Future Perspective

The introduction of new technologies, including new training strategies to increase self-awareness of allergy (online teaching, mobile apps, telemedicine) and the possibility of new ways to administer adrenaline for anaphylaxis in the following years could drastically change the attitude among AYA compliance.<sup>33</sup>

### Conclusions

Ultimately, only a minority of anaphylaxis cases amongst AYA are treated appropriately and this has been associated with increased risk-taking behaviour in this population.<sup>16,17</sup> AYA are at a significantly higher risk of fatal allergic reactions, signifying a clear need to probe this suboptimal adherence to food allergy-related self-care behaviours.<sup>4,5</sup> This study suggests that healthcare professionals working with AYA with food allergies recognize AAI design, peer influence, and emotional attitudes as significant factors

influencing AYA adherence. Also, AYA benefit from feeling included in decisions regarding their allergy management and empowerment in making their own decisions regarding their food allergy may improve their self-care behaviours. A paucity of information concerning their socio-economic status, ethnicity, and social media influence on the compliance of this population was identified by this review. Therefore, further research directed at these factors is imperative in facilitating the design of guidelines to maximize the adherence of AYA to food allergy-related self-care behaviours.

## Conflict of interest

The authors declare no potential conflicts of interest with respect to research, authorship, and/or publication of this article.

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