

# Allergists' self-reported adherence to anaphylaxis practice parameters and perceived barriers to care: an American College of Allergy, Asthma, and Immunology member survey

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## ARTICLE INFO

### Article history:

Received for publication June 18, 2013.

Received in revised form August 29, 2013.

Accepted for publication September 30, 2013.

## ABSTRACT

**Background:** Anaphylaxis is life-threatening and requires rapid medical intervention. Knowledge of treatment guidelines and addressing barriers to care are essential for appropriate management.

**Objective:** To investigate allergists' self-reported practices in managing patients at risk for anaphylaxis, specifically in following practice parameters for diagnosis, treatment, and appropriate use of epinephrine, and to identify perceived barriers to care.

**Methods:** Online questionnaires were distributed to members of the American College of Allergy, Asthma, and Immunology. The US physicians who self-identified as "allergist/immunologist" were eligible to participate. The first 500 completed questionnaires were analyzed.

**Results:** Nearly all ( $\geq 95\%$ ) reported adherence to practice parameters in prescribing an epinephrine auto-injector and instructing patients on its use, taking a detailed allergy history, counseling patients on avoidance measures, and educating patients on the signs and symptoms of anaphylaxis. More than 90% stated they determined the best diagnostic procedures to identify triggers and coordinated laboratory and allergy testing. Adherence to practice parameters was less robust for providing patients with written action plans and in-office anaphylaxis preparedness. Perceived barriers to care included a significant proportion of patients who were uncomfortable using epinephrine auto-injectors and inadequate knowledge of anaphylaxis among referral physicians.

**Conclusion:** Allergists overwhelmingly adhere to practice parameter recommendations for the treatment and management of anaphylaxis, including appropriate use of epinephrine as first-line treatment, educating patients, and testing to diagnose anaphylaxis and identify its triggers. Opportunities for improvement include preparing staff and patients for anaphylactic events, providing written action plans, and improving knowledge of referring physicians.

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## Introduction

Evidence-based clinical practice guidelines play an ever-increasing role in clinical decision making. By describing widely accepted practices for the diagnosis and management of specific diseases or conditions, practice guidelines are an important tool for physicians in treatment planning. Because of the severe, potentially fatal consequences of anaphylaxis and its often rapid onset requiring immediate medical intervention, knowledge of best

practices in anaphylaxis management is essential to improving care and preventing fatalities.

Anaphylaxis is likely underdiagnosed owing to uncertainty by patients and lack of a universal clinical definition.<sup>1–3</sup> Worldwide, 0.05% to 2% of people are estimated to have anaphylaxis at some point in their lives,<sup>4</sup> and data based on the number of prescriptions for self-administered epinephrine injectors suggest that prevalence may be as high as 2%<sup>5,6</sup> overall and higher in the northern US states.<sup>6–8</sup> There also are studies indicating that prevalence may be increasing, especially in the young,<sup>9</sup> and other data suggest an increase in fatalities<sup>9,10</sup> and hospitalizations.<sup>11</sup>

The Diagnosis and Management of Anaphylaxis: A Practice Parameter was first developed in 1999 and updated in 2005 and 2010.<sup>12</sup> The parameter was developed by the Joint Task Force on Practice Parameters, comprised of members from the American Academy of Allergy, Asthma, and Immunology; the American

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**Disclosures:** Dr Dowling has served on the speaker's bureau of Integrity Continuing Education.

**Funding:** This research was supported by an educational grant from Mylan Specialty LP.

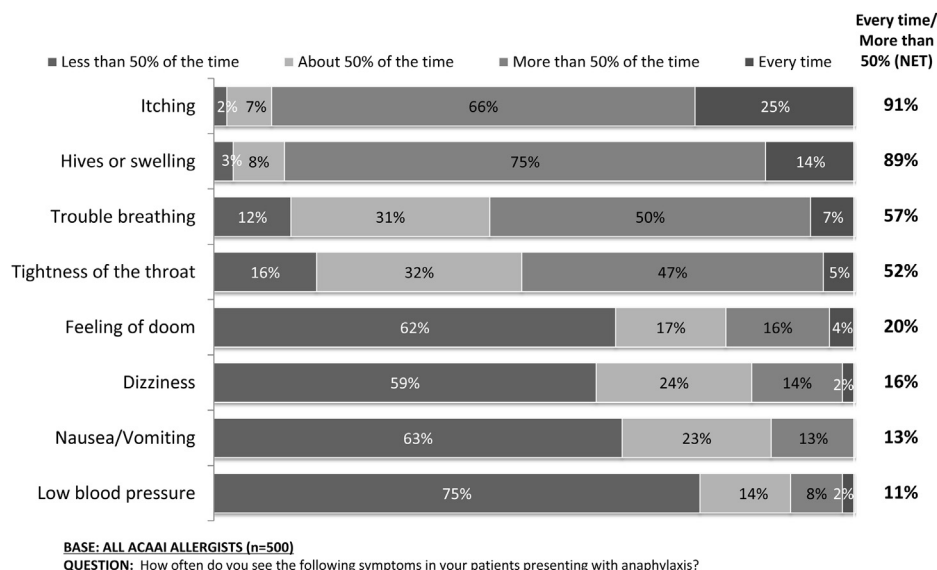


**Figure 1.** Frequency of symptoms of anaphylaxis. ACAA, American College of Allergy, Asthma, and Immunology.

College of Allergy, Asthma, and Immunology (ACAAI); and the Joint Council on Allergy, Asthma, and Immunology. The document contains guidelines and recommendations based on a systematic review and synthesis of the best available scientific evidence and clinical consensus. The parameter presents 2 algorithms: (1) the evaluation of the patient who presents to the physician's office with a previous episode of anaphylaxis or a condition simulating an anaphylactic event and (2) the recommended management of an episode occurring in the office.

Although adherence to anaphylaxis practice parameters by allergists has not been studied previously, there is evidence that in general the dissemination of practice guidelines alone does not significantly affect physician or patient behavior.<sup>13,14</sup> The authors conducted a survey among members of the ACAAI to assess their self-reported practices and procedures in the management of anaphylaxis. The survey focused on comparing physician practices with those recommended in the parameters regarding diagnosis, treatment, and patient education, including the appropriate use of epinephrine. The study also sought to identify perceived barriers to care and areas for improvement. This included looking at factors such as whether patients carry their epinephrine auto-injectors and are comfortable using them and the knowledge and skills of emergency department (ED) and other referring physicians in diagnosing and managing anaphylaxis.

## Methods

The online survey was conducted on behalf of the ACAAI by Harris Interactive (Rochester, New York) from January 10 to 23, 2013. Survey questionnaires were electronically mailed to 3,454 members of the ACAAI, comprising all US members for whom e-mail addresses were available at the time of the survey (of a total membership of 3,870). Scales were used throughout that have been validated in prior "research on research" conducted by Harris Interactive. The US physicians who self-identified as allergists or immunologists were eligible to complete the survey. A quota of 500 respondents was determined to provide a large-enough sample to look at the total data and at subgroups that might be of interest. At the conclusion of the 2-week study period, the overall participation rate was 19%, including 538 who completed the survey and 121 who responded but did not complete the survey. Of the 538 who completed the survey, 38 did not meet at least 1 survey criterion,

including 9 who did not identify their primary medical specialty as allergist or immunologist, 2 whose primary practice was not in the United States, 22 who were not licensed in the state where they practiced, and 5 who did not complete the survey before the quota was reached. Results from the remaining 500 completed surveys were analyzed for this report. Results were weighted for age, sex, region, and years in practice, when necessary, to reflect overall demographics of the ACAAI membership population.

## Results

Unless noted otherwise, all percentages reflect the responses of all 500 allergists included in the survey analysis.

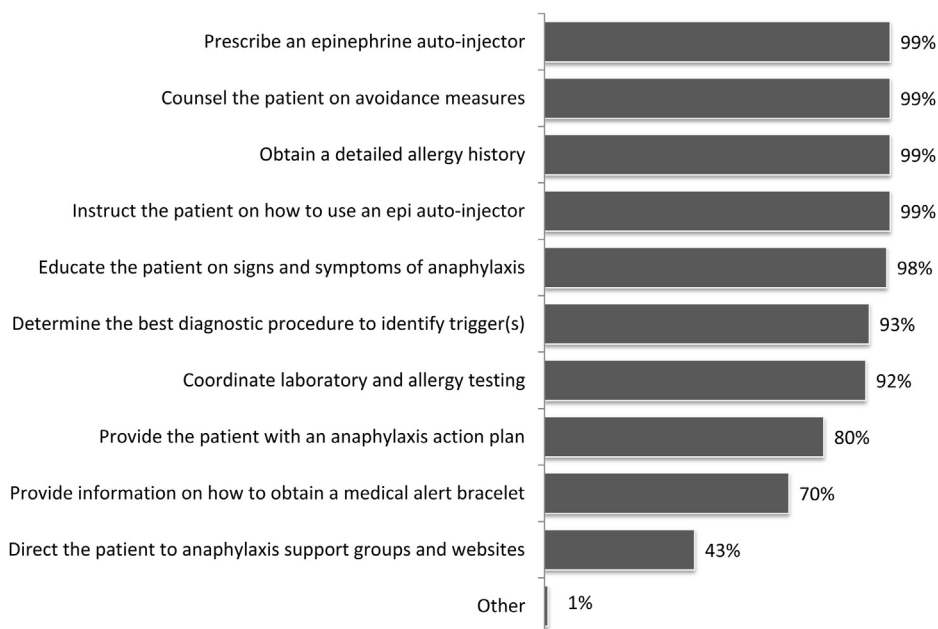
### Respondent Demographics

Of the 500 allergists whose responses were included in the survey, 68% were men and 32% were women. The mean age was 49 years. Half (51%) reported their office setting as a single-specialty partnership or group, 27% practiced in a multispecialty partnership or group, and 22% were in solo practice. Respondents described their practices as based mostly in an office or a clinic (89%), mostly in a hospital or a laboratory (3%), exclusively in a hospital or laboratory (3%), or equally in a hospital and an office or a clinic (5%). When asked to describe the age of their patient populations, 10% stated no older than 18 years, 10% stated at least 19 years, and 80% stated all ages. Eight percent reported completing their residency before 1980, 51% from 1980 to 1999, 33% from 2000 to 2009, and 8% in 2010 or later.

### Diagnosis and Treatment

Diagnosing anaphylaxis in adults was perceived as very or somewhat easy by 79% of allergists surveyed compared with 66% who stated diagnosis was very or somewhat easy in children. Identifying anaphylaxis triggers in adults was viewed as more challenging, with 61% stating it was very or somewhat difficult compared with 40% who stated identifying triggers was very or somewhat difficult in children.

Obtaining a patient's medical history and running diagnostic tests were viewed as equally important by 78%, and 77% stated it was essential to perform laboratory tests in a timely manner to confirm a diagnosis of anaphylaxis.



BASE: ALL ACAAI ALLERGISTS (n=500)

QUESTION: Which of the following, if any, do you typically do when treating a patient at risk for anaphylaxis? Please select all that apply.

**Figure 2.** Treating patients at risk for anaphylaxis. ACAAI, American College of Allergy, Asthma, and Immunology.

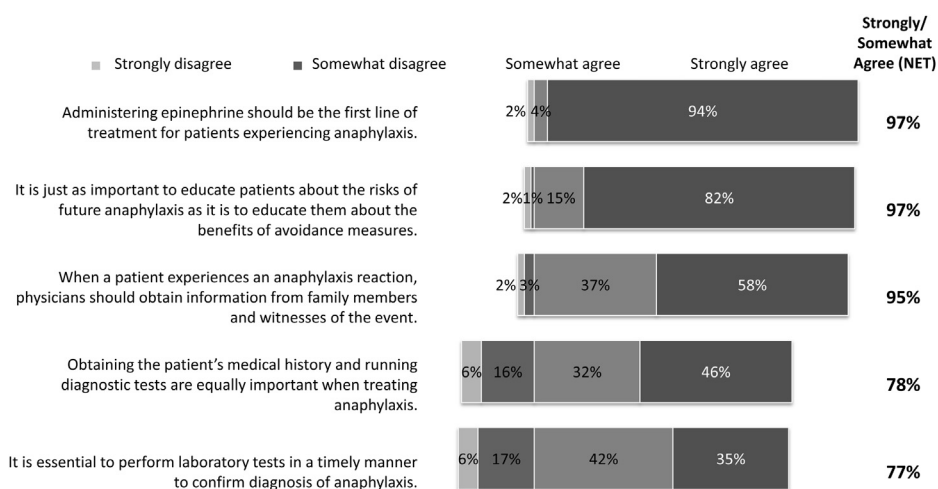
Symptoms of anaphylaxis the allergists reported seeing most frequently (>50% of the time) were itching (reported by 91%), hives or swelling (89%), trouble breathing (57%) or tightness of the throat (52%). They also reported seeing patients' "feeling of doom" (20%; Fig 1).

When treating patients at risk for anaphylaxis, nearly all allergists stated they adhered to practice parameters in prescribing an epinephrine auto-injector (99%), counseling the patient on avoidance measures (99%), obtaining a detailed allergy history (99%), instructing the patient on how to use an epinephrine auto-injector (99%), educating the patient on signs and symptoms of anaphylaxis (98%), determining the best diagnostic procedure to identify triggers (93%), and coordinating laboratory and allergy

testing (92%). A smaller proportion provided an anaphylaxis action plan (80%), information on how to obtain a medical alert bracelet (70%), or directed the patient to anaphylaxis support groups and Web sites (43%; Fig 2).

The allergists were asked if they agreed or disagreed with a list of statements regarding specific recommendations from the practice parameters, including the use of epinephrine as the first line of treatment, educating patients about risk factors and avoidance measures, taking the patient's medical history, running laboratory tests, and obtaining information from the patient's family and witnesses to probable anaphylactic events (Fig 3).

Although most allergists followed the guidelines in educating patients about self-administered epinephrine, the proportion that



BASE: ALL ACAAI ALLERGISTS (n=500)

QUESTION: How strongly do you agree or disagree with each of the following statements regarding procedures related to anaphylaxis management?

**Figure 3.** Agreement/disagreement with key treatment guidelines. ACAAI, American College of Allergy, Asthma, and Immunology.

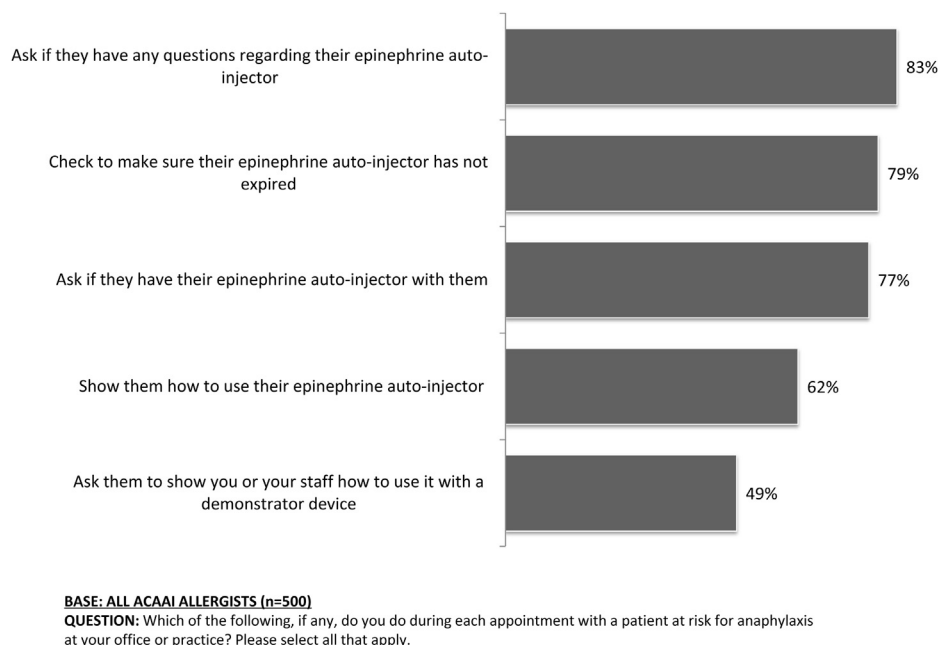


**Figure 4.** Procedures performed during each appointment. ACAAI, American College of Allergy, Asthma, and Immunology.

performed certain recommended actions during each appointment decreased significantly. Although 92% stated it was important to have a discussion about epinephrine auto-injector usage and knowledge at each appointment, 17% did not ask patients if they had any questions regarding their epinephrine auto-injector, 38% did not demonstrate auto-injector use, and 51% did not ask their patients to show them or their staff members how to use their auto-injector with a demonstrator device at each appointment (Fig 4).

#### Anaphylaxis Preparedness

To prepare for emergency anaphylactic events in the office setting, a large majority of allergists adhered to practice parameters

in assuring emergency medications were up to date (98%), informing staff of instructions in the case of an emergency (89%), and making sure everyone involved in anaphylaxis treatment could locate necessary supplies (89%). Yet one third (34%) stated they had not made sure staff certifications were up to date (ie, Basic Cardiac Life Support, Advanced Cardiac Life Support, and Pediatric Advanced Life Support certification), 44% had not identified a person responsible for calling emergency medical services, and 57% had not conducted anaphylaxis drills (Fig 5). Of those who did conduct practice drills, 71% stated they did so 1 to 2 times a year.

In the management of an anaphylactic event in the office setting, nearly all allergists stated they required patients to remain in the office for observation after administration of epinephrine, with 41%

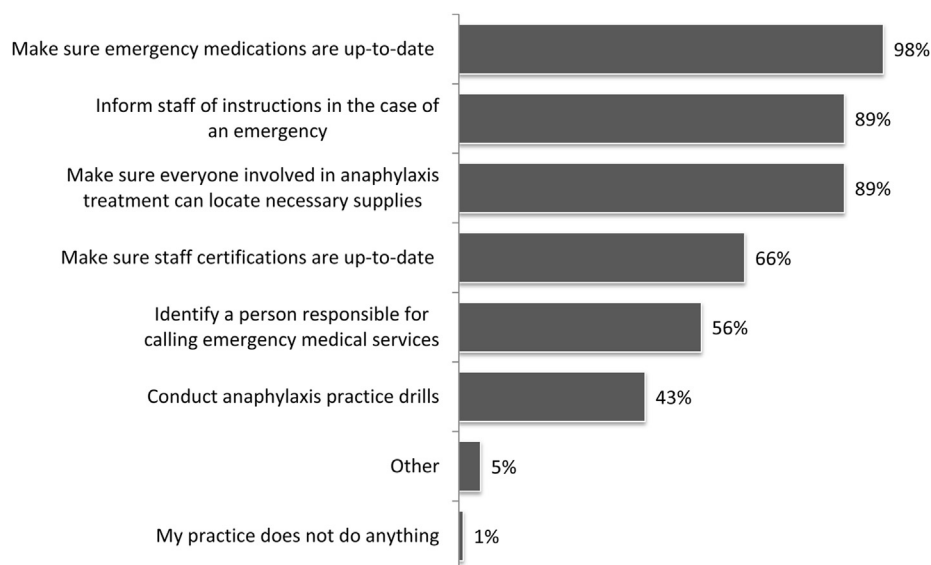


**Figure 5.** Anaphylaxis preparedness. ACAAI, American College of Allergy, Asthma, and Immunology.

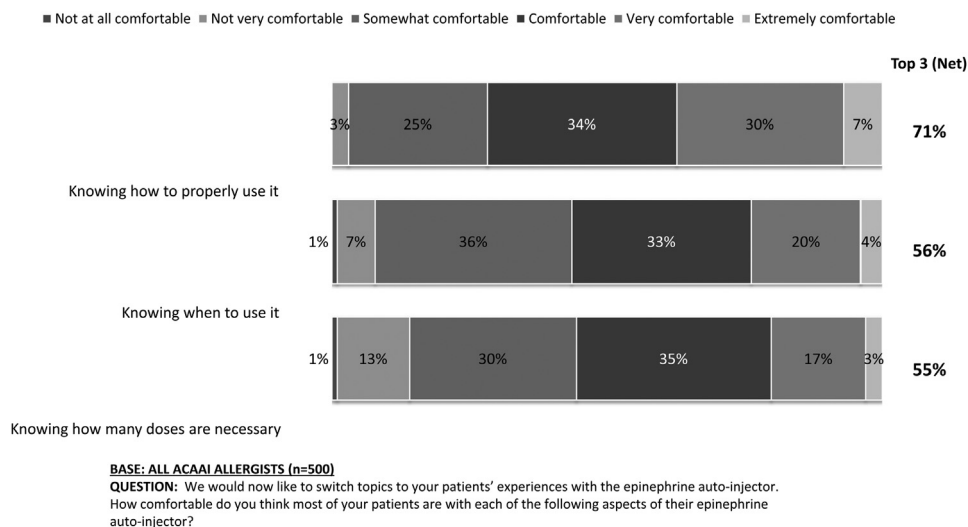


**Figure 6.** Patient comfort with epinephrine auto-injectors. ACAAI, American College of Allergy, Asthma, and Immunology.

stating they required patients to wait for 1 hour, 40% longer than 1 hour, 18% for 30 minutes, and 1% for 15 minutes. In addition, on average, the allergists surveyed stated they typically gave 93% of their patients an oral antihistamine and administered an oral corticosteroid to 70% of patients after successful treatment with epinephrine.

Although 80% stated they provided their patients with an anaphylaxis action plan, 20% did not. When asked what percentages of their patients at risk for anaphylaxis had an action plan, the physicians stated that, on average, 74% did.

#### Patient Comfort with Epinephrine Auto-Injectors

When asked how comfortable they thought their patients were with the epinephrine auto-injector, a significant number of allergists stated their patients were less than comfortable with knowing how to use it properly (29%), when to use it (44%), and how many doses were necessary (45%; Fig 6).

Fear of injection was cited as a patient concern by 68% and 56% mentioned cost. Among allergists whose patients had expressed concern, 89% (n = 486) stated they showed their patients how to use the epinephrine auto-injector by using demonstrator devices in the office. A similar proportion (84%) stated they had their patients practice with demonstrator auto-injectors, and 71% stated they gave their patients an anaphylaxis or allergy plan with instructions. Nearly all (99%) agreed it was important to educate family members about epinephrine auto-injectors.

The allergists were asked about their perceptions of why patients did not have their epinephrine auto-injector with them. Among the 77% (n = 389) of allergists who asked their patients if they had their epinephrine auto-injector with them, the most frequently mentioned reasons for not having the auto-injector were that patients forgot it (84%), patients stated they didn't think they'd need it (54%), patients switched bags (43%), and patients could not afford to fill the prescription (38%). Further, 78% said their patients were likely to use an expired epinephrine auto-injector if they could not afford a new one.

#### Perceptions of Referral Physicians' Management of Anaphylaxis

Most allergists (57%) surveyed stated they believed primary care physicians (PCPs) were somewhat knowledgeable about anaphylaxis, 18% stated they are very knowledgeable or knowledgeable,

and 26% stated they were not very or not at all knowledgeable about anaphylaxis.

The ACAAI allergists stated that, on average, nearly half (48%) their patients were referred to them after visiting an ED and being diagnosed with anaphylaxis, 45% had an allergic reaction before diagnosis, and 20% were misdiagnosed with any condition other than anaphylaxis. Fewer than one third the allergists (30%) believed ED physicians or PCPs accurately diagnosed anaphylaxis more than 50% of the time, 43% stated referring providers gave patients presenting with anaphylaxis a prescription for an epinephrine auto-injector, and 10% stated referring physicians provide the patient with directions on how to use the device more than 50% of the time.

When asked who was responsible for educating PCPs about anaphylaxis, 89% said allergists and immunologists and 59% believed that this responsibility fell primarily to them. Approximately 9 in 10 stated they shared with PCPs their patients' diagnosis (93%), specific anaphylaxis triggers (91%), or prescribed treatments such as an epinephrine auto-injector (86%) when PCPs referred patients presenting with anaphylaxis to them. Significantly fewer shared additional information, including the patient's written action plan (47%), information on how to diagnose anaphylaxis (26%), and how to use an epinephrine auto-injector (21%; Fig 7).

#### Useful Tools

More than half (55%) the allergists named at least 1 tool not currently available that they would like to see created to help their patients at risk for anaphylaxis. Among the tools mentioned were Web-based and other educational and awareness materials and programs for patients and providers and support groups.

#### Discussion

Allergists are the specialists with the most training in evaluating, diagnosing, and treating patients with anaphylaxis. Therefore, it is not surprising that their adherence to practice parameter recommendations is high. Although there are no universally accepted anaphylaxis management practice parameters,<sup>15</sup> the 2010 Joint Task Force parameters<sup>12</sup> were used for this comparison because they are most germane to the ACAAI allergists in the present population sample.

The ACAAI allergists surveyed overwhelmingly prescribed an epinephrine auto-injector as first-line treatment, instructed

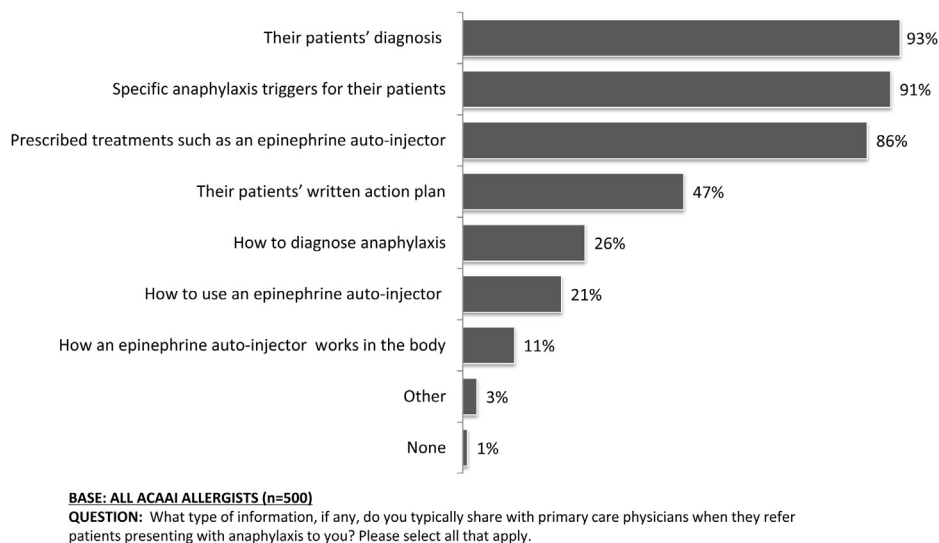


**Figure 7.** Information shared with primary care physicians. ACAAI, American College of Allergy, Asthma, and Immunology.

patients on how to use it, counseled patients on avoidance measures, obtained a detailed allergy history, educated patients on signs and symptoms of anaphylaxis, determined the best diagnostic procedure to identify triggers, and coordinated laboratory and allergy testing. The survey also shows room for improvement. Three areas in which allergists were less likely to follow the practice parameters were (1) providing patients with written action plans, (2) preparing for an in-office emergency, and (3) performing certain actions at every appointment, especially in promoting patient comfort and compliance with epinephrine auto-injector use.

Interestingly, allergists who were most likely to follow recommendations in these 3 areas also were significantly more likely to follow other guidance based on the practice parameters. For example, 43% ( $n = 218$ ) of physicians who reported conducting anaphylaxis practice drills were more likely to take other recommended steps to prepare for emergencies compared with those who did not conduct drills. Adherent allergists were more likely to inform staff of instructions in case of an emergency (95% vs 85% for those who did not conduct drills), make sure everyone involved in anaphylaxis treatment could locate necessary supplies (95% vs 84%), made sure staff certifications (ie, Basic Cardiac Life Support, Advanced Cardiac Life Support, and Pediatric Advanced Life Support) were up to date (79% vs 57%), and identified a person responsible for calling emergency medical services (67% vs 48%). They also were more likely to perform recommended procedures at each appointment, such as show patients how to use their epinephrine auto-injector (68% vs 57%), generate and update the patient's written action plan (67% vs 54%), ask patients to show staff how to use their epinephrine auto-injector with a demonstrator device (59% vs 41%), provide information on medical alert bracelets (47% vs 34%), encourage family members to attend appointments

(48% vs 28%), and require patients to bring their epinephrine auto-injector to each appointment (33% vs 16%).

Similarly, 60% ( $n = 305$ ) who generated or updated their patients' written action plan during each appointment reported they were significantly more likely than those who did not to determine the best diagnostic procedure to identify trigger(s) (96% vs 89%), provide the patient with an anaphylaxis action plan (95% vs 57%), coordinate laboratory and allergy testing (94% vs 89%), provide information on how to obtain a medical alert bracelet (78% vs 59%), and direct the patient to anaphylaxis support groups and Web sites (52% vs 30%).

Further, perceptions of patient comfort increased significantly among those who required patients to bring their auto-injector to each appointment, generated or updated their patients' written action plan, and/or conducted practice drills compared with those who did not.

Although allergists were nearly unanimous in their agreement that epinephrine should be the first line of therapy (97%) and 98% stated that, when in doubt, it is better that patients use their epinephrine auto-injectors, they reported a large proportion of patients who were uncomfortable with knowing how and when to use their epinephrine injectors and the correct dosage. The proportion of patients who were perceived as uncomfortable decreased significantly among allergists who required patients to bring their auto-injector to each appointment, generated or updated their patients' written action plan, and/or conducted practice drills compared with those who did not (Table 1).

Patient anxiety and uncertainty about when to use epinephrine auto-injectors has been documented previously,<sup>16–20</sup> and educating patients on when and how to use the devices should be a top priority for allergists. Steps also are needed to encourage

**Table 1**  
Patient comfort with epinephrine auto-injectors

|                                      | Extremely/very comfortable/comfortable     |                  |                                         |                  |                         |                  |
|--------------------------------------|--------------------------------------------|------------------|-----------------------------------------|------------------|-------------------------|------------------|
|                                      | Require them to bring to every appointment |                  | Generate and update written action plan |                  | Conduct practice drills |                  |
|                                      | Yes ( $n = 122$ )                          | No ( $n = 378$ ) | Yes ( $n = 305$ )                       | No ( $n = 195$ ) | Yes ( $n = 218$ )       | No ( $n = 282$ ) |
| Knowing how to use it properly       | 84%                                        | 67%              | 75%                                     | 66%              | 76%                     | 67%              |
| Knowing when to use it               | 68%                                        | 53%              | 59%                                     | 52%              | 65%                     | 49%              |
| Knowing how many doses are necessary | 66%                                        | 52%              | 61%                                     | 46%              | 62%                     | 50%              |

patients to carry their auto-injectors with them. Among the allergists surveyed, 77% stated they asked patients if they had their auto-injectors with them at each appointment, but only 23% stated they required patients to bring the device to each appointment. Further, those who asked patients if they had the device with them ( $n = 389$ ) reported that, on average, 62% of patients did. Allergists who also required patients to bring their auto-injectors to each appointment reported that, on average, 69% had the device with them. Nonetheless, these results show that a significant proportion of patients (31%–38%) did not have their epinephrine auto-injectors at the time of their appointment.

The present survey results suggest that specific interventions by allergists may improve patient adherence to recommendations for carrying their epinephrine auto-injectors, a conclusion that is borne out by other research. A recent study of self-behaviors among food-allergic adolescents, including those carrying self-injected epinephrine, concluded that provider efforts to elicit personal barriers to adherence and to address perceptions of severity and the unpredictable nature of symptoms may be effective in improving adherence.<sup>21</sup> Another study found that children with asthma who were asked to demonstrate inhaler technique and/or whose providers discussed a written action plan during an office visit were significantly more likely to perform a larger percentage of inhaler steps correctly 1 month later.<sup>22</sup> Others have concluded that the greatest improvements in adherence are the result of a combination of measures, such as directly asking patients, watching for appointment nonattendance, providing information about the treatment regimen, counseling about the importance of adherence, reminders about appointments, rewards and recognition for the patient's efforts to follow the regimen, and enlisting social support from family and friends.<sup>23</sup> Other successful strategies include a combination of objective adherence monitoring, identification of the cause(s) of nonadherence, delivery of specific strategies for each cause, and the use of motivational interviewing communication skills.<sup>24</sup>

Inadequate management of anaphylaxis by ED and other referring physicians cited by allergists in the survey also has been documented in the literature, including under- and misdiagnoses, insufficient use of epinephrine in children and adults, under-prescribing of auto-injectable epinephrine, and lack of referrals to allergists and immunologists.<sup>25–27</sup>

This survey highlights the perceived gaps in anaphylaxis education of PCPs and ED physicians, with allergists stating that 20% of patients referred to them are misdiagnosed. Most allergists also stated that ED physicians or PCPs accurately diagnosis anaphylaxis, give patients presenting with anaphylaxis a prescription for an epinephrine auto-injector, or provide the patient with directions on how to use the device less than 50% of the time.

Other surveys of physician practices in the management of anaphylaxis have been conducted, with varying results. One survey of 620 pediatric emergency physicians concluded that although most (93.5%) reported using epinephrine in pediatric anaphylaxis, fewer (70%) used the preferred intramuscular administration route, and many (37%) discharged patients home after an abbreviated period.<sup>28</sup> In another survey, 486 pediatricians answered questions about a clinical scenario involving a child having an anaphylactic reaction after ingesting a peanut. Most respondents (70%) agreed that the clinical scenario was consistent with anaphylaxis, and 72% chose to administer epinephrine. However, only 56% of respondents agreed with the diagnosis of anaphylaxis and treatment with epinephrine. Most pediatricians (70%) did not recognize that a 30-minute observation period after anaphylaxis was too short.<sup>29</sup>

Of the allergists surveyed, 89% stated allergists and immunologists are responsible for educating PCPs, and of them, 59% stated that this responsibility fell primarily to allergists. Although most allergists stated they shared information about patients' diagnoses,

triggers, and recommended treatment, less than half shared the patient's written action plan (47%), information on how to diagnose anaphylaxis (26%), how to use an epinephrine auto-injector (21%), and how the epinephrine auto-injector works in the body (11%).

Limitations of this study include the potential for ascertainment bias, because the study was designed to look only at the practices of allergists who are members of the ACAAI; nonresponse bias, because 81% did not respond to the survey; and early response bias, because 19% ( $n = 121$ ) of a total of 659 respondents did not complete the survey before the quota of 500 was reached. Although the number of allergists for whom e-mail addresses were not available is relatively small ( $n = 416$ ), survey results also may disproportionately represent allergists who are most electronically "connected." In addition, the finding that 66% of allergists stated the diagnosis of anaphylaxis is very or somewhat easy in children may be misleading because the survey did not specifically ask about infants, for whom diagnosis may be more difficult.<sup>30</sup>

Typically, patients are referred to an allergist after the initial episode of anaphylaxis has occurred and been treated. There may be opportunities for ACAAI and/or other professional groups to provide their members or others with educational materials aimed at improving anaphylaxis management by nonallergist physicians and design interventions to improve patients' adherence and comfort levels with epinephrine auto-injector use. As the specialists most extensively trained in the diagnosis and management of anaphylaxis, allergists should carefully consider the educational needs of referring physicians and patients and explore innovative ways to meet those needs that will ultimately improve outcomes for patients with anaphylaxis.

## Acknowledgments

The authors thank Jaclyn R. Holmes, MA (Project Researcher, Harris Interactive) for data collection and analysis, and Nancy E. Ryan, CAE (Director of Communications, ACAAI) for administrative oversight and assistance in survey design and editing.

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