

Needs assessment survey for a food allergy control tool

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Clinical Implications

- This survey suggests that allergists and pediatricians support the need to develop a clinical tool that can evaluate and track food allergy disease control over time. This novel tool can enhance the ability of clinicians to provide targeted interventions.

TO THE EDITOR:

As many as 9 million adults and 6 million children in the United States have food-allergic disorders.¹⁻³ These individuals suffer poor health-related quality of life (HRQOL) because of the physical and psychosocial impact of food-allergic reactions and the daily limitations inherent to food-allergen avoidance.⁴ Encouraging results from food allergy desensitization and immunotherapy clinical trials herald unprecedented opportunities for these individuals. These challenges and opportunities make it imperative for patients and providers to weigh the burden of disease against the burden of treatment in food allergy care.

The concept of “control” is well established in the management of chronic conditions such as asthma and diabetes. Asthma control refers to “the extent to which the various manifestations of asthma have been reduced or removed by treatment,” with the key components being the degree of clinical impairment and the risk of future adverse events.⁵ There are validated HRQOL questionnaires to measure the impact of food allergy from the patient’s perspective; however, the concept of control has hitherto not been applied to food allergy management. The multifaceted nature of this condition, including the emergence of novel therapeutic and prevention strategies designed to alter food allergy manifestations, begs for control to be an integral element of food allergy management. Validated clinical tools to assess control of other chronic conditions (eg, Asthma Control Test for management of asthma) are endorsed by national guidelines.^{6,7} There is a potential unmet need for a validated instrument to assess the degree of food allergy control in patients with these disorders.

We hypothesized that a screening tool to assess food allergy control in ambulatory settings may benefit primary care providers (PCPs), specialists, patients, and families, enhance standardization of care, and identify targeted interventions for individual patients. Because the concept of assessing control in food allergy care is novel and a paradigm shift, we conducted a pilot feasibility and needs assessment survey to explore:

1. Whether a tool designed to assess food allergy control fulfills a clinical need
2. Whether PCPs and allergists would use such a tool
3. The content of such a tool

The authors identified a convenience sample of pediatricians ($n = 57$) and allergists ($n = 53$) on the basis of affiliation with the American Academy of Pediatrics and the American Academy of Allergy, Asthma & Immunology/American College of Allergy, Asthma & Immunology, respectively, selecting for physicians from diverse geographic locations and clinical practice settings. Participants were invited to fill out an anonymous, 13-question, online survey. The survey included a sample or “mock” food allergy control tool as an illustration, exploring prospective domains of food allergy control (eg, reaction rate/severity, emergency medication/action plan, reducing cross-contamination, and HRQOL; see [Figure E1](#) in this article’s Online Repository at www.jaci-inpractice.org). Participants were asked about their experience managing food-allergic patients, whether they would use the control tool, and whether it would benefit patients, allergists, or PCPs. The study was exempted by the Stanford University institutional review board. Allergist and pediatrician responses were compared using a Fisher exact test.

The survey response rate was 51%, with subgroup response rates of 62% for allergists and 40% for pediatricians. Academic and community practitioners were adequately represented among allergists (45%, 42%) and pediatricians (57%, 44%). Most responders (59%) were in clinical practice for over 10 years (see [Table E1](#) in this article’s Online Repository at www.jaci-inpractice.org). Of the surveyed pediatricians, 84% spend 10 minutes or less making a food allergy diagnosis compared with 18% of allergists ($P < .001$). Similarly, 95% of pediatricians spend 10 minutes or less on food allergy counseling/education compared with 36% of allergists ($P < .001$). Approximately equal proportions of pediatricians and allergists addressed physical, logistic, and prevention aspects during a food allergy encounter. However, fewer pediatricians addressed HRQOL issues (zero pediatricians vs 58% of allergists; $P < .001$), therapy (upcoming strategies) versus avoidance (26% vs 85%, respectively; $P < .001$), or self-perception of control (43% vs 82%, respectively; $P < .004$). To maintain brevity, physicians were not asked how they addressed these domains.

All responders stated they would use the tool in some capacity. Furthermore, 79% of allergists and 65% of pediatricians indicated they would use the tool for all or most food-allergic patients ([Figure 1, A](#)). Allergists and pediatricians indicated that the tool would benefit allergists (85%, 87%), patients (91%, 78%), and PCPs (55%, 70%; [Figure 1, B](#)). Allergists and pediatricians suggested that the tool content should evaluate the number/severity of reactions (78%, 88%), the availability/carriage of emergency medications (94%, 74%), and the availability of an emergency/anaphylaxis action plan (85%, 65%). More allergists than pediatricians indicated that the tool should assess HRQOL concerns ([Table 1](#)) and patient/parent self-assessment of disease burden/control (76% vs 48%; $P = .05$). Conversely, more pediatricians than allergists recommended addressing medication restrictions due to food allergy (35% vs 12%; $P = .05$).

Although study limitations include small sample size and use of convenience sampling, our data indicate that pediatricians and allergists acknowledge the need for an ambulatory food allergy control tool that can be completed by patients/caregivers, help trend disease control over time, and target specific interventions. For example, surveyed pediatricians stated that they seldom have

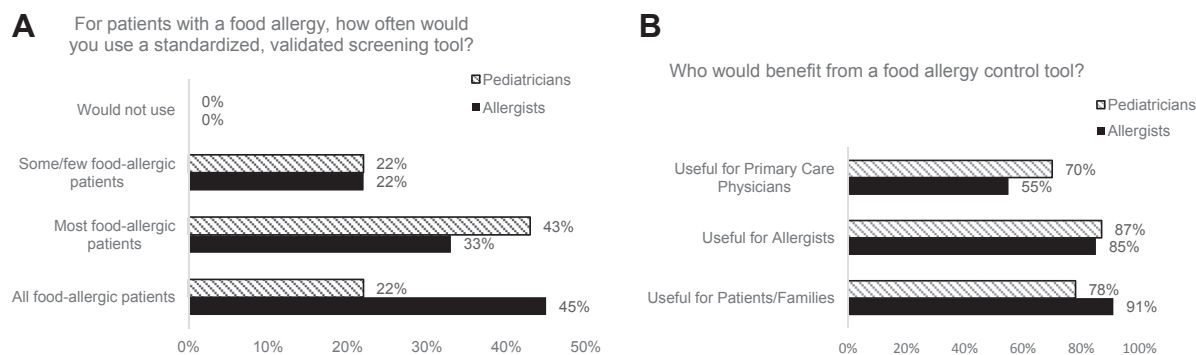


FIGURE 1. Allergist and pediatrician responses regarding the clinical utility of a validated food allergy control screening tool with respect to the frequency of use during food allergy encounters (**A**) and the perceived benefit for PCPs, allergists, and patients/families (**B**).

TABLE I. Suggested food allergy control tool content*

Content	Allergists, %	Pediatricians, %	P value
Number and severity of reactions	87.9	78.3	0.46
Availability/carriage of emergency medications	93.9	73.9	0.05
Competency/use of emergency medications	87.9	78.3	0.46
Availability of food allergy emergency/anaphylaxis plan	84.8	65.2	0.11
Understanding of food allergy emergency/anaphylaxis plan	75.8	69.6	0.76
Use of food allergy emergency communication tree	21.2	34.8	0.36
Cross-contamination risk (eg, comfort reading food labels)	63.6	47.8	0.28
Limitation on travel/activities/dinning out	63.6	34.8	0.05
Missed school/workdays	63.6	43.5	0.18
Growth/nutrition concerns	66.7	43.5	0.11
Fear of airborne/contact reaction	45.4	21.7	0.09
Psychosocial concerns (anxiety, bullying, etc)	78.8	30.4	<0.001
Ability to obtain allergen-free foods	57.6	39.1	0.19
Self-assessment/perception of control	75.8	47.8	0.05
Therapy vs avoidance	24.2	17.4	0.74
Prevention, eg, early introduction of high-risk foods	36.4	39.1	1
Comorbid conditions, eg, atopic diseases	48.5	47.8	1
Oral allergy syndrome	30.3	30.4	1
New-onset food allergies	42.4	26.1	0.26
Effect on medications (eg, lactose, Advair; Atrovent; soy)	12.1%	34.8%	0.05
Effect on other conditions (eg, latex and banana/avocado; shrimp and dust mites)	6.1%	21.7%	0.11
Complementary and alternative practices for diagnosing food allergy (eg, kinesthesiology)	6.1%	0.0%	1
Complementary and alternative practices for managing food allergy (eg, acupuncture)	6.1%	0.0%	1
Educational, eg, safely conducting activities of daily living	72.7%	56.5%	0.26

*Allergist and pediatrician responses to the following survey question: "Any clinical tool to address food allergy control should contain/cover the following" (select all that apply).

dedicated food allergy encounters and spend less than 10 minutes on food allergy counseling. Utilization of a food allergy control tool could focus the discussion on patient-centered, high-risk food allergy concerns. Despite several studies affirming poor HRQOL scores in patients,⁴ our survey showed that HRQOL concerns were addressed less than half, or none of the time during visits with allergists and pediatricians, respectively. Utilization of a food allergy control tool could identify specific interventions such as counseling for patients being bullied or referral to a dietician for poor weight gain.

As the doctrine of food allergy management evolves, medical providers and patients must evaluate emerging therapies and define disease control. Our survey endorses a need for, and the

utility of, an ambulatory tool to assess the degree of control in food allergy management. Initial feedback from pediatricians and allergists suggests that the food allergy control tool content should include assessment of reactions, prevention and management, and psychosocial/HRQOL issues. We will be embarking on the development of such a tool for cross-sectional and longitudinal assessment (Food Allergy Control Test [FACT], Stanford University, Stanford, CA) with appropriate stakeholder input and qualitative and quantitative validation studies.

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mock Food Allergy Control Test (FACT)

- Please answer these questions as honestly as possible. Your answers will help you and your doctor figure out whether your food allergy is as well controlled as it could be.
- In the past 4 weeks, how many food-related allergic reactions (other than worsening eczema) did you/your child **have**?
 - none
 - 1-2 reactions
 - 3-5 reactions
 - more than 5 reactions
 - In the past 4 weeks, how many food-related allergic reactions required **epinephrine or immediate medical attention** (911, Emergency Department, Urgent Care visit)?
 - none
 - 1-2 reactions
 - 3-5 reactions
 - more than 5 reactions
 - In the past 4 weeks, how often did you/your child **carry an epinephrine auto-injector**?
 - none
 - some days/situations
 - most days/situations
 - at all times
 - In the past 4 weeks, how many food-related allergic reactions (other than worsening eczema) were you/your child **able to anticipate and prevent**?
 - none
 - 1-2 reactions
 - 3-5 reactions
 - more than 5 reactions
 - In the past 4 weeks, how often **did you miss work/school or social activities/ travel** due to food allergy reactions/concerns?
 - never
 - less than half the time
 - about half the time
 - more than half the time
 - In the past 4 weeks, how often were there **concerns about you/your child's growth and nutrition** due to food allergy restrictions?
 - None
 - 1-2 times
 - 3-4 times
 - greater than 5 times
 - In the past 4 weeks, how often were you **unable to obtain alternate allergen-free foods** for you/your child?
 - None
 - 1-2 times
 - 3-4 times
 - greater than 5 times
 - In the past 4 weeks, how often have you felt **anxiety/fear about your/your child's food allergy**?
 - none
 - less than once per week
 - 2-4 times per week
 - daily
 - In the past 4 weeks, how often have you or your child **felt isolated from peers or bullied** due to food allergy related issues?
 - none
 - less than once per week
 - 2-4 times per week
 - daily
 - In the past 4 weeks, how would you/your child rate your **food allergy control**?
 - Not controlled
 - Poorly controlled
 - Somewhat controlled
 - Well controlled

Total score: _____

Examples of Possible Targeted Interventions Triggered by the Responses:

Question content/domain	Suggested Intervention(s)
Q 4. Anticipation and prevention of food reactions	• Education on cross-reactive allergens • Education on identification of "safe foods" • Early introduction of high-risk foods per guidelines • Supervised Oral Food Challenges • Consideration of desensitization therapies versus continued avoidance
Q 7. Inability to obtain alternate foods	• Uncovering economic and social barriers • Referral to social worker/other resources • Nutritionist referral
Q 8. Anxiety/fear	• Proximity Challenge Test • Referral to Psychologist • Food allergy advocacy/support groups

FIGURE E1. A “mock” food allergy control test created by the investigators and provided to survey participants to illustrate potential domains of food allergy control and targeted interventions.

TABLE E1. Participants' demographic characteristics and practice patterns

Characteristic	Allergists, n (%)	Pediatricians, n (%)
Survey participants	n = 33	n = 23
Time in practice (y)		
<10	17 (51.5)	6 (26.1)
11-20	7 (21.2)	8 (34.8)
>21	9 (27.3)	9 (39.1)
Practice setting		
Academic mostly clinical	15 (45.5)	13 (56.5)
Academic mostly research	3 (9)	0
Nonacademic mostly clinical	15 (42.5)	10 (43.5)
Industry	0	0
Other: nonacademic clinical + teaching affiliation	1 (3)	0
Frequency of food allergy encounters		
<10% of clinical encounters	0	9 (31)
10%-20%	8 (24.2)	14 (61)
21%-30%	6 (18.2)	0
31%-50%	10 (30.3)	0
>50%	9 (27.3)	0
Time per food allergy encounter spent on diagnosis (min)		
≤5	1 (3)	6 (26.1)
5-10	5 (15)	14 (61)
10-20	12 (36)	3 (13)
≥20	15 (45.5)	0
Time per food allergy encounter spent on education/counseling (min)		
≤5	3 (9)	7 (30.4)
5-10	9 (27.3)	15 (65.2)
10-20	16 (48.9)	1 (4.3)
≥20	5 (15.1)	0