



**Report: PCORI PAPER Training Videos Evaluation
December 2017**

In August 2017, AAFA contracted with Michael Pistiner, MD, MMSc, director of Food Allergy Advocacy, Education and Prevention at Massachusetts General Hospital, in Boston, MA, to narrate the PAPER online video series. Dr. Pistiner is also a medical advisory board member of Asthma & Allergy Foundation of America, New England Chapter and is a voluntary consultant for the Massachusetts Department of Public Health School Health Service Unit.

The PAPER online video series, posted on AAFA's website, <http://www.aafa.org/page/patient-engagement-in-asthma-research.aspx> is comprised of the following titles with associated behavioral objectives:

- *Asthma Basics*: Learn what asthma is, what happens during an asthma episode, and what asthma feels like.
- *Asthma Symptoms*: Learn about the most common symptoms of asthma and how asthma is diagnosed.
- *Different Levels of Asthma*: Learn about the four types of asthma and signs you could have uncontrolled asthma.
- *Warning Signs of an Asthma Attack*: Learn what the signs of a severe asthma attack and asthma zones. Learn what to look for and when to seek emergency medical help.
- *Asthma Triggers*: Learn about common asthma triggers which can cause your airway to become inflamed.
- *Asthma Treatment*: Learn about how a proper treatment plan can help you manage asthma. A treatment plan can include medicine, avoiding triggers, and following an Asthma Action Plan. In addition, you'll learn about the types of asthma medicine and how your involvement in research can improve future asthma treatments.
- *Why We Need Asthma Research*: You'll learn how research helps experts to better understand asthma and develop more effective treatment.
- *Finding Accurate Research Information*: Learn about how to be an active part of your medical care and how to find trustworthy medical information.
- *Outcome Measures*: Learn about what outcome measures are and what role they play in research results.
- *Clinical Research*: Learn about what clinical research is, who conducts the research and who can participate.
- *Clinical Trials*: Learn about the 4 phases of clinical trials and what your role could be in helping researchers find new treatments.

The entire video series can be watched at once in the 37:20 video titled, *How People with Asthma Can Influence the Future of Research*.

Video Reporting and Promotion

The online training video reporting period began on November 16 and continued through December 6, 2017. During this period, the videos were watched 2,796 times. AAFA utilized a diverse and comprehensive approach to promote the training videos, one that leveraged AAFA's significant online/social media presence. On Facebook alone, AAFA has 139,000 followers. AAFA promoted the *Understanding Asthma Research* video series by:

- Posting banners and promotional content on AAFA.org;
- Writing 6 articles about the PAPER project and posting them on AAFA's online blog and forums; and

- Promoting the PAPER project on Facebook through targeted paid advertising. AAFA boosted posts by targeting specific demographics and geo-locations (high poverty DMA or zip codes) and purchasing \$5,000 worth of Facebook advertising to target groups that often use severe asthma-related keywords such as "asthma", "asthma attack", "wheezing".
- Sending an invitation on November 20 via email to 34,564 AAFA subscribers. The email was opened by 5,984 of these subscribers.

Community PAPER Blog Articles

To promote the online videos, AAFA wrote and posted the following six *Understanding Asthma Research* blog articles onto its website and online forums:

- *Patient Involvement in Asthma Research Creates New and Better Treatments* was posted on November 16 and viewed 1,128 times.
 - <https://community.aafa.org/blog/patient-involvement-in-asthma-research-creates-new-and-better-treatments>
- *The National Institutes of Health* was posted on November 21 and viewed 72 times.
 - <https://community.aafa.org/blog/understanding-asthma-research-the-national-institutes-of-health>
- *Working with Your Health Care Providers* was posted on November 22 and viewed 40 times.
 - <https://community.aafa.org/blog/understanding-asthma-research-working-with-your-health-care-providers>
- *How Research is Prioritized* was posted on November 29 and viewed 57 times.
 - <https://community.aafa.org/blog/understanding-asthma-research-how-research-is-prioritized>
- *Informed Consent* was posted on November 30 and viewed 30 times.
 - <https://community.aafa.org/blog/understanding-asthma-research-informed-consent>
- *Get Involved* was posted on December 1 and viewed 75 times.
 - <https://community.aafa.org/blog/understanding-asthma-research-get-involved>

Facebook

Between November 16th and December 6th AAFA posted PAPER-related information 11 times and Kids With Food Allergies posted once to its more than 88,000 followers.

Twitter

During this same time period, AAFA posted PAPER-related information 12 times to its 8,198 followers and KFA posted twice to its more than 10,600 followers.

Survey Results

After watching each short video, participants were asked to complete a survey with 2 – 4 questions to assess their knowledge, attitudes and behaviors related to content within the video.

The survey also included demographic-related questions. For Video 12, the full-length compilation, respondents were asked the entire set of 15 questions.

AAFA received 424 survey responses across the 12 videos with a range of 198 to 11 responses. The largest number of responses came from Videos 1: *Asthma Basics* (198), 3: *Different Levels of Asthma*

(80) and 12: Compilation—*How People with Asthma Can Influence the Future of Research* (79). The majority identified as a patient with asthma (359 responses) or as a caregiver of a person with asthma (111 responses). The vast majority (87.3%) who watched Video 12 felt that it was extremely useful.

After watching the videos, the data suggest that respondents:

- Believe it is important to speak with their medical provider about asthma and triggers and that people with asthma to get involved with research;
- Are more likely to talk to a medical provider about asthma triggers and how to control them.
- Correctly identified cockroaches to be a common allergen that can trigger asthma symptoms;
- Feel confident that they can be active participants whenever they obtain healthcare;
- Know what the signs of an asthma attack are and that an asthma attack requires immediate medical attention; and
- Believe that an Asthma Action Plan can prepare them for a life-threatening asthma attack.

Survey Question Summary

Knowledge Questions

1. When your airways are inflamed, what can make it harder to breathe?
Correct Answer: All of the Above (*Airways become red and swollen, Airways produce extra mucous, Muscles tighten around airways*)
Video 1: 91.4% of respondents (181 people)
Video 12: 92.4 of respondents (73 people)
2. Which of the following is not a common asthma symptom?
Correct Answer: Headache
Video 2: 96.7% of respondents (29 people)
Video 12: N/A
3. Your asthma might be well-controlled if you use your reliever medicine 1 time a week.
Correct Answer: True
Video 3: 71.20% of respondents (57 people)
Video 12: 50.60% of respondents (40 people)
4. What are signs of a severe asthma attack, requiring immediate medical attention?
Correct Answer: All of the Above (*Fast breathing with chest retractions: skin sucks in or around chest plate, cyanosis: pale or blue face, lips, or fingernails, rapid movement of nostrils, stomach or ribs, expanded chest that does not deflate with exhaling*)
Video 4: 97.10% of respondents (33 people)
Video 12: N/A
5. Which of the following is a common allergen that can trigger asthma symptoms?
Correct Answer: Cockroaches
Video 5: 93.3% of respondents (14 people)

Video 12: 62% of respondents (49 people)

6. Using quick-relief medicine more than 2 times per week is a sign that asthma is not well controlled.

Correct Answer: True

Video 6: 100% of respondents (12 people)

Video 12: N/A

7. Asthma research can provide information on:

Correct Answer: All of the Above (*Causes of asthma, the effect of asthma on patients, the long-term effects of different asthma treatments*)

Video 7: 100% of respondents (12 people)

Video 12: 98.7% of respondents (78 people)

8. Which organization provides information about medical products or foods that maintain or improve health?

Correct Answer: US Food and Drug Administration (fda.gov)

Video 8: 100% of respondents (11 people)

Video 12: N/A

9. Which of the following is not an example of an asthma research outcome measure?

Correct Answer: How many patients enroll in a study.

Video 9: 61.5% of respondents (8 people)

Video 12: 63.30% of respondents (50 people)

10. Patient-reported outcome measures (PROMS) tend to focus on a patient or caregiver's quality of life.

Correct Answer: True

Video 9: 100% of respondents (13 people)

Video 12: N/A

11. A clinical trial might seek to prove a new asthma treatment works by giving the treatment to some and not to others.

Correct Answer: True

Video 11: 87.5% of respondents (14 people)

Video 12: N/A

12. Researchers must inform patients about the benefits and risks of participating in a clinical trial.

Correct Answer: True

Video 10: 94.4% of respondents (17 people)

Video 12: 94.9% of respondents (75 people)

Attitude Questions

13. After watching this video, my commitment to share what a severe attack feels like with key people has:

Ideal Answer: Increased

Video 1: 63.1% of respondents (125 people)
Video 12: N/A

14. I feel confident that nighttime asthma symptoms can be controlled.
Ideal Answer: Agree
Video 2: 73.3% of respondents (22 people)
Video 12: N/A
15. After watching this video, I am more likely to seek medical treatment for a severe asthma attack.
Ideal Answer: Agree
Video 2: 76.7% of respondents (23 people)
Video 12: This video has a slightly different question, so N/A.
16. After watching this video, I am more likely to seek medical treatment if asthma is not well controlled.
Ideal Answer: Agree
Video: N/A
Video 12: 75.9% of respondents (60 people)
17. After watching this video, my commitment to making sure I have an up-to-date Asthma Action Plan has increased.
Ideal Answer: Increased
Video 4: 79.4% of respondents (27 people)
Video 12: 77.2% of respondents (61 people)
18. After watching this video, I am more likely to talk to a medical provider about asthma triggers and how to control them.
Ideal Answer: Increased
Video 5: 93.3% of respondents (14 people)
Video 12: N/A
19. It is important to understand asthma triggers and how to avoid them to prevent asthma episodes.
Ideal Answer: Agree
Video 5: 100% of respondents (15 people)
Video 12: 97.5% of respondents (77 people)
20. It is important for people with asthma to get involved with research.
Ideal Answer: Agree
Video 7: 100% of respondents (12 people)
Video 12: N/A
21. It is important for people with asthma to get involved with research.
Ideal Answer: Agree
Video 11: 100% of respondents (15 people)
Video 12: N/A

22. It is important for patients and family members to participate in clinical trials.
Ideal Answer: Agree
Video 10: 83.3% of respondents (15 people)
Video 12: 75.9% of respondents (60 people)
23. It is important for asthma patients to be involved in the research process to help create the treatments that are needed.
Ideal Answer: Agree
Video 6: 100% of respondents (12 people)
Video 12: N/A
24. After watching this video, I am more likely to find out more about participating in asthma research.
Ideal Answer: Agree
Video 6: 75% of respondents (9 people)
Video 12: 68.4% of respondents (54 people);
25. I feel confident that I understand the seriousness of asthma.
Ideal Answer: Agree
Video 1: 92.3% of respondents (184 people)
Video 12: N/A
26. I feel confident that I can be an active participant whenever I am obtaining healthcare.
Ideal Answer: Agree
Video 8: 90.9% of respondents (10 people)
Video 12: N/A

Behavior Questions

27. An Asthma Action Plan can prepare me for a life-threatening asthma attack.
Correct Answer: Agree
Video 4: 91.2% of respondents (31 people)
Video 12: 92.40% of respondents (73 people)
28. After watching this video, I am more likely to find out more about participating in asthma research.
Ideal Answer: Agree
Video 6: 75% of respondents (9 people)
Video 12: 68.4% of respondents (54 people)
29. Because of what I saw in this video I am _____ to participate in a research study.
Ideal Answer: More likely
Video 10: 38.90% (7 people)
Video 12: N/A
30. After watching this video, I am more likely to find out more about participating in asthma research.

Ideal Answer: Agree

Video 11: 68.8% of respondents (11 people)

Video 12: 68.4% of respondents (54 people)

Demographics

Q13 I am a: (check all that apply)

- | | |
|---|--------------------------------|
| • Patient with asthma | 81% of respondents (64 people) |
| • Caregiver/parent of a patient with asthma | 19% of respondents (15 people) |
| • Family member of a patient with asthma | 19% of respondents (15 people) |
| • Write-In Response | 2.5% of respondents (2 people) |
| ○ Pediatric Nurse | |
| ○ Healthcare Provider | |

Q14 I (or my family member) was diagnosed with asthma (check all that apply)

- | | |
|---|----------------------------------|
| • less than a year ago | 1.3% of respondents (1 person) |
| • 1 to 3 years ago | 7.6% of respondents (6 people) |
| • 3 to 5 years ago | 6.3% of respondents (5 people) |
| • More than 5 years ago | 84.8% of respondents (67 people) |
| • Not applicable | 3.8% of respondents (3 people) |
| ○ not a patient/caregiver/family member | |

Evaluation of Videos

Q15 How useful did you find this video?

- | | |
|---------------------|----------------------------------|
| • Extremely useful | 43% of respondents (34 people) |
| • Extremely useful | 44.3% of respondents (35 people) |
| • Not very useful | 10.1% of respondents (8 people) |
| • Not at all useful | 2.5% of respondents (2 people) |