

2017 AAFA PCORI Trainings: Summary of Findings from Participant Survey

Overview

In 2016, the Asthma and Allergy Foundation of America (AAFA) received a PCORI (Patient-Centered Outcomes Research Institute) Engagement Award (Contract #2207-AAFA) to implement their initiative, *Training Patients with Asthma to Understand and Participate in Patient Centered Outcomes Research*. More specifically, with this funding, AAFA designed and conducted training sessions for asthma patients, family, and caregivers. The project sought to increase participant knowledge and confidence to be empowered to make informed decisions regarding asthma treatment, as well as introducing PCORI concepts and deepening understanding of research and the patient’s role in research. These sessions were developed through consideration of needs assessments and the results of a pilot field test.

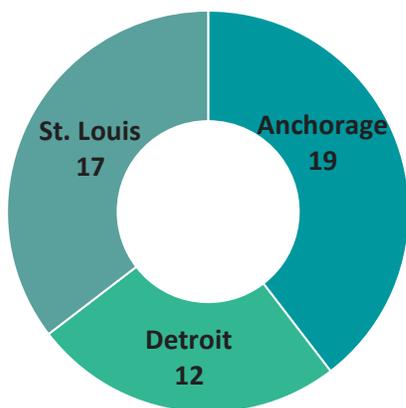
During each of the three sessions implemented in the spring of 2017, participants completed a pre-post knowledge assessment as well as a post-only satisfaction survey. The following report summarizes these findings. Appendix A presents a more detailed breakdown of the knowledge assessments; Appendix B presents a more detailed breakdown of the open-ended satisfaction survey responses.

Training Attendees

In 2017, AAFA sponsored a total of three PCORI trainings, with one training held in each of the following cities: April 2017 in Anchorage, AK (n=19); May 2017 in Detroit, MI (n=12); and June 2017 in St. Louis, MO (n=17).

In spring 2017, a total of 48 participants across three locations attended a PCORI training.

Chart 1: Participant Attendance (n=48)



A total of 48 participants attended the 2017 PCORI trainings. The Anchorage training had highest attendance with 19 participants, followed by St. Louis with 17 and Detroit with 12 participants. At each training, participants were asked to identify as either a patient, caregiver/parent, or family member. In Anchorage and St. Louis, multiple participants identified themselves as fitting more than one of these areas. The majority of Anchorage participants identified as caregivers/parents (n=12; 63%), with patients being most represented in Detroit and in St. Louis (n=6; 50% and n=10; 59%, respectively).

Nearly half of participants (41%) identified as a caregiver/parent with one-third (34%) identifying as a patient.

Chart 2: Participant Role as Caregiver/Parent, Patient, and/or Family Member (n=48)

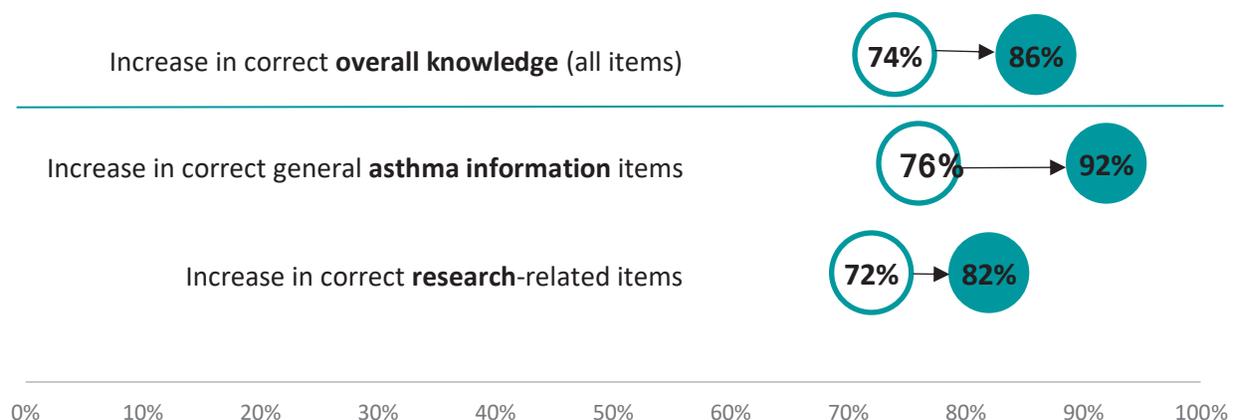


Pre-Post Knowledge Assessment Results

Both before and after the training session, participants completed a fifteen-question assessment designed to measure their knowledge in two areas: 1) general information about asthma, and 2) asthma research, including information about clinical trials and PCORI. These pre- and post-assessments were evaluated to analyze the effect the training had on participant knowledge related to the program curriculum. The overall average of all participant scores on the pre-assessment was 74% (n=48) with a post-assessment average of 86% (n=47), yielding a 12% increase in participants' demonstrated understanding of asthma and research.

From pre (○) to post (●), participants demonstrated an average increase of 12% on their knowledge assessment, with a post-test average of 86%. Among the two groups of items, those related to general asthma information rose by an average of 16%, while the research-related items rose by an average of 10%

Chart 3: Aggregate change in knowledge items correct from pre-test (n=48) to post-test (n=47)



As shown above, when comparing only the asthma information questions from pre to post, there was a 16% increase in average score from 76% to 92%. Most notably, there was a 35% increase in correct responses to the question, “Approximately how many people die from asthma in the U.S. every year?”, with 56% correct responses prior to training and 91% on the post-assessment.

When comparing only the research-related questions from pre to post, there was a 10% increase in average score from 72% to 82%. Among these items, the largest change in correct response (28%) was observed for the question, “Asthma research is important because...”, with 47% correct responses prior to training and 75% on the post-assessment.

For a detailed look at the change in percent correct for each item, please refer to **Appendix A**.

Training Satisfaction

Respondents used a one-to-five scale, 1-Low, 3-Medium, 5-High, to report the overall quality and value of the training. The majority of participants reported high overall quality and value of the training (72%; n=34) with less than one-fourth of participants (23%; n=11) reporting between medium and high value [scale response of 4]. (n=47)

The majority of participants (72%; n=34) reported high quality and value of the training.

Chart 4: Overall quality and value of the training (n=47)



Using a one-to-five scale, 1-Not at all, 3-Somewhat, 5-A lot, participants (n=47) reported the extent to which what they learned in the training session would help with their future healthcare decisions. More than three-fourths (77%; n=36) of respondents reported that the training session would help a lot.

77% of participants reported that knowledge gained from this training helped them a lot with respect to future healthcare decisions.

Chart 5: Extent to which knowledge from this training will help participants with future healthcare decisions (n=47)



Participants were also asked to report on their satisfaction with the length of the training on a one-to-five scale, 1-Too short 3-Just right, 5-Too long. Among the 46 respondents, the majority of participants reported that the length of the training session was just right (78%; n=36) with

22% (n=10) reporting between just right and too long [scale response of 4]. Additionally, the majority of respondents indicated Saturday mornings as the ideal timeframe for training sessions.

78% of participants reported that the length of the training session was just right.

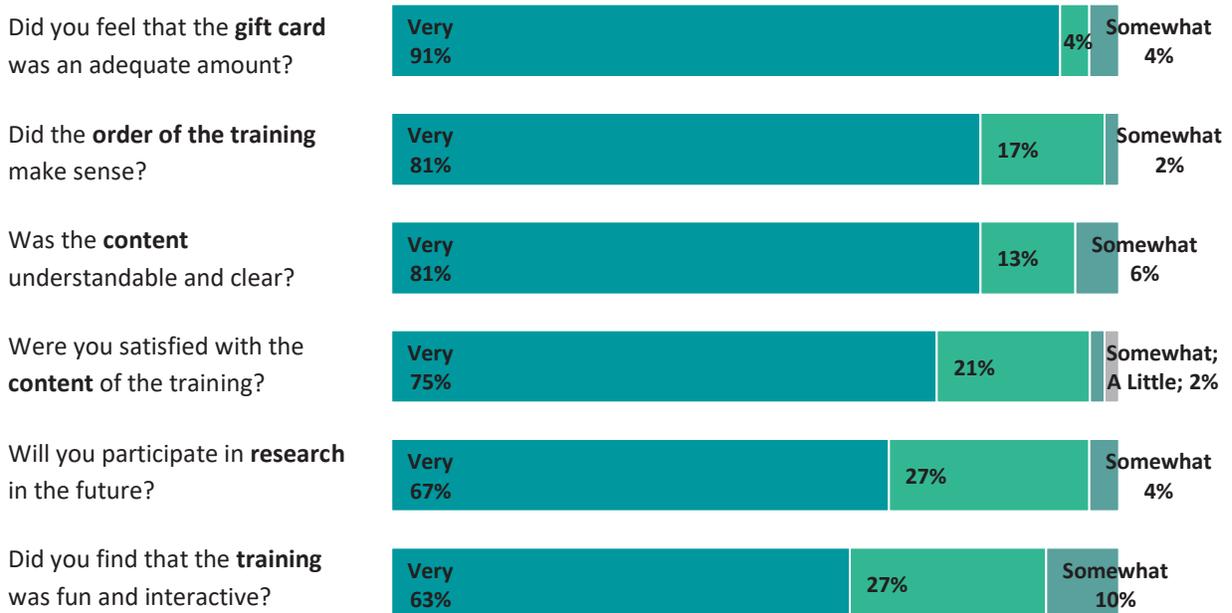
Chart 6: Satisfaction with length of training session (n=47)



Using a one-to-five scale, 1=Not at all, 3-Somewhat, 5-Very, participants were asked a set of six questions specifically related to the training session. These ranged from the quality and presentation of training content to the level of satisfaction with the incentive provided to participants. Participants responded positively to all six questions, with 91% reporting being very satisfied with the amount of gift card distributed as an incentive, 81% very satisfied with the order of the session, and 81% reporting that the content was very clear and understandable.

The vast majority of participants (81%) reported high satisfaction with the order of the training and clarity of content.

Chart 7: Satisfaction with training and clarity of content (n=47)



Open-Ended Responses

For a more detailed breakdown of the open-ended responses as well as direct quotes from participants, please refer to **Appendix B**.

LEARNING OUTCOMES

The evaluation included a space for participants to provide three open-ended responses to the prompt, “List three things you learned in this training.” From the 47 participants who responded to this item, 133 responses emerged. Five major themes emerged including general asthma information, research-related information, provider communication and treatment, available resources, and knowledge about PCORI.

FUTURE INTENTIONS

Participants were given space to share three open-ended responses to the prompt, “As a result of attending this training, I will do the following.” Among the 46 participants who responded to this item, 123 responses were generated. Five main themes emerged related to education of others, research engagement, and changes in behavior including provider communication and PCORI involvement.

TRAINING HIGHLIGHTS

Participants were given space to share three open-ended responses to the question, “What did you like most about the training?” Among the 47 participants who responded to this item, 108 responses were generated. Five main themes emerged relating to the informative content; the interactive nature of the session; the dynamic facilitators; the resources, activities, and development; and the structure of the program.

TRAINING CRITIQUES

Participants were also asked to share three open-ended responses to the question, “What did you like least about the training?” From the 23 participants who responded with something they liked the least, 41 responses were generated. Six main themes emerged relating to the accommodations; time management of the session; the information being too general and, in contrast, the information being too advanced or overwhelming; the communication and organization of the session; and the focus on clinical research. Notably, the majority of the feedback regarding the information being too general came from participants in the Anchorage training. The majority of feedback regarding the advanced and/or overwhelming information was reported by participants in the Detroit training.

RECOMMENDATIONS FOR IMPROVEMENT

Participants were also asked to share three open-ended responses to the question, “What about the training session could be improved?” From the 19 participants who responded with a suggested improvement, 35 responses were generated. Five main themes emerged relating to communication and structure, increased interaction, a more in-depth focus on asthma, accommodations, and providing State-specific information. Notably, only participants from the St. Louis training shared improvements related to accommodations, and more in-depth asthma information was only suggested by participants from Detroit and Anchorage.

Appendix A: Knowledge Assessment Items, Pre-to-Post

The below table lists each assessment item with aggregate pre-training scores (n=48) and post-training scores (n=47) as well as the change in percent correct. The items are listed in descending order beginning with the highest percent change. The highest percent change (35%) was seen for the item regarding the U.S. annual mortality rate attributed to asthma with a post-assessment average of 91% correct. Three items had post-assessment averages of 95%, including items regarding a warning sign of uncontrolled asthma, the focus of patient-defined asthma outcomes, and the main goal of clinical research. Due to the unmatched sample at pre- and post-test, small cohort, and pilot nature of the program, tests of statistical significance were not run.

Table 1: Pre-Post Comparison of percent of correct responses to all fifteen assessment items

KNOWLEDGE ITEMS	% CORRECT AT PRE	% CORRECT AT POST	CHANGE IN % CORRECT
a) Approximately how many people die from asthma in the U.S. every year?*	56%	91%	35%
b) Which group of people in the U.S. has the highest rate of asthma?*	64%	93%	29%
c) Asthma research is important because: ^	47%	75%	28%
d) A research plan is also called...^	27%	55%	28%
e) Medical treatment is different from clinical research because...^	62%	89%	27%
f) Asthma outcomes as defined by patients usually focus on...*	73%	95%	22%
g) An institutional review board (IRB) should...^	80%	89%	9%
h) Informed consent during the research process must be signed by participant showing that the participant was given information on...^	87%	93%	6%
i) Goals of asthma treatment include which of the following...^	80%	86%	6%
j) When a patient has chronic asthma this usually means that asthma will be present...^	89%	93%	4%
k) Asthma patients experiencing asthma that is NOT well controlled might have the following warning sign...^	93%	95%	2%
l) Clinical researchers have many reasons for doing research. The main goal usually is...^	98%	95%	(-3%)
m) Webster Dictionary defines research as...^	87%	84%	(-3%)
n) The best way for proving that a medical treatment or approach works is...^	71%	68%	(-3%)
o) Clinical research is usually defined as the study of health and illness in...^	91%	86%	(-5%)
Average	74%	86%	12%

*Asthma-related items; ^Clinical research items

Appendix B: Open-Ended Responses

The following series of pages present the key themes and selected quotations from each of the open-ended responses in the survey, by item.

Learning Outcomes

Themes and select responses to: “List three things you learned in this training”

<p>General asthma information 38%</p>	<p><i>“What happens inside your body during an asthma attack”</i></p> <p><i>“Most deaths by asthma can be prevented”</i></p> <p><i>“Signs and triggers”</i></p> <p><i>“Inflammation problems”</i></p> <p><i>“I really didn’t know that people were allergic to food”</i></p> <p><i>“How to prevent asthma symptoms”</i></p>
<p>Research-related information 26%</p>	<p><i>“How ethics in regards to research have changed for the better”</i></p> <p><i>“How to participate in clinical research”</i></p> <p><i>“Steps in a clinical study”</i></p> <p><i>“Technique to research for my own and others benefit”</i></p>
<p>Provider communication and treatment 18%</p>	<p><i>“Ask questions – ALWAYS”</i></p> <p><i>“How to regulate your asthma”</i></p> <p><i>“The important of daily medications”</i></p>
<p>Available resources 10%</p>	<p><i>“How to find the best information”</i></p> <p><i>“Organizations to contact about asthma”</i></p>
<p>Knowledge about PCORI 6%</p>	<p><i>“PCORI – from the Affordable Care Act – Awesome!”</i></p>

Future Intentions

Themes and select responses to: “As a result of this training, I will do the following...”

<p>Individual behavior changes 30%</p>	<p><i>“Feel more confident discussing asthma”</i></p> <p><i>“Be more of an advocate for myself and my own asthma”</i></p> <p><i>“Maintain my own care”</i></p> <p><i>“I will substantially take my asthma a lot more seriously”</i></p> <p><i>“Take an active role in my health care”</i></p>
<p>Engage in / promote asthma research 25%</p>	<p><i>“Participate in research studies”</i></p> <p><i>“Do more research for self and family”</i></p> <p><i>“I will volunteer to be a part of a clinical study”</i></p> <p><i>“Review and compare research articles”</i></p> <p><i>“Provide evidence based research”</i></p>
<p>Educate others about asthma / research 23%</p>	<p><i>“Use the information I learned to today to educate myself and my [patients] and coworkers”</i></p> <p><i>“Be a resource”</i></p> <p><i>“Inform my siblings who have it”</i></p> <p><i>“Help others to get information to prevent asthma attacks”</i></p>
<p>Change communication with health care provider 13%</p>	<p><i>“Ask more questions”</i></p> <p><i>“More informed conversations with my healthcare provider”</i></p>
<p>Get involved with PCORI 5%</p>	<p><i>“Spread the word of AAFA and education events”</i></p>

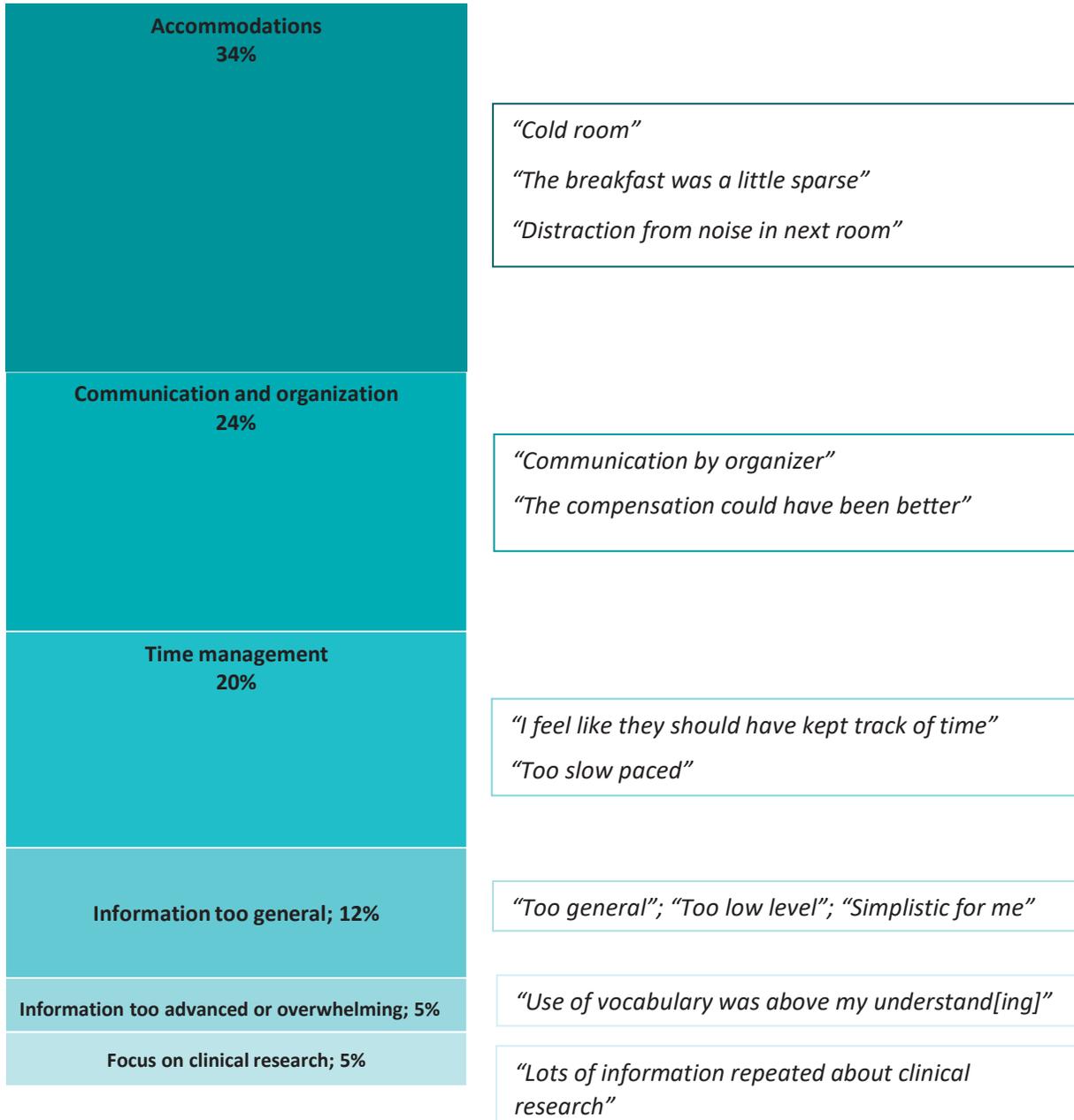
Training Highlights

Themes and select responses to: “What did you like most about the training?”

<p>Informative content 30%</p>	<p><i>“There was no stone unturned”</i></p> <p><i>“Tells uneducated people how to read research”</i></p> <p><i>“The quality and wealth of the information”</i></p> <p><i>“The abundance of information”</i></p>
<p>Dynamic facilitators 27%</p>	<p><i>“Presenters knowledgeable and well skilled”</i></p> <p><i>“Speakers were engaging, answered questions and explained clearly”</i></p> <p><i>“Speakers were fantastic”</i></p>
<p>Structure of the program 19%</p>	<p><i>“It was very well organized and easy to follow”</i></p> <p><i>“Being able to ask questions openly while presentation was going on”</i></p>
<p>Resources, activities, and development 13%</p>	<p><i>“Gives lots of research resources”</i></p>
<p>Interactive nature of the session, 8%</p>	<p><i>“The fact that everyone participated in the workshop”</i></p>

Training Critiques

Themes and select responses to: “What did you like the least about the training?”



Recommendations for Improvement

Themes and select responses to: “What about the training session could be improved?”

