

Life with EoE:

The Patient Experience
and Opportunities
to Improve Care
in the U.S.

Eosinophilic

Esophagitis



Asthma and Allergy
Foundation of America



Kids with Food Allergies

Apfed

American Partnership
for Eosinophilic Disorders

Life with EoE: The Patient Experience and Opportunities to Improve Care in the U.S.

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About the Asthma and Allergy Foundation of America (AAFA)

Founded in 1953, AAFA is the oldest and largest nonprofit patient organization dedicated to saving lives and reducing the burden of disease for people with asthma, allergies, and related conditions through research, education, advocacy, and support. AAFA empowers patients and their families by providing practical, evidence-based information and community programs and services. For more information, visit aafa.org.

About the American Partnership for Eosinophilic Disorders (APFED)

The American Partnership for Eosinophilic Disorders (APFED) is a non-profit organization with a mission to passionately embrace, support, and improve the lives of patients and families affected by eosinophil-associated diseases through education and awareness, research, support, and advocacy. For more information, visit apfed.org.

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The views and opinions expressed in this report are those of the study participants and the AAFA/APFED authors and do not necessarily reflect the policies or positions of other individuals, organizations, or companies.

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Introduction

Eosinophilic esophagitis was first characterized in 1993. In the 30 years since the disease was recognized, research has increased significantly.¹ It is currently described as an allergic reaction to a food or environmental allergen that causes inflammation in the esophagus, leading to narrowing and scarring.²

EoE is increasingly recognized as a cause of dysphagia (difficulty swallowing), food regurgitation (spitting up food), and food impaction (food getting stuck in the throat), with an estimated prevalence of 1 out of 2,000 people in the United States,³ and 50–100 per 100,000 individuals worldwide.⁴ In the U.S., the estimated annual health care cost for EoE is as much as \$1.4 billion, underscoring the significant economic toll and disease burden.⁵

EoE significantly impacts patients and their families physically, socially, mentally, and financially.^{6,7} People living with EoE face many challenges throughout their disease journey. The process of diagnosis can be lengthy and frustrating for people with EoE.^{8,9} Symptoms may not be readily recognized by people experiencing them, and when medical care is finally sought, a person may then experience dismissal of symptoms by their doctor, multiple clinic visits with different specialists, and misdiagnoses.

Dietary restriction, one of the recommended treatments, is burdensome to patients and their family members,⁷ particularly without access to ancillary services such as a registered dietitian. Food is an integral part of life and dietary restrictions due to EoE can negatively impact activities such as dining out, holidays, family gatherings, social or professional engagements, and travel.

People with EoE also encounter barriers to accessing pharmacological treatments.¹⁰ Proton pump inhibitors and topical corticosteroids are two pharmacological treatments often prescribed to treat EoE; however, they are not specifically indicated for EoE treatment. Patients who are prescribed off-label budesonide are instructed to mix it into a slurry with various carrier ingredients, such as artificial sweetener or applesauce, or take a prescription to a compounding pharmacy for mixing. Patients who are prescribed dupilumab (a biologic therapy and the only FDA-approved treatment for EoE at the time of this publication) may encounter barriers to access such as insurance requirements, which can further delay treatment.

This report looks at insights from patients, caregivers, and health care providers to highlight the current state of EoE care in the United States—including challenges and barriers to timely diagnosis, quality medical care, effective treatments, and access to resources for EoE. These challenges also present opportunities to address the unmet needs and improve future care for people living with eosinophilic esophagitis in the United States.



What is EoE?

Eosinophilic esophagitis (EoE) is a chronic inflammatory condition of the esophagus (the tube that connects the mouth to the stomach). It is characterized by excessive numbers of eosinophils, a type of white blood cell, that have accumulated in the esophagus.

The inflammation caused by the eosinophils damages the surrounding tissue. Left untreated, EoE may cause the esophagus to narrow, contributing to food impactions.

EoE can make eating difficult and painful. It affects people of all ages, genders, and ethnic backgrounds, but is more prevalent in adults than children and more prevalent in men than women.

People with EoE commonly have other atopic conditions such as food or environmental allergies, asthma, and/or eczema. Certain families may have an inherited tendency to develop EoE.



Key Findings

Due to the breadth of topics covered by this study, data from the patient/caregiver interviews, patient/caregiver survey, and health care provider (HCP) survey provided a great deal of insights into patient/caregiver and HCP experiences, beliefs, and knowledge. Throughout this report, data presented will focus on the following key findings in seven areas: diagnosis, symptoms, medical care, treatments, disease management, psychosocial impact, and resources.

Many patients experience delays in diagnosis for EoE, leading to delayed symptom relief, clinical care, and treatment.

- The majority of patients/caregivers (53%) said it took a year or more for them to receive an EoE diagnosis, including 14% who indicated it took more than 10 years to get diagnosed.
- Challenges to timely and accurate diagnosis include having to see multiple doctors before finding one knowledgeable in EoE, experiencing initial misdiagnoses, not recognizing symptoms as indicative of an underlying condition, and doctors dismissing symptoms.
- The majority (87%) of non-GI HCPs reported that non-responsiveness to PPI would prompt referral to a GI specialist for diagnosis of EoE (contradicting updated consensus recommendation to remove PPI as a diagnostic tool¹⁴).

Signs and symptoms of EoE are not well-understood and mimic many other diseases, further delaying EoE diagnosis.

- The most challenging symptoms reported by patients vary significantly by age.
- Lack of awareness of EoE symptoms among patients/caregivers and HCPs is a key driver of delayed diagnosis.
- HCPs reported that the most common reason for delayed diagnosis is that patients learn to cope with symptoms (64%).

Multidisciplinary care teams are common for EoE management.

- Patients/caregivers see multiple HCPs for EoE; four in five (81%) reported seeing a GI doctor, three in five (62%) reported seeing an allergist/immunologist, and two in five (38%) reported seeing a PCP.
- Two thirds of patients/caregivers reported seeing more than one type of doctor for EoE; one in eight (13%) reported seeing four or more doctors for EoE. Children were more likely than adults to see multiple doctors for EoE.
- HCPs reported high levels of collaboration between GI doctors, allergists/immunologists, PCPs, and dietitians/nutritionists.

EoE=eosinophilic esophagitis; GI doctor=gastroenterologist; HCP=health care provider; PCP=primary care physician; PPI=proton pump inhibitor

Limited options in FDA-approved treatments for EoE leads to frustration and challenges.

- Elimination diets, PPI, and topical steroids were commonly-reported treatments for EoE, but patients/caregivers and HCPs reported concerns and challenges with all treatments.
- Efficacy, side effects, and doctor recommendation were reported as the three most important factors for patients/caregivers when choosing a treatment option.
- Though patient/caregiver awareness of emerging treatments was low, patients/caregivers said they are likely to participate in clinical trials if asked.
- Though biologics are a new treatment option for EoE, patients/caregivers who have tried a biologic report high utility of treatment.

Adherence to treatment plans—particularly dietary therapies—poses the greatest challenge in managing EoE.

- Nearly two thirds (64%) of patients/caregivers indicated diet management as one of the biggest challenges in managing EoE. Two in five (38%) cited the effectiveness of care and treatment as challenges.
- HCPs reported patient adherence to treatment plans as the biggest challenge with EoE management; with reported adherence to dietary therapy significantly lower than pharmacological treatment.
- Other reported challenges were related to financial impact, such as the cost of treatment, formula, and specialty food, as well as issues with insurance coverage for EoE treatments.

EoE has a significant impact on social and emotional well-being.

- Patients/caregivers reported a sense of “mourning” following diagnosis related to the impact of EoE on diet, eating habits, and social activities.
- Patients reported that EoE has a high impact on emotional health (35%) and social life (34%). Caregivers and HCPs reported higher perceived impact on patients.
- The majority (66%) of HCPs reported that their patients with EoE typically experience anxiety and/or depression more than once a year.

Patients/caregivers and HCPs acknowledge a greater need for support and resources for EoE.

- Patients/caregivers were dissatisfied with general awareness of EoE (57%), financial resources to support medical care (51%), and social and emotional support (43%).
- Patients/caregivers expressed a need for comprehensive resources that cover everything from symptoms to treatment options. They also stressed the need for resources to manage EoE at various stages of the patient journey.
- HCPs were dissatisfied with the availability of insurance reimbursable expenses for patient diagnostics or treatments (37%), awareness/education of EoE among other HCPs (35%), and availability of knowledgeable ancillary service providers such as dietitians and psychologists (30%).
- HCPs expressed a need for better educational materials to provide patients with EoE.

EoE=eosinophilic esophagitis; GI doctor=gastroenterologist; HCP=health care provider; PCP=primary care physician; PPI=proton pump inhibitor

Study Design

Objectives

Beginning in 2022, the Asthma and Allergy Foundation of America (AAFA) and the American Partnership for Eosinophilic Disorders (APFED) conducted a multi-component cross-sectional needs assessment study for eosinophilic esophagitis (EoE).

This study aimed to:

- Understand the current state of EoE care in the U.S.
- Understand the patient journey for EoE
- Understand health care providers' awareness of and practice around EoE
- Identify unmet needs for EoE patients and family members
- Identify unmet needs for health care providers caring for EoE patients

This report uses insights from the needs assessment to identify and provide opportunities for improving EoE care in the United States.

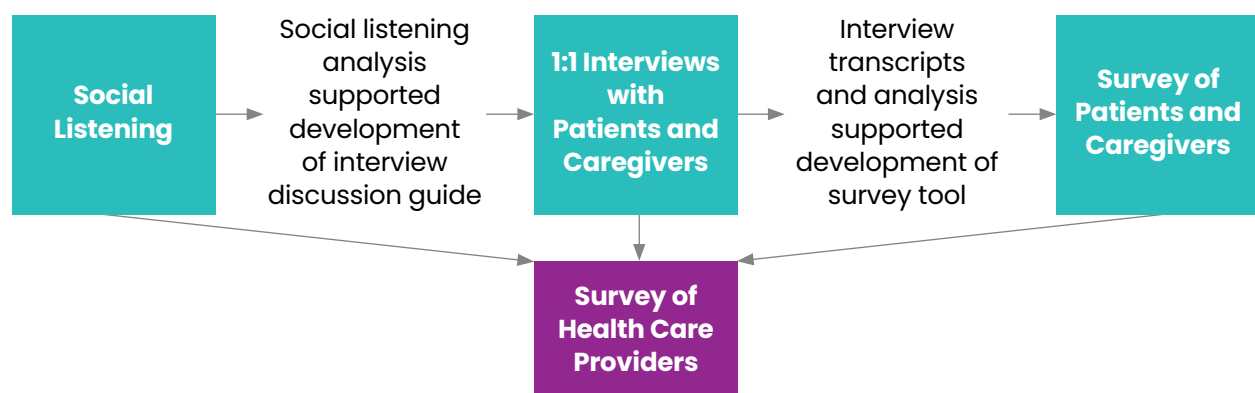
Methodology

This study involved several components. To get an understanding of EoE from the patient perspective, AAFA and its Kids with Food Allergies (KFA) division first conducted social listening through its communities and channels. This included insights from peer-to-peer conversations on AAFA and KFA online patient communities, conversations on social media, and incoming requests through AAFA's Support Center and Ask the Allergist service.

AAFA used the findings from the social listening analysis to develop a conversation guide for one-on-one semi-structured interviews with patients and caregivers. Interview participants were recruited through a targeted list of EoE patients and caregivers in AAFA's community. Additional interviewees were identified through APFED membership.

Using the findings from the patient and caregiver interviews, AAFA and APFED developed a survey tool to collect more information from EoE patients and caregivers. Invitations to complete the survey were sent to AAFA and APFED community members, social followers, and email subscribers.

Finally, AAFA and APFED developed a survey for health care providers who treat patients with EoE. AAFA and APFED contracted a sample through Dynata, and additional invitations were sent to targeted APFED contacts.



	Patient and Caregiver Interviews	Patient and Caregiver Survey	Health Care Provider Survey
Mode	Semi-structured, 1:1 virtual interview	Online survey	Online survey
Average Length	31 minutes	13 minutes	12 minutes
Dates	February 2–18, 2022	June 14–July 18, 2022	February 7–March 18, 2023
Qualification Criteria	<ul style="list-style-type: none"> • Have EoE or be the primary caregiver to someone with EoE • Live in the U.S. 	<ul style="list-style-type: none"> • Have EoE or be the primary caregiver to someone with EoE • Be over the age of majority in their state of residence • Live in the U.S. 	<ul style="list-style-type: none"> • Be a health care provider • Have at least 1% of patient base diagnosed with EoE • Practice in the U.S.

About this Report

This document focuses on select data from the patient/caregiver survey and the health care provider (HCP) survey. Throughout this report, most of the graphs represent the aggregated results of N=160 respondents from the patient/caregiver survey and N=110 respondents from the HCP survey.

Percentages shown in the graphs have been rounded and may not always equal 100. At times, we have analyzed various subgroups of respondents or combined results of similarly worded questions from both surveys.

To better capture the patient and caregiver voice directly, we have also included quotes from interview participants as well as open-text responses from survey respondents. Quotes have been edited for length and clarity.

Throughout the report, we use the following icons to identify the source of information:

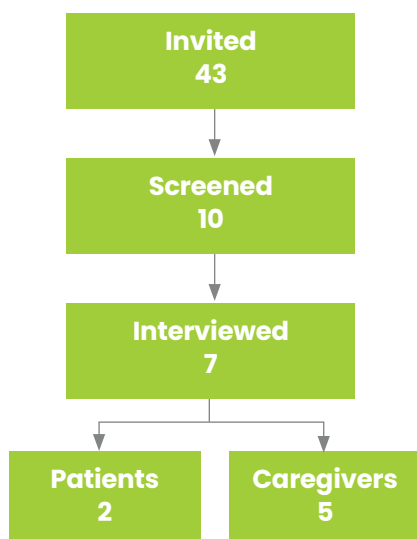


It is important to note that this survey is not representative of the U.S. population or the reported demographics of people with EoE. We acknowledge there may be selection bias in that the members of AAFA and APFED's communities who responded to the survey may be significantly impacted by EoE or related diseases and therefore may be most motivated to participate. Additional limitations are addressed on page 60.

Study Sample

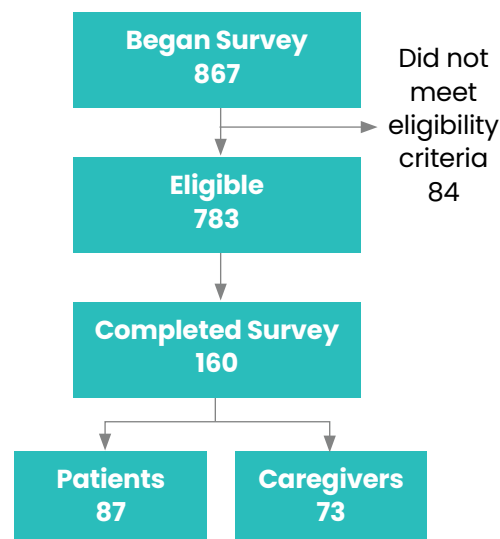
Patient and Caregiver Interviews

AAFA and APFED invited 43 candidates to participate in the interviews. After screening 10 respondents, we interviewed 7 patients and caregivers for the study.



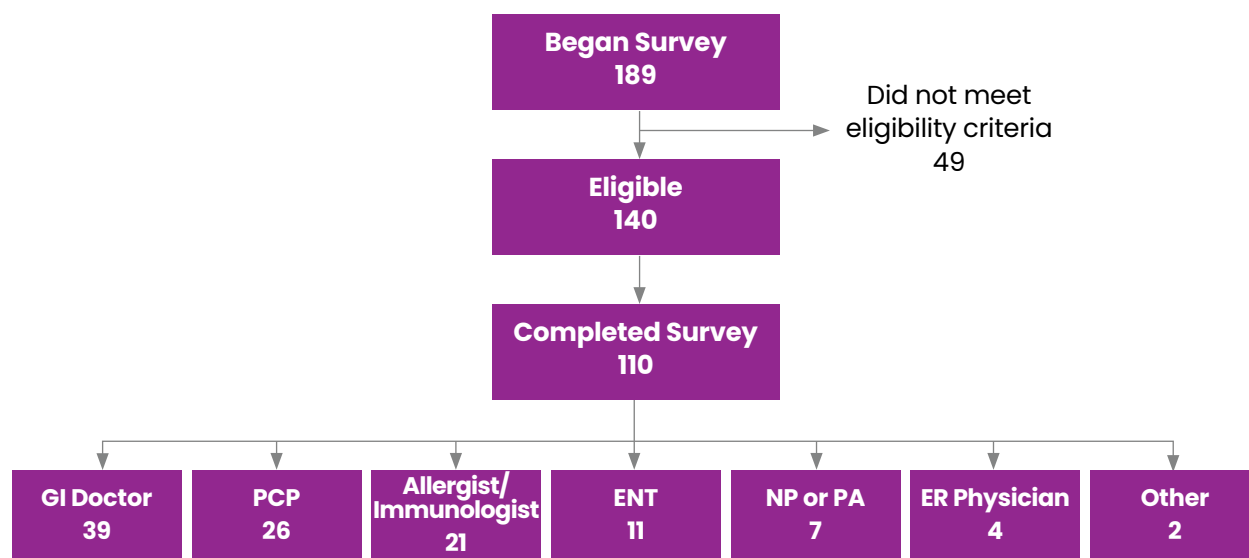
Patient and Caregiver Survey

There were 867 people who began the patient and caregiver survey. Based on self-reported diagnoses and location, 160 people qualified and completed the survey.



Health Care Provider Survey

There were 189 people who began the HCP survey. Based on self-reported percentage patient base with EoE, 140 people qualified for the survey and 110 completed the survey. Among those who completed the survey, 39 were gastroenterologists (GI doctor), 26 were primary care physicians (PCP), 21 were allergists/immunologists, 11 were ear, nose, and throat (ENT) doctors, seven were nurse practitioners (NP) or physician assistants (PA), four were emergency room (ER) physicians, and two identified as other types of HCPs.

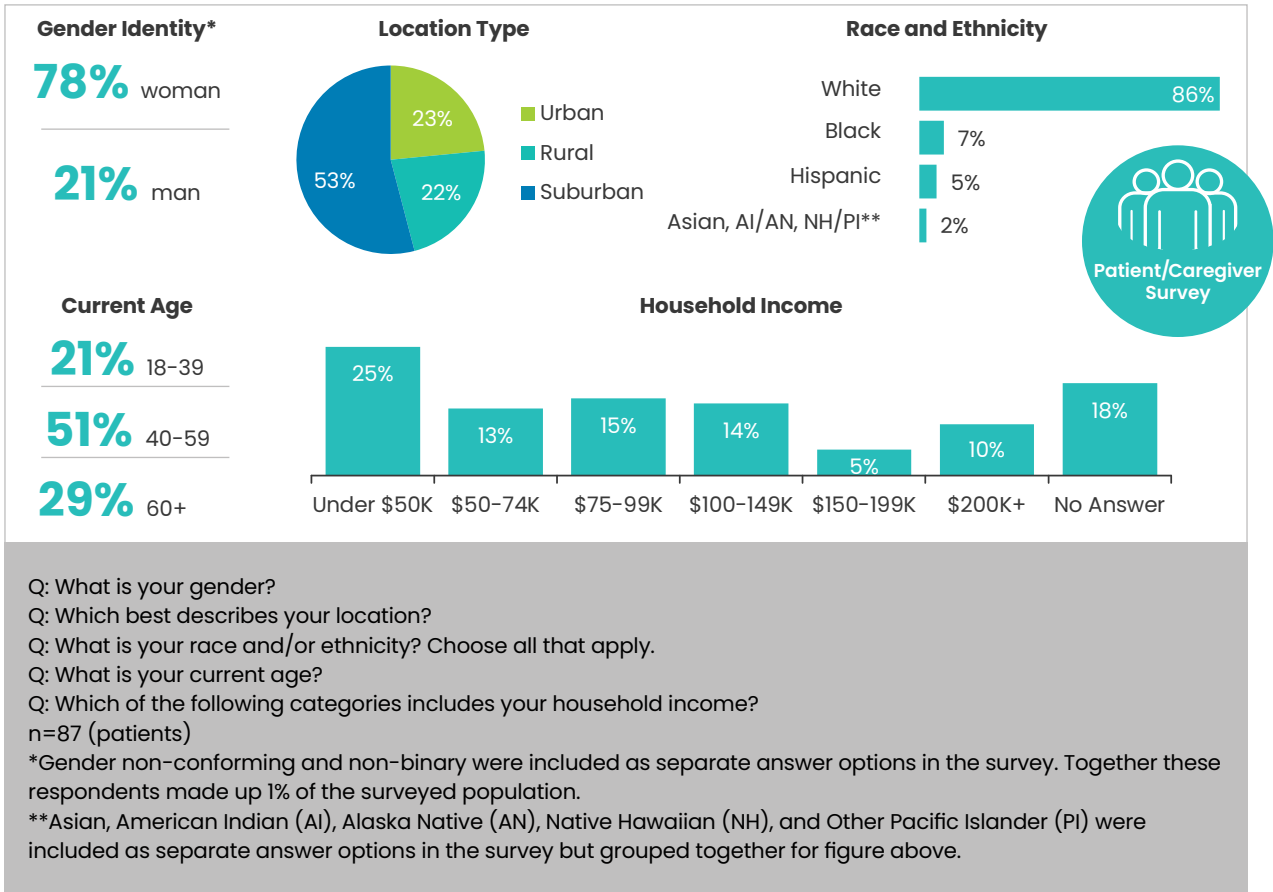


Overview of Respondents

Patient and Caregiver Respondents

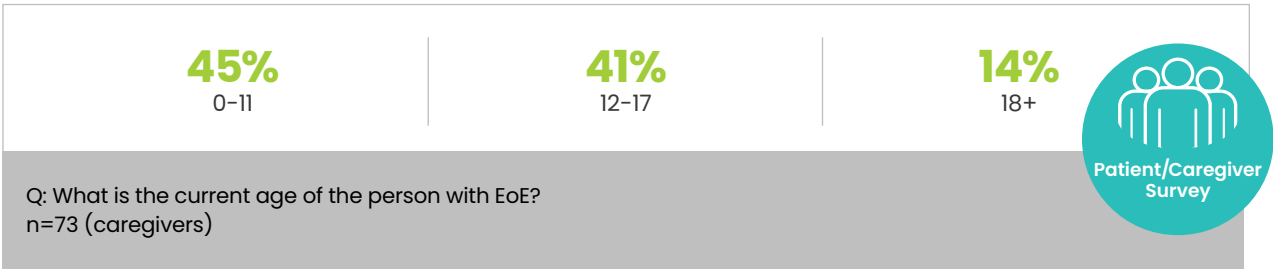
A vast majority of adult patient survey respondents self-identified as white and as women. While EoE is reportedly more common in white populations,¹¹ it is more prevalent in men than women.¹² The majority of patients indicated they live in suburban areas, and the majority of patients were between 40–59 years old at the time of the survey. Reported household incomes for respondents were distributed evenly.

Figure 1. Adult Patient Respondent Demographics



Caregiver responses were split evenly among caregivers of children 0–11 years old (45%) and caregivers of children 12–17 years old (41%). About one in seven (14%) caregiver respondents were caregivers to adults 18 years and older with EoE.

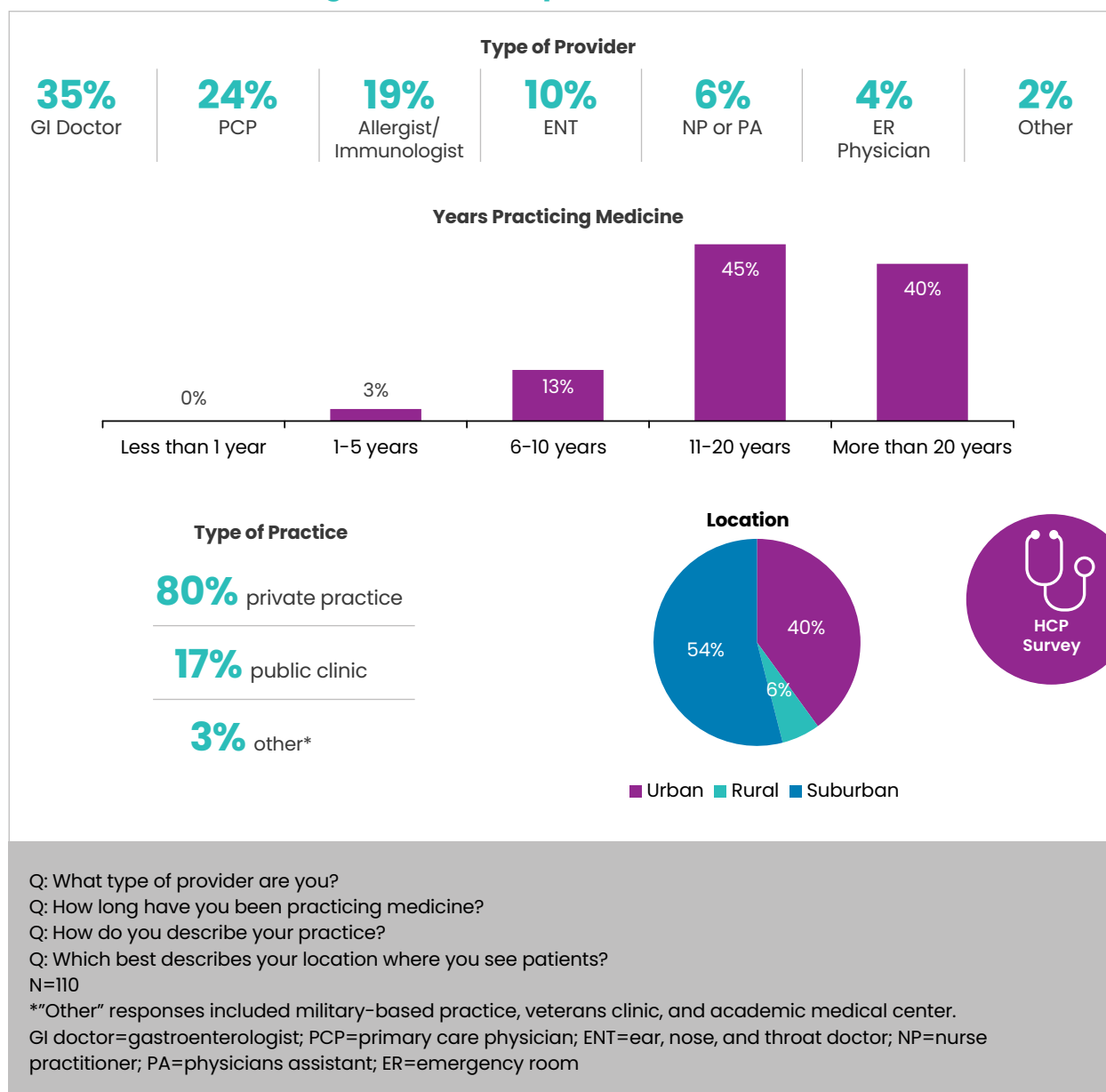
Figure 2. Current Age of Person with EoE (Caregivers)



Health Care Provider Profiles

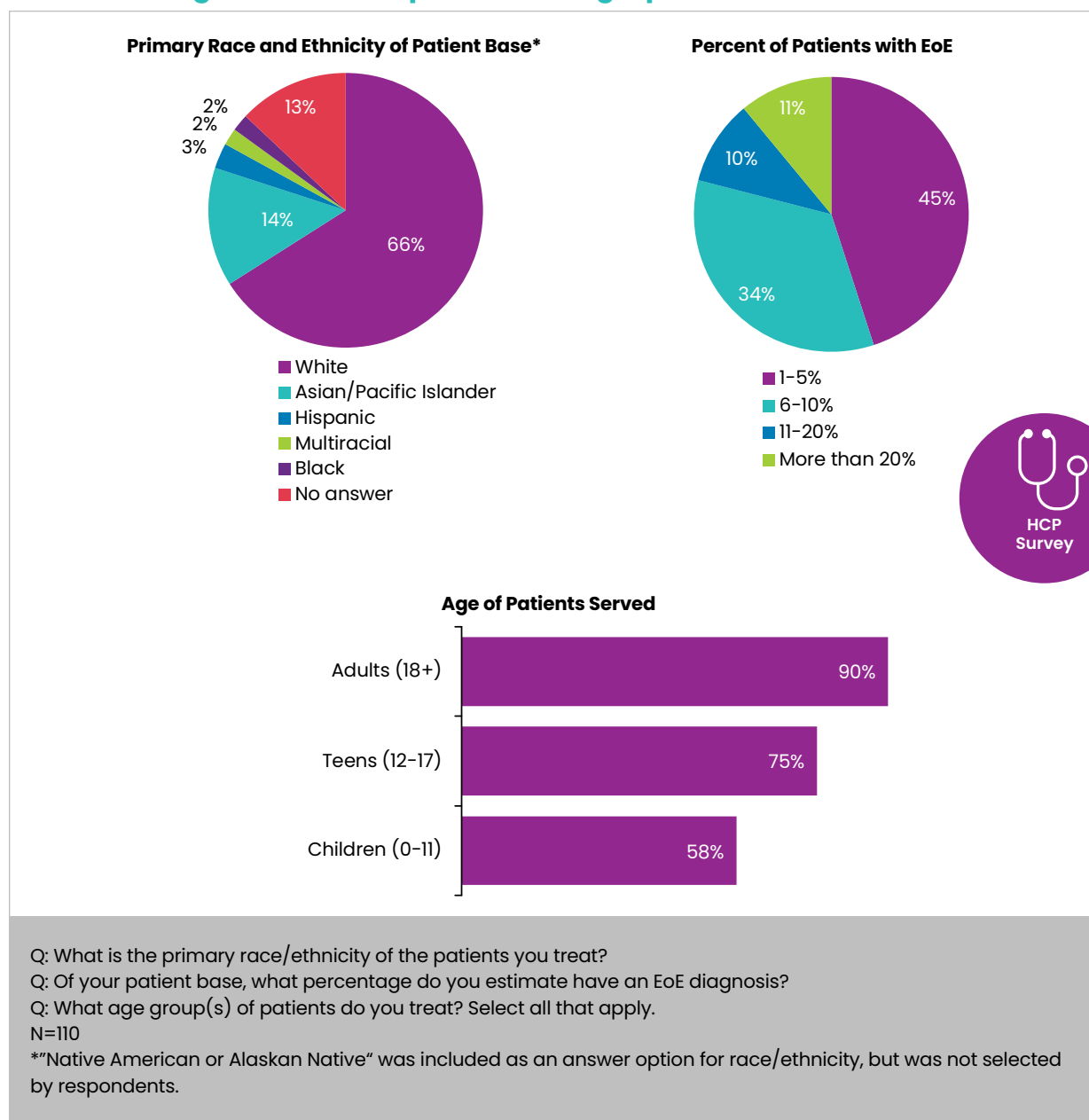
AAFA and APFED sampled for certain provider types in order to get a range of experiences from different health care providers who treat EoE. One third of respondents (35%) were GI doctors, one quarter (24%) were primary care physicians, and one fifth (19%) were allergists/immunologists. To qualify for the survey, HCPs had at least 1% of patient base diagnosed with EoE. A vast majority (85%) have been practicing medicine for over a decade. Four in five (80%) work in private practice. Nearly all practice in suburban (54%) or urban (40%) areas. No qualification criteria were set for years practicing medicine, type of practice, or location of practice.

Figure 3. HCP Respondents Overview



The HCPs in this study treated adults, teens, and children with EoE. The majority of HCPs (66%) reported that their patient base was primarily white, but others reported seeing patients who are Asian/Pacific Islander (14%), Hispanic (3%), Black (2%), and multi-racial (2%).

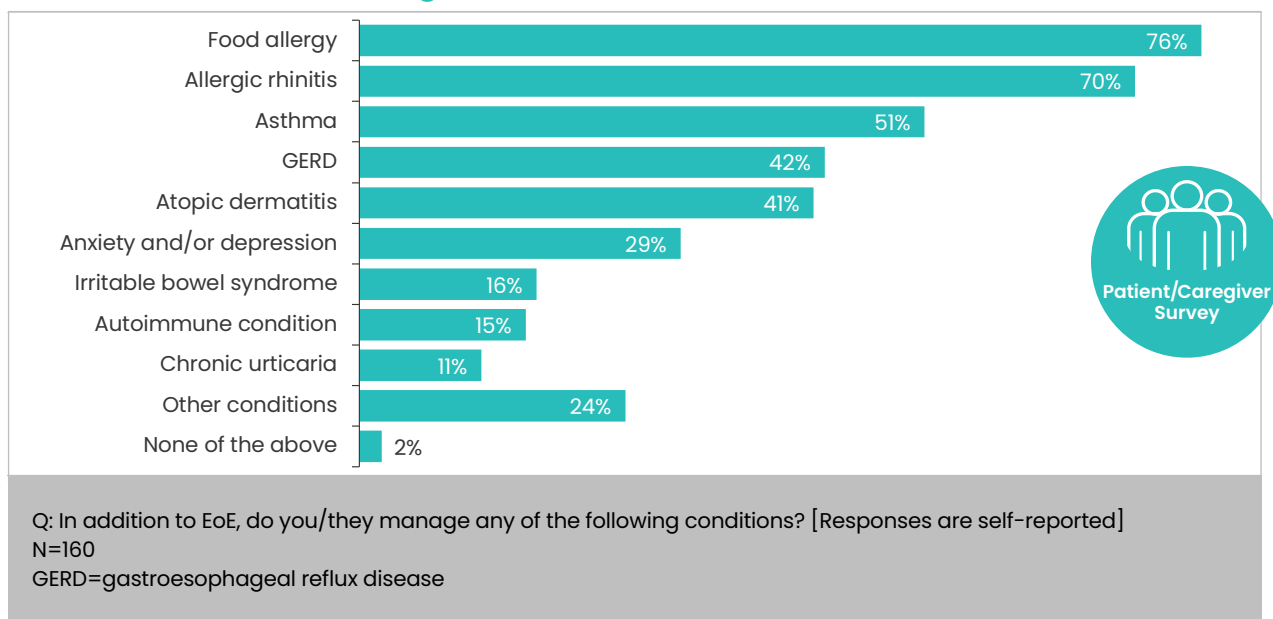
Figure 4. HCP-Reported Demographics of Patient Base



Comorbid Conditions

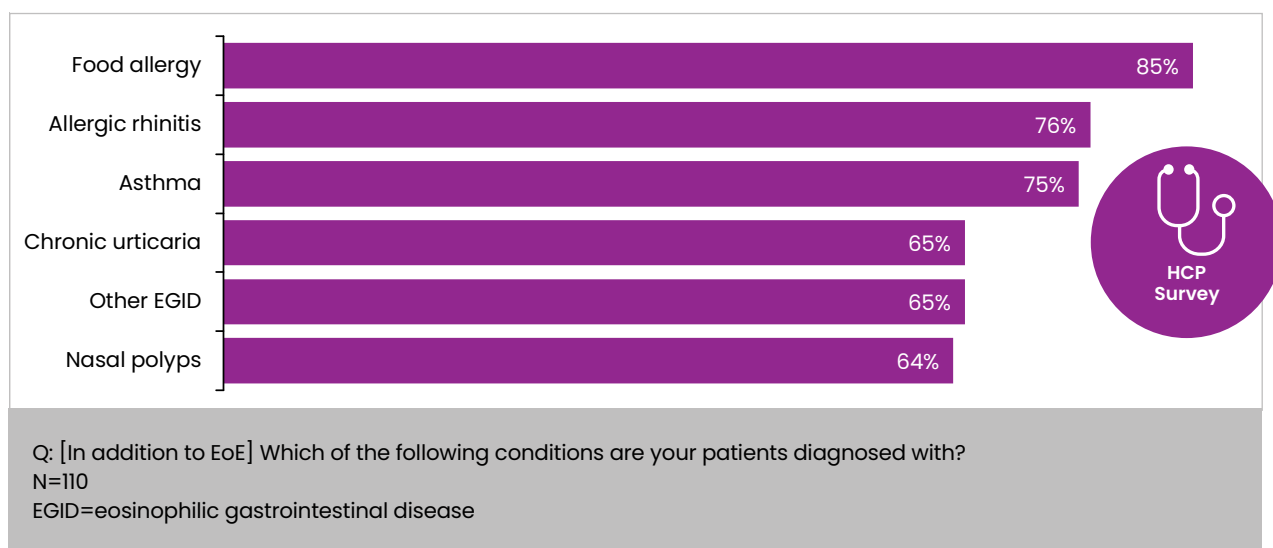
Many people with EoE also have other allergic conditions, such as environmental allergies (allergic rhinitis), food allergies, asthma, and eczema.¹³ These related conditions are driven by type 2 inflammatory response (see page 20). In this study, the most common comorbid conditions were food allergy (76%) and allergic rhinitis (70%). The majority (51%) manage asthma as well. One quarter (24%) of respondents reported having “other” comorbid conditions including attention deficit hyperactivity disorder (ADHD), celiac disease, diabetes, mast cell activation syndrome (MCAS), oral allergy syndrome (OAS), psoriasis, and sinusitis.

Figure 5. Comorbid Conditions



In addition to EoE, over three quarters of HCPs also treated people with food allergy (85%), allergic rhinitis (76%), and asthma (75%). These are reflective of the comorbid conditions noted by EoE patients and caregivers.

Figure 6. Conditions Patients Have Been Diagnosed With



Interview Participants

One-on-one, semi-structured interviews were conducted with seven patients and caregivers managing EoE. Five of the seven interviewees were caregivers to children with EoE. One interviewee was both a patient and a caregiver to a child with EoE, and another interviewee was an adult patient with EoE. In most cases, children managing EoE were in their early teens.



Participants*	
Lisa	Caregiver to a 13-year-old son with EoE. Son was diagnosed with EoE at age eight. Following a rare reaction to budesonide slurry and an unsuccessful elimination diet, his EoE is under control after starting biologics.
Charlotte	Adult patient with recent diagnosis of EoE (has been diagnosed for less than two years), who has had trouble swallowing for 20+ years. Currently working through elimination diets.
Melissa	Caregiver to a son with EoE. Son was diagnosed with EoE at age six after dealing with recurring cough. EoE is now controlled with proton pump inhibitors (PPI).
Ellie	Caregiver to a 16-year-old daughter with EoE. Daughter was diagnosed with EoE at age eight. Following a strict elimination diet, her EoE is now controlled with swallowed steroids and no diet restrictions.
Lauren	Caregiver to a 13-year-old son with EoE. Son was diagnosed with EoE at age two. Son was previously using a G-tube but has not had any issues with EoE since removing the G-tube five years ago.
Eva	Caregiver to a son with EoE who has a previous diagnosis of severe IgE-mediated food allergies. Son was diagnosed with EoE at age 10. His EoE is now managed with budesonide slurry.
Rebecca	Adult patient and caregiver to a 12-year-old son with EoE. Rebecca was diagnosed over 12 years ago after first experiencing symptoms 22 years ago. Her EoE is now well-managed after starting a biologic treatment used off-label but currently being studied for EoE. Her son was diagnosed at age five and his EoE is managed through a combination of elimination diet and budesonide slurry.

*Pseudonyms have been used

EoE Diagnosis

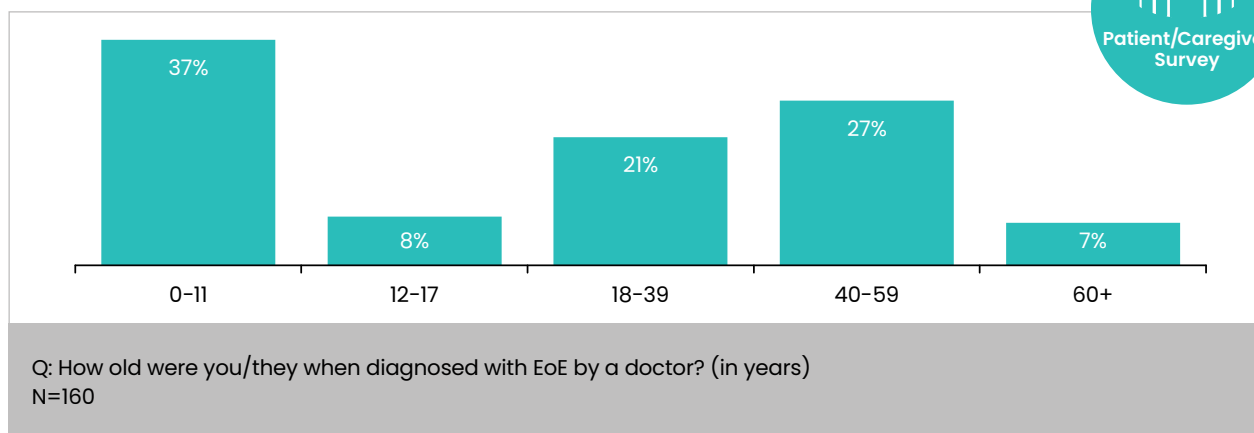
The path to receiving an EoE diagnosis can be long and challenging. EoE is usually diagnosed by a gastroenterologist (GI doctor) using a test called an upper GI endoscopy, or EGD. An endoscopy, or “scope,” is when a small tube is inserted into the mouth and the stomach. Small tissue samples, or “biopsies,” are taken for a pathologist to analyze under a high-powered microscope. A pathologist counts the number of eosinophils that are visible. Increased numbers of eosinophils (usually greater than 15 eosinophils per high-powered microscopic field) are highly suggestive of EoE.¹⁴ An endoscopy with biopsies is the “gold standard” for diagnosing EoE.¹⁵ Less-invasive tools to diagnose and monitor EoE—such as transnasal endoscopy, esophageal string test, and cytosponge—are emerging and available in some clinics.^{16,17}

EoE can be tricky to diagnose for several reasons:

- Symptoms can vary from person to person and between age groups.
- Symptoms can be mild or overlap with symptoms of other conditions, making it difficult for both patients and HCPs to interpret.
- People with EoE may not recognize that symptoms are indicative of an underlying condition
- People with EoE may have learned to manage their symptoms. They may cut food into smaller pieces, drink liquids when eating dry foods, put off meals, and avoid pills.
- Eosinophils can be found in the esophagus for other diseases as well.

More than one third (37%) of patients/caregivers in this study reported receiving an EoE diagnosis before age 12, with an additional 27% receiving a diagnosis between 40–59 years old. This tends to mirror epidemiological distribution of EoE, wherein symptoms typically present in childhood, or into a patient’s 30s and 40s.¹⁸

Figure 7. Age at Diagnosis



“The cough was his main symptom. When it was really bad, he would cough to the point of vomiting. Especially if we were eating a meal, then he would cough so hard and regurgitate what he had just chewed and swallowed.” – Melissa

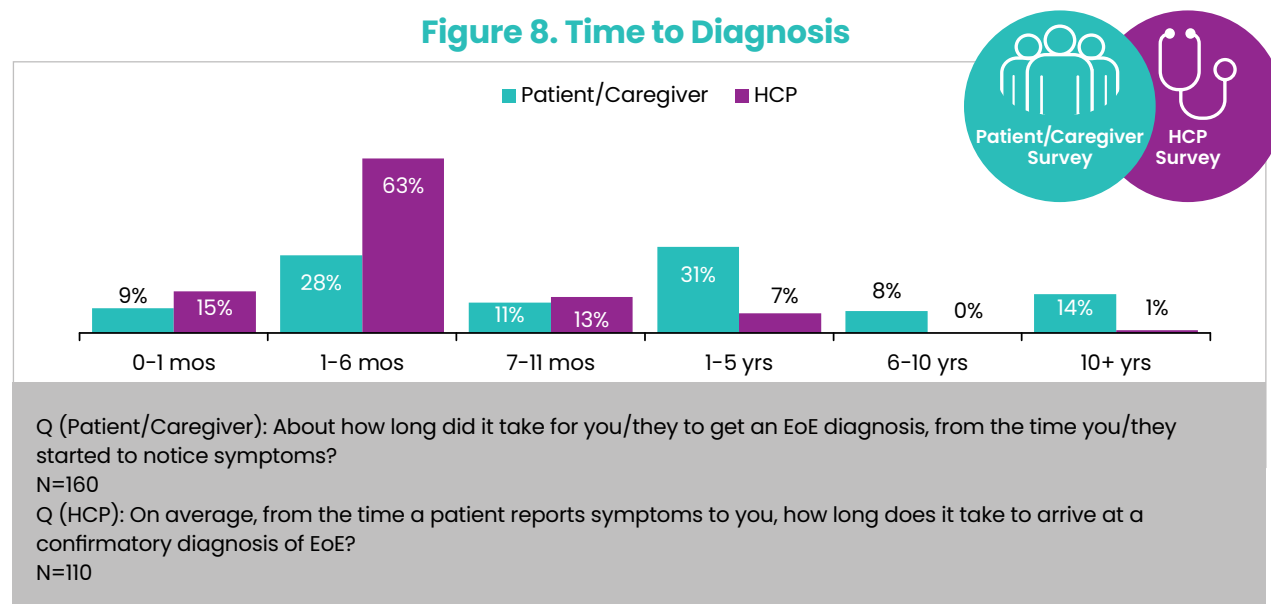
“We got to the point where eating was torture. Taking forever swallowing, constantly drinking a lot of water.” – Eva

“I realized that she was matching me bite for bite and then doubling it, and she wasn’t gaining weight.” – Ellie



It can take a long time to get an accurate diagnosis for EoE. The majority of patients and caregivers (53%) said that from the time they first started to notice symptoms, it took a year or more for them to receive an EoE diagnosis, including 14% who indicated it took more than 10 years to get diagnosed. This varies greatly from HCP responses, in which over three quarters (78%) indicated patients receive an EoE diagnosis within the first six months of seeing them. These results indicate the importance of seeing the right doctors for a timely and accurate EoE diagnosis, as the time between symptom onset and diagnosis can present a major challenge while patients and caregivers continue to manage symptoms without answers. Connecting patients to doctors who are knowledgeable about EoE is critical to reducing the wait time.

Figure 8. Time to Diagnosis



We found no significant differences in time to diagnosis based on location type (rural, urban, and suburban). However, it should be noted that patients may encounter diagnostic delays regardless of geography and proximity to specialists.

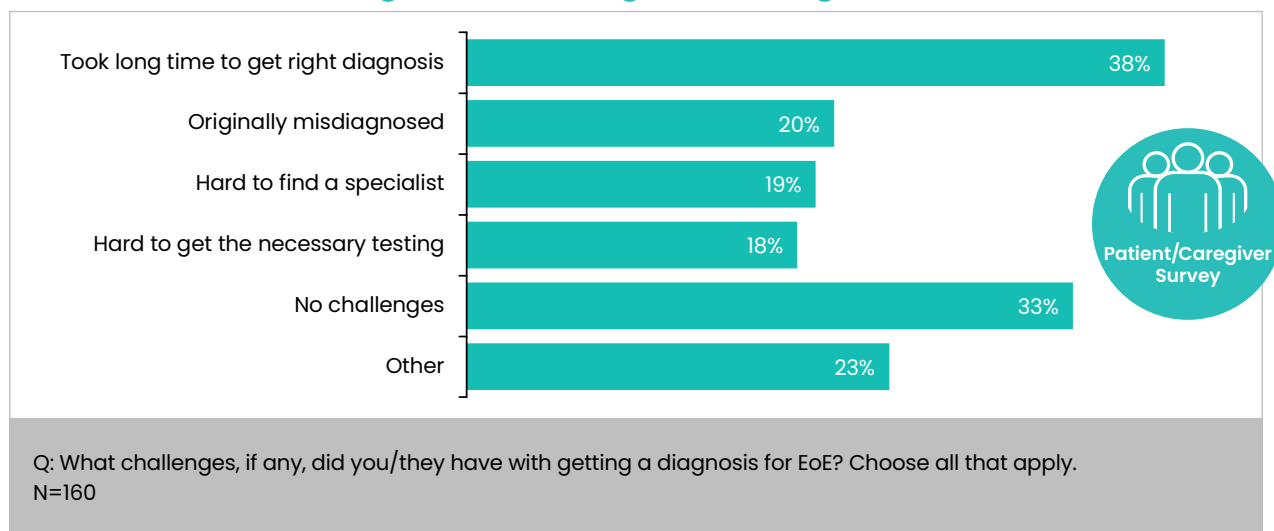
One factor that can significantly delay diagnosis is having to see multiple doctors to get answers. Patients and caregiver interviews described how doctors who are often first seen when experiencing symptoms, such as primary care physicians or emergency care, may not be well-versed in EoE. In turn, they may spend a long time trying to diagnose and treat patients themselves, or refer out to other specialists who also may not be able to provide patients with an accurate EoE diagnosis. Patient/caregiver interviews revealed the variety of HCPs patients see, such as dietitians, nutritionists, oncologists, homeopathic providers, mental health providers, allergists/immunologists, and gastroenterologists. In some cases, wait lists for specialists well-versed in EoE also caused a delay in diagnosis.

"Our pediatrician suggested trying an inhaler. I tried to find an acupuncturist and a naturopath, and we tried a few different things. With the naturopath, we tried an elimination and reintroduction diet. And we noticed that when eliminating dairy, the cough reduced a lot. But a naturopath can't do an endoscopy and take biopsies and actually diagnose EoE. Eventually we got a referral to GI because celiac runs in my family, and so we asked to get him a bunch of testing. And that came out inconclusive. And so over the years we eventually saw a different GI. And that second GI thought we could do an endoscopy and see what's going on. And so he was diagnosed then. It took about three years to find a doctor who thought to check for EoE." – Melissa



With these delays in diagnosis, it is no surprise that patients/caregivers indicated the biggest diagnostic challenge was the length of time to get the right diagnosis (38%). One in five patients/caregivers also said they were originally misdiagnosed with another condition (20%) and that it was hard to find a specialist (19%).

Figure 9. Challenges with Diagnosis



Unsurprisingly, challenges and barriers to diagnosis can impact the length of time to diagnosis. Of patients/caregivers who reported that it took one year or longer to get diagnosed for EoE, 29% were originally misdiagnosed, 27% had trouble finding a specialist, and 23% had trouble getting the necessary testing. These numbers were significantly lower in patients/caregivers who reported that it took three months or less to get diagnosed.

Figure 10. Challenges with Diagnosis by Length of Time to Diagnosis

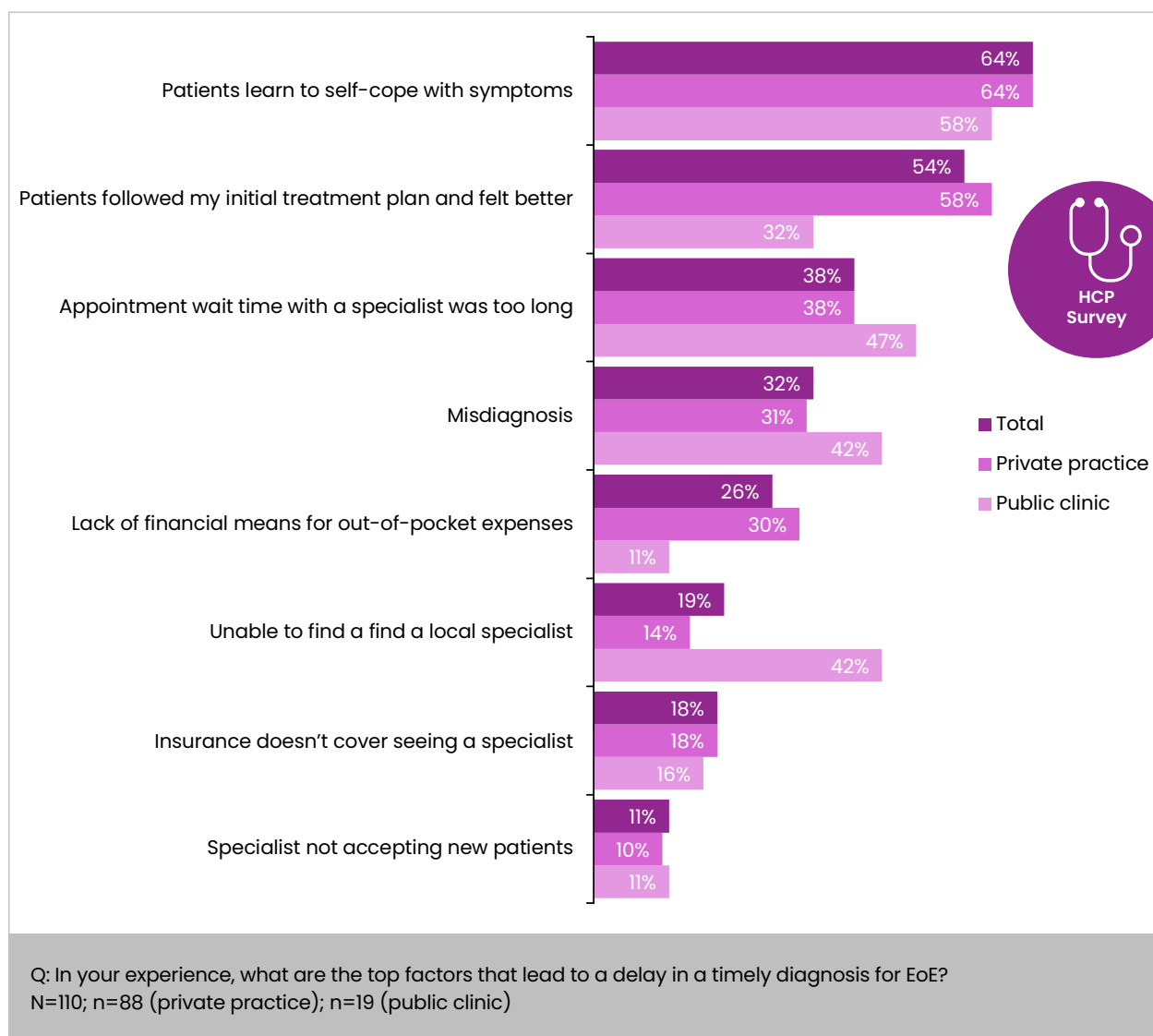
Of those who reported 0–3 months to diagnosis	Of those who reported 4–11 months to diagnosis	Of those who reported 1 year or more to diagnosis
9% were originally misdiagnosed	12% were originally misdiagnosed	29% were originally misdiagnosed
9% had trouble finding a specialist	12% had trouble finding a specialist	27% had trouble finding a specialist
6% had trouble getting the necessary testing	16% had trouble getting the necessary testing	23% had trouble getting the necessary testing

Q: About how long did it take for you/they to get an EoE diagnosis, from the time you/they started to notice symptoms?
Q: What challenges, if any, did you/they have with getting a diagnosis for EoE?
N=160 (total); n=33 (0–3 months to diagnosis); n=43 (4–11 months to diagnosis); n=83 (1+ years to diagnosis)

From the HCP perspective, the most common reasons for a delay in diagnosis included patients learning to self-cope with their symptoms (64%) such as learning to avoid certain foods or changing their eating habits, and patients feeling better on the initial treatment plan (54%). However, HCPs also recognized challenges that may delay getting a diagnosis, including lengthy wait times for specialists (38%), misdiagnoses (32%), and financial barriers (26%).

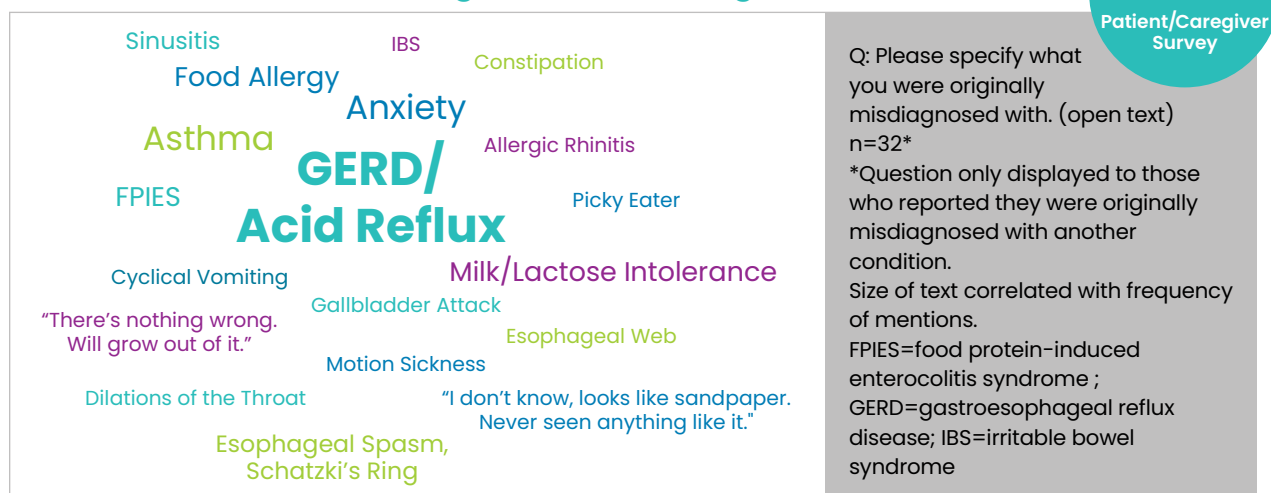
Reasons for delays in diagnosis can differ by practice type. HCPs working in private practice were more likely to say patients feel better after initial treatment plans. They also cited financial means as a barrier to care. Those working in public clinics were more likely to believe that patients experience challenges finding a local specialist to make a diagnosis, long wait times to see specialists, and misdiagnoses. These results highlight the need for increased access and affordability of specialty care, especially for patients who may receive care from public clinics.

Figure 11. Challenges to Timely Diagnosis by Practice Type



Among patients/caregivers who indicated they were initially diagnosed with another condition, the most common misdiagnoses were other conditions that impact the esophagus, such as gastroesophageal reflux disease (GERD), also known as acid reflux. Misdiagnoses were closely tied with food, such as food allergy, food intolerance, and food protein-induced enterocolitis syndrome (FPIES). Others focused on gastrointestinal symptoms (IBS, constipation), or psychosomatic (anxiety).

Figure 12. Initial Diagnosis



Type 2 Inflammation and Allergic Comorbidities

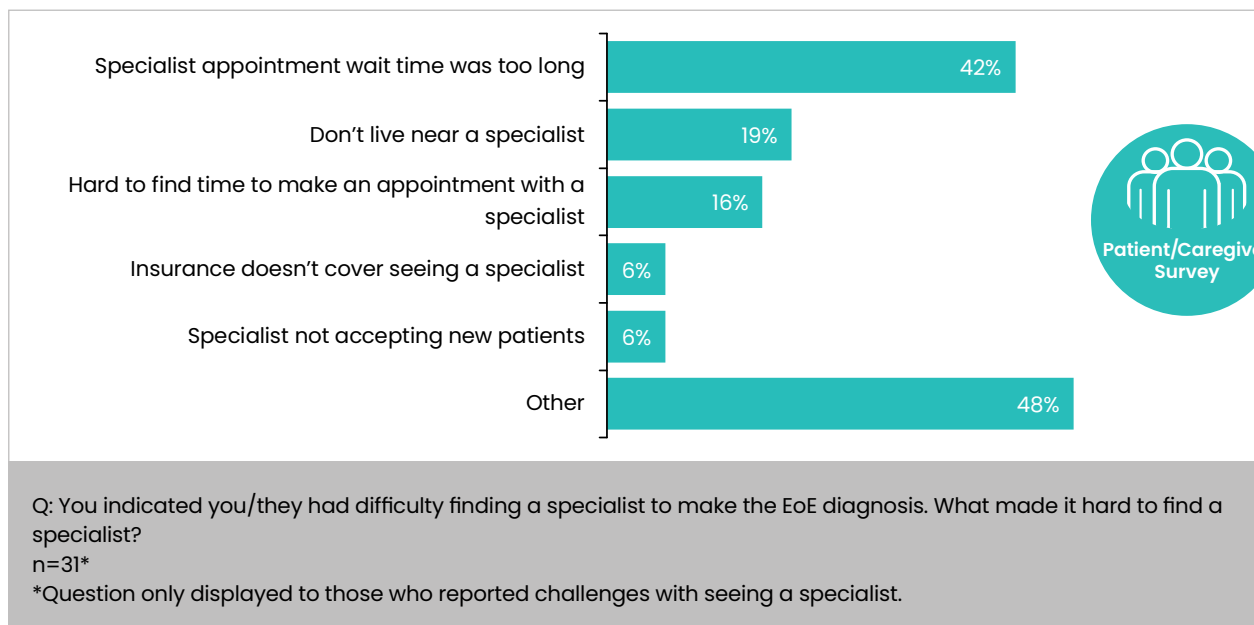
EoE is driven by type 2 inflammation and people with EoE often have related allergic conditions.¹³ Because allergic comorbidities are higher in people with EoE than the general population,¹⁹ optimal EoE management also includes evaluation and treatment of other type 2 conditions.

In addition to EoE, allergic diseases caused by type 2 inflammation include:

- **Asthma** – From coughing and wheezing to difficulty breathing, asthma symptoms may impact daily life, especially if it's not controlled. Type 2 inflammation drives both allergic and eosinophilic asthma.
- **Atopic Dermatitis (AD)** – People with AD (a form of eczema), often have frequent dry, scaly skin and red or dark rashes that cause intense itching. Many people are diagnosed with this chronic disease as children and experience unpredictable symptoms into and throughout adulthood.
- **Food Allergies** – Sensitivities to allergens in different foods can cause anaphylaxis, a severe allergic reaction. Symptoms of anaphylaxis can include cause rashes, hives, trouble breathing, wheezing, dizziness, vomiting, diarrhea, and swelling of the lips, tongue, and throat. The most common foods that cause allergic reactions are eggs, milk, peanuts, tree nuts, fish, shellfish, sesame, soy, and wheat.
- **Nasal Polyps or Chronic Rhinosinusitis with Nasal Polyposis (CRSwNP)** – Nasal polyps are non-cancerous growths in the sinuses that lead to frequent runny noses, trouble breathing, facial pain, and congestion. Many people experience loss of smell which can cause people to miss out on experiences like enjoying a meal and can make them feel unsafe if they can't sense smoke in the event of a fire.
- **Prurigo Nodularis (PN)** – People with PN have many lumps and bumps that create an intense, persistent itch lasting over six weeks. The stinging, burning, and pain that come with PN worsen get worse with irritation, and can cause people with PN to scratch themselves, leaving their skin damaged and scarred. This can lead to skin infections.

Among those who indicated they had challenges seeing a specialist, two in five (42%) indicated the specialist appointment wait time was too long, reflecting sentiments expressed in the patient and caregiver interviews. One in five (19%) also indicated they don't live near a specialist, which can add another barrier to getting needed care.

Figure 13. Challenges with Seeing Specialist



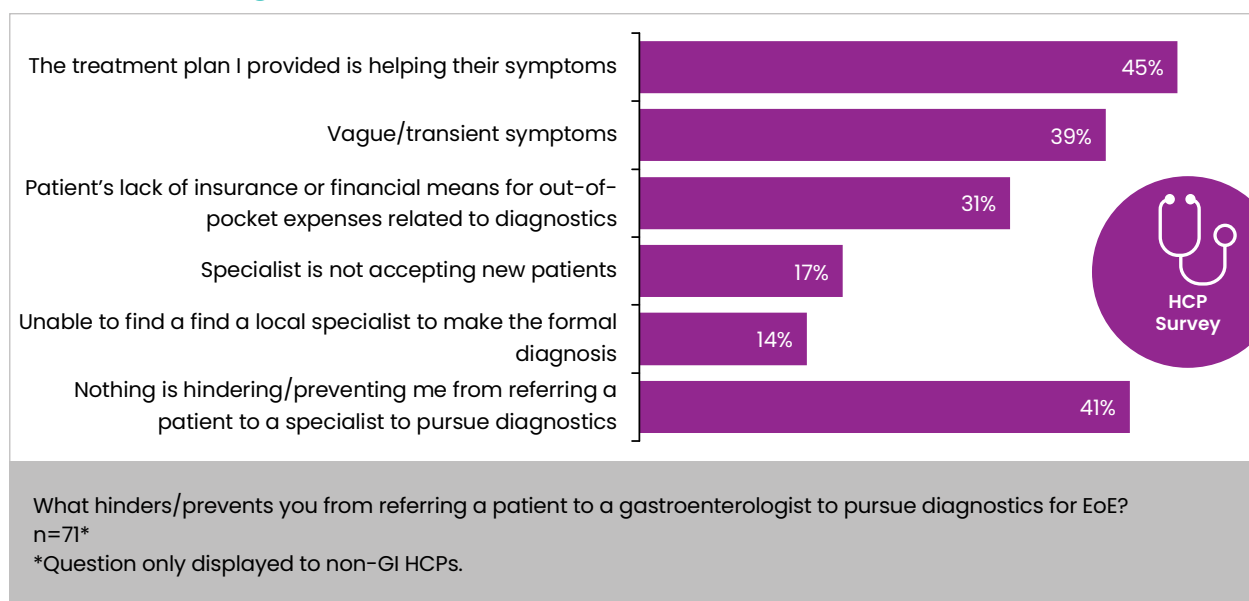
In many cases, patients/caregivers experienced challenges seeing a specialist that were not included in the answer options. Some mentioned a general lack of awareness around EoE, in that they couldn't be referred if their doctors didn't know what to look for or where to refer them to. However, in some cases, patients report doctors as being dismissive of their symptoms and unwilling to refer them out. Even after seeing specialists, some patients note that their doctors may not have all the diagnostic tools or knowledge of the condition to effectively diagnose and develop an effective treatment plan.

Figure 14. Other Challenges Seeing a Specialist



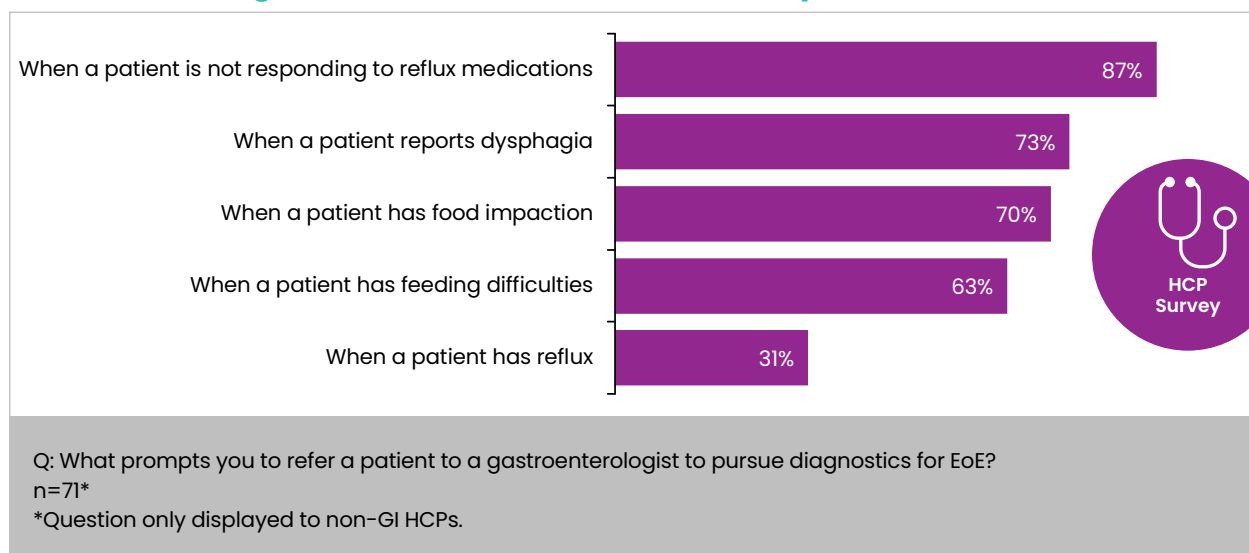
From the HCP point of view, nearly half (45%) indicated they do not refer patients out to GI specialists when the treatment plan they provide is helping patient symptoms. Two in five HCPs (39%) also cite vague or transient symptoms as a reason for not referring a patient to a GI specialist. HCPs were less likely to cite access challenges as barriers to referral, such as specialists not accepting new patients (17%) or being unable to find a local specialist (14%).

Figure 15. Circumstances That Prevent Referral to GI



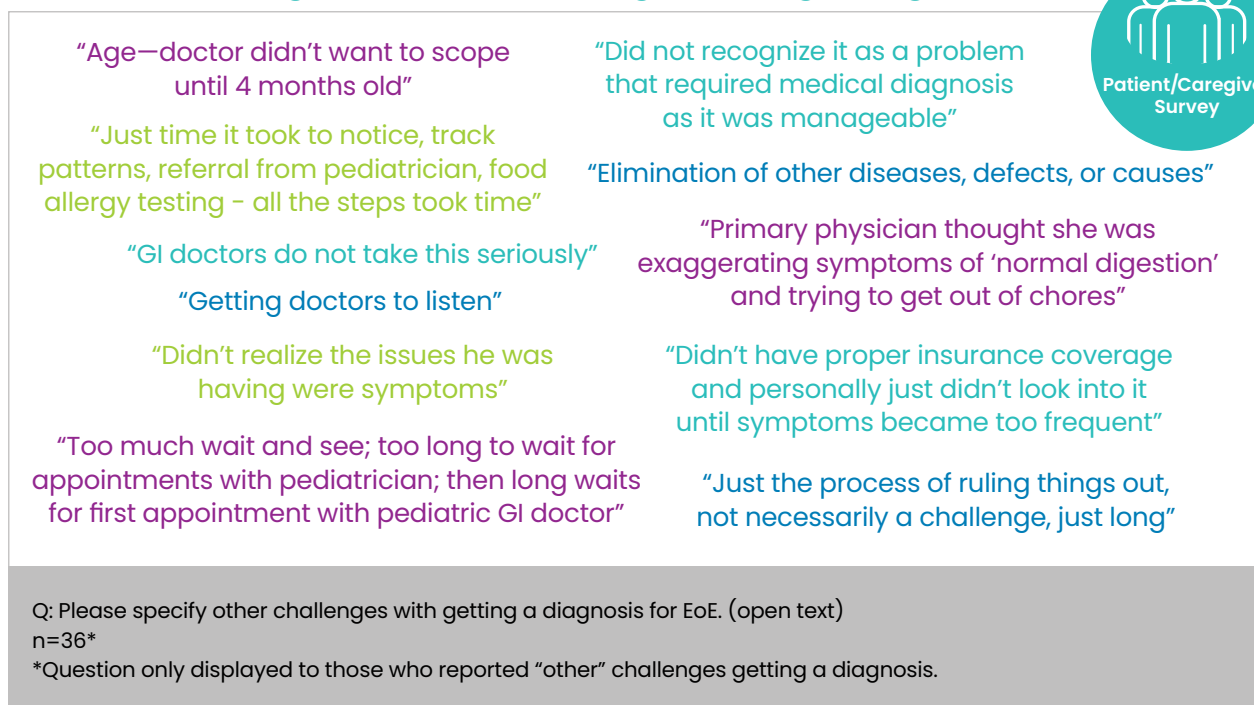
When asked about symptoms that prompt referral to a GI specialist, a majority of non-GI HCPs (87%) said that non-response to proton pump inhibitor (PPI) would prompt them to refer to a GI doctor to pursue an EoE diagnosis. This aligns with the 2007²⁰ and 2011²¹ consensus reports but contradicts the 2018 updated consensus¹⁴ recommendation to remove PPI as a diagnostic tool. A majority of HCP respondents also referred patients to a GI specialist when a patient reports dysphagia (73%), has a food impaction (70%), or has feeding difficulties (63%). HCPs were less likely to refer patients to GI for diagnosis when the patient has reflux (31%), likely due to the relative commonality and treatability of this symptom alone.

Figure 16. Circumstances That Prompt Referral to GI



Some patients/caregivers also indicated they experienced “other” challenges in diagnosis. Among these, many cited the trial-and-error process of seeing a doctor, noting symptoms, running diagnostic tests, and trying treatment options that ultimately didn’t work. Others mentioned the challenge of not realizing symptoms as indicative of an underlying condition, or having doctors take their symptoms seriously.

Figure 17. Other Challenges Getting a Diagnosis



Themes around lack of awareness delaying diagnosis were echoed in patient/caregiver interviews. Some patients reported waiting to seek a diagnosis in cases where symptoms were manageable or if self-treatments were helping. Others reported cases where they sought a diagnosis, but lack of awareness around EoE led to dismissing symptoms that were indicative of EoE.

“At the time, I didn’t even think about going to a doctor for it. When I went to my parents about it, they were just like, ‘You need to eat smaller food and actually chew your food.’ I told them ‘I am, but I’m still having problems swallowing things.’ But then I went off to college and it got worse. So, I basically lived off of mashed potatoes, really overcooked mac and cheese, and smoothies.” – Rebecca

“I could breathe, I just couldn’t swallow...they called the hospital and they sent an ambulance, and they were insistent that I was having a heart attack. I told them ‘I don’t think so. I think it’s just a swallowing problem.’ But they said, ‘No, I think we really need to put you into the van and cart you off.’” – Charlotte

“The first doctor we had who looked at my son said to him (in front of him) that ‘it’s all in his head, this isn’t real.’” – Lisa

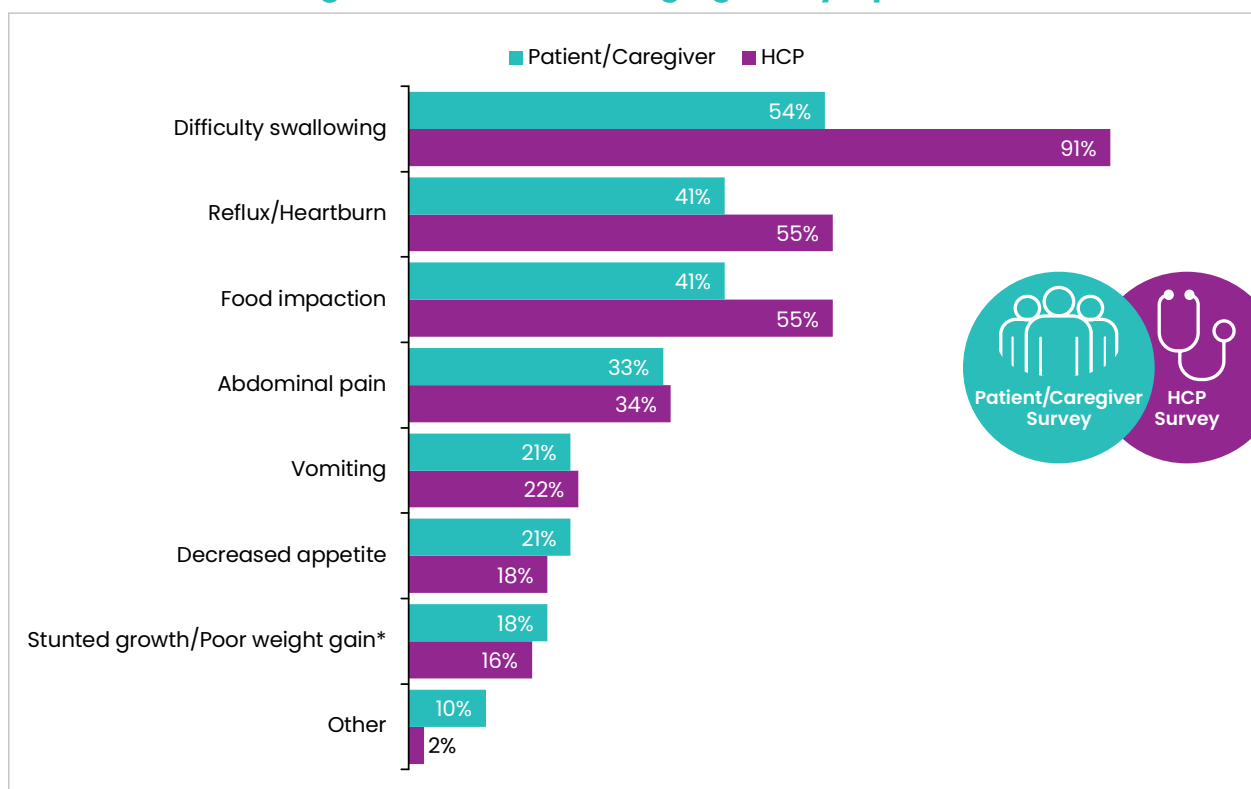
EoE Symptoms

Common symptoms of EoE include difficulty swallowing (dysphagia), food impactions (food gets stuck in the esophagus), reflux that does not respond to medication (acid suppressors), nausea and vomiting, failure to thrive (poor growth, malnutrition, or weight loss) and poor appetite, abdominal or chest pain, feeding refusal/intolerance or poor appetite, and difficulty sleeping due to chest or abdominal pain, reflux, and/or nausea.²²

Symptoms of EoE may vary from one individual to the next and often differ depending on age. Infants and toddlers may refuse their food or exhibit poor growth, malnutrition, or weight loss. School-age children may have chronic abdominal pain, trouble swallowing, and/or vomiting. Adolescents and adults most often have difficult or painful swallowing. Their esophagus may narrow and cause food to become stuck (impaction), causing a medical emergency.

In this study, patients/caregiver and HCPs agreed that the most challenging symptom is difficulty swallowing (dysphagia) followed by both food impaction and reflux. In general, HCPs were more likely to indicate symptoms as challenging, but both groups agreed on the challenging aspects of symptoms such as stomach pain, vomiting, decreased appetite, and stunted growth/poor weight gain. One in ten patients/caregivers (10%) also listed “other” symptoms as challenging. Other responses included symptoms such as diarrhea, difficulty breathing, anxiety, cough, constipation, and fatigue.

Figure 18. Most Challenging EoE Symptoms



Q (Patient/Caregiver): What are the most challenging symptoms of EoE? Select all that apply.

N=160

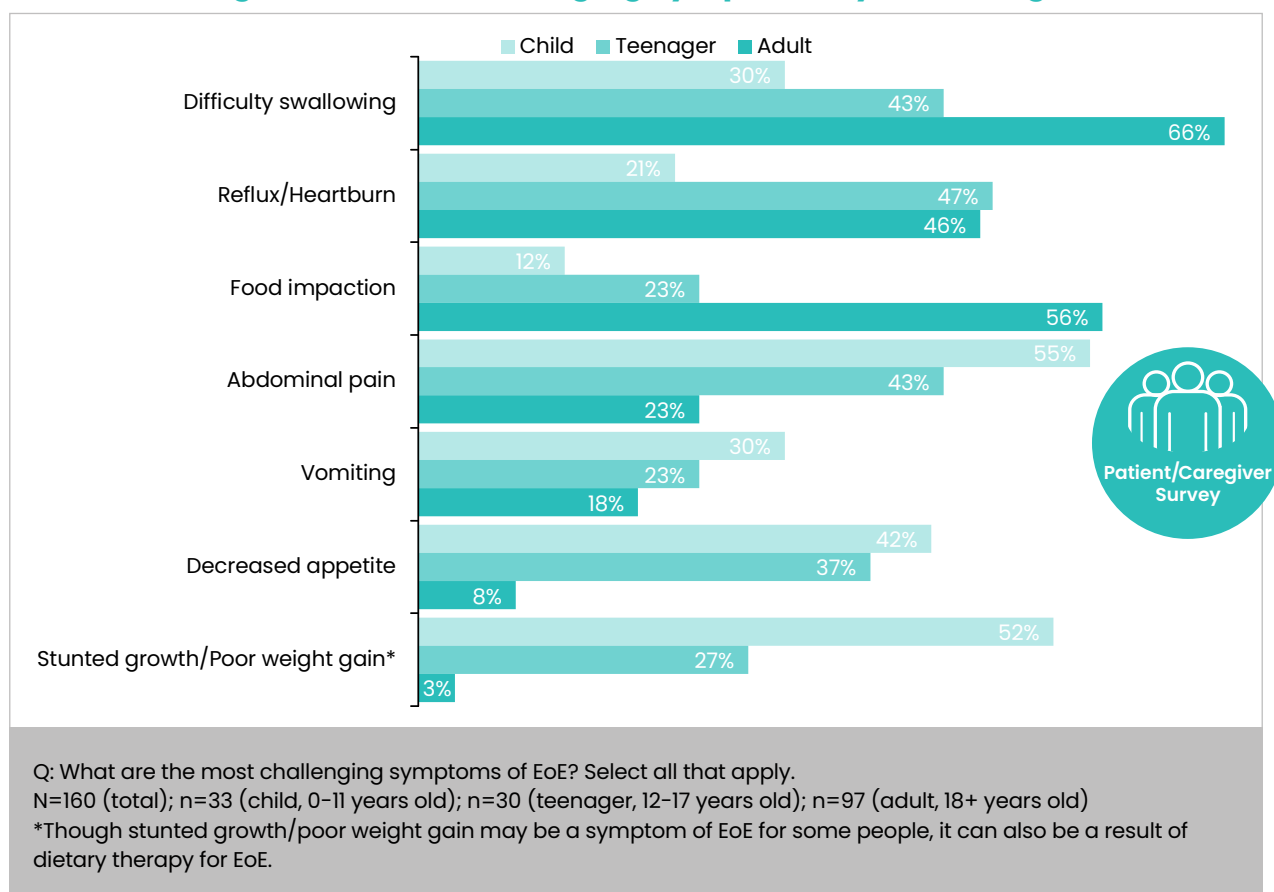
Q (HCP): What are the top three symptoms your patients with EoE struggle most with?

N=110

*Though stunted growth/poor weight gain may be a symptom of EoE for some people, it can also be a result of dietary therapy for EoE.

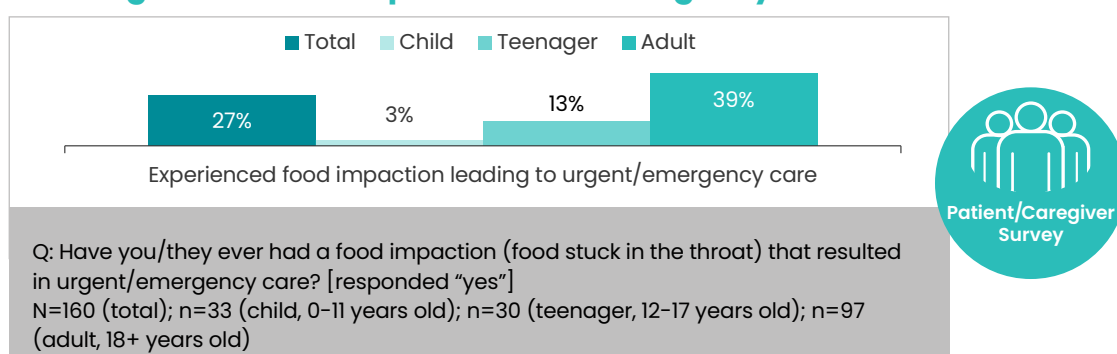
When looking at challenging symptoms by patient age, adult patients were much more likely to cite difficult swallowing (dysphagia), reflux/heartburn, and food impaction as the most challenging symptoms. Caregivers of children with EoE were more likely to report gastrointestinal symptoms, such as abdominal pain, decreased appetite, and vomiting as challenging. Over half (52%) of caregivers to young children also reported stunted growth and poor weight gain as one of the most challenging symptoms.

Figure 19. Most Challenging Symptoms by Patient Age



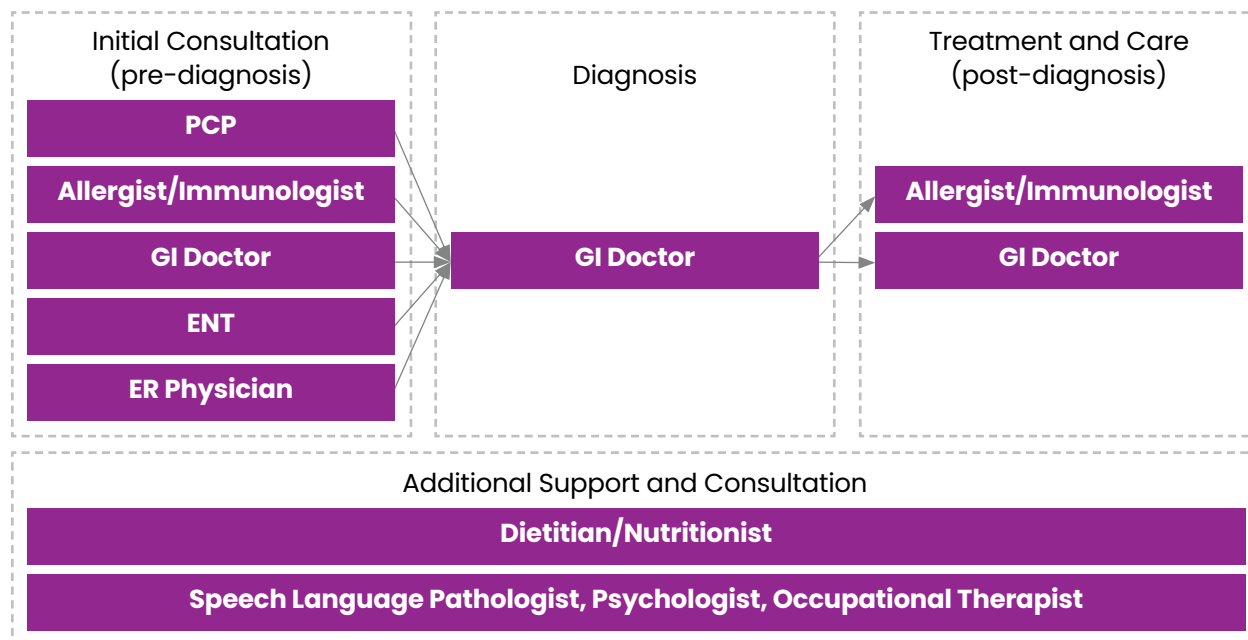
Over one fourth (27%) of patients/caregivers say they have experienced a food impaction that resulted in urgent or emergency care. Adult patients are much more likely to have experienced a food impaction, potentially indicating a higher use of emergency care for EoE in this population.

Figure 20. Food Impaction and Emergency Care



Medical Care for EoE

Following diagnosis, people with eosinophilic esophagitis (EoE) often have to adopt a new schedule for medical care. Scopes, testing, and treatment evaluations become part of their management plan. People with EoE may have more than one doctor or specialist involved with their care. The care team may include:*



*Diagram provides a general overview of roles and does not necessarily represent every EoE journey

A person with EoE may initially see one of several HCPs due to symptoms of EoE (initial consultation or pre-diagnosis). A **gastroenterologist (GI doctor)** specializes in diagnosis and treatment of disorders of the digestive system, including the liver and pancreas. They can conduct endoscopies to diagnose EoE. An **allergist or immunologist** specializes in the diagnosis and treatment of allergic conditions, including asthma, allergic rhinitis, and food allergies. An allergist or immunologist can help recognize symptoms for EoE and refer patients to biopsies. They can also help determine triggers for EoE and help manage and guide EoE treatment. In addition to GI doctors and allergists/immunologists, a person with EoE may see a **primary care physician** (including pediatricians). The PCP may refer to a specialist and help with long-term care and coordination of care for EoE.

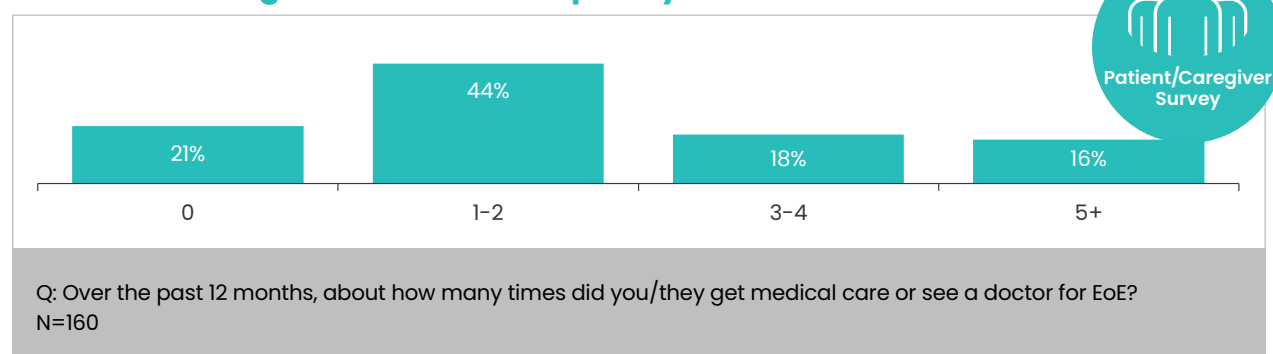
For additional support, a person with EoE may see a registered **dietitian**. Dietitians specialize in organizing food and nutrition plans and can help provide strategies for identifying allowed foods, recognizing hidden ingredients, and determining appropriate food substitutes to maintain a balanced diet. Often time, “registered dietitian” and “nutritionist” are terms that are used interchangeably, however, while both professions are related, education, credentialing, and licensing may differ between the two. Other ancillary services may include an occupational therapist, speech-language pathologist, or psychologist. An **occupational therapist (OT)** specializes in interventions to help patients develop, recover, or maintain meaningful activities, despite physical or health challenges. In children with EoE, an OT may recommend feeding therapy to address oral motor function and sensory issues related to food. A **speech-language pathologist (SLP)** specializes in assessment, diagnosis, treatment, and prevention of communication and swallowing disorders. SLPs develop feeding therapy plans to address optimal growth and development for a child with EoE, often collaborating with occupational therapists to address functional fine motor skill interventions. A **psychologist** specializes in wellness and provides strategies to cope with anxiety, depression, and other mental health issues related to chronic health conditions.

The EoE health care team can help set goals for treatment, which will likely include:

- Helping to heal the lining of the esophagus
- Managing existing narrowings (“strictures”) of the esophagus
- Preventing or reducing risk of long-term complications
- Improving symptoms and quality of life

Caring for EoE requires multiple visits to a health care provider. In our study, over three quarters (78%) of patients/caregivers reported seeing a doctor for EoE at least once per year, with one in six (16%) reporting they receive medical care for EoE five or more times per year.

Figure 21. Annual Frequency of Doctor Visits for EoE



The Role of Allergists in EoE Care

EoE is an immune response to an allergen—which can often be a food allergen or environmental trigger. Additionally, many people with EoE also have other allergic diseases, such as asthma, allergic rhinitis, eczema, and IgE-mediated food allergies. Allergists specialize in allergy testing and can help identify the exact triggers of EoE. They can also develop treatment plans, monitor dietary therapies, manage swallowed steroid or biologic treatments, and educate patients about EoE management.

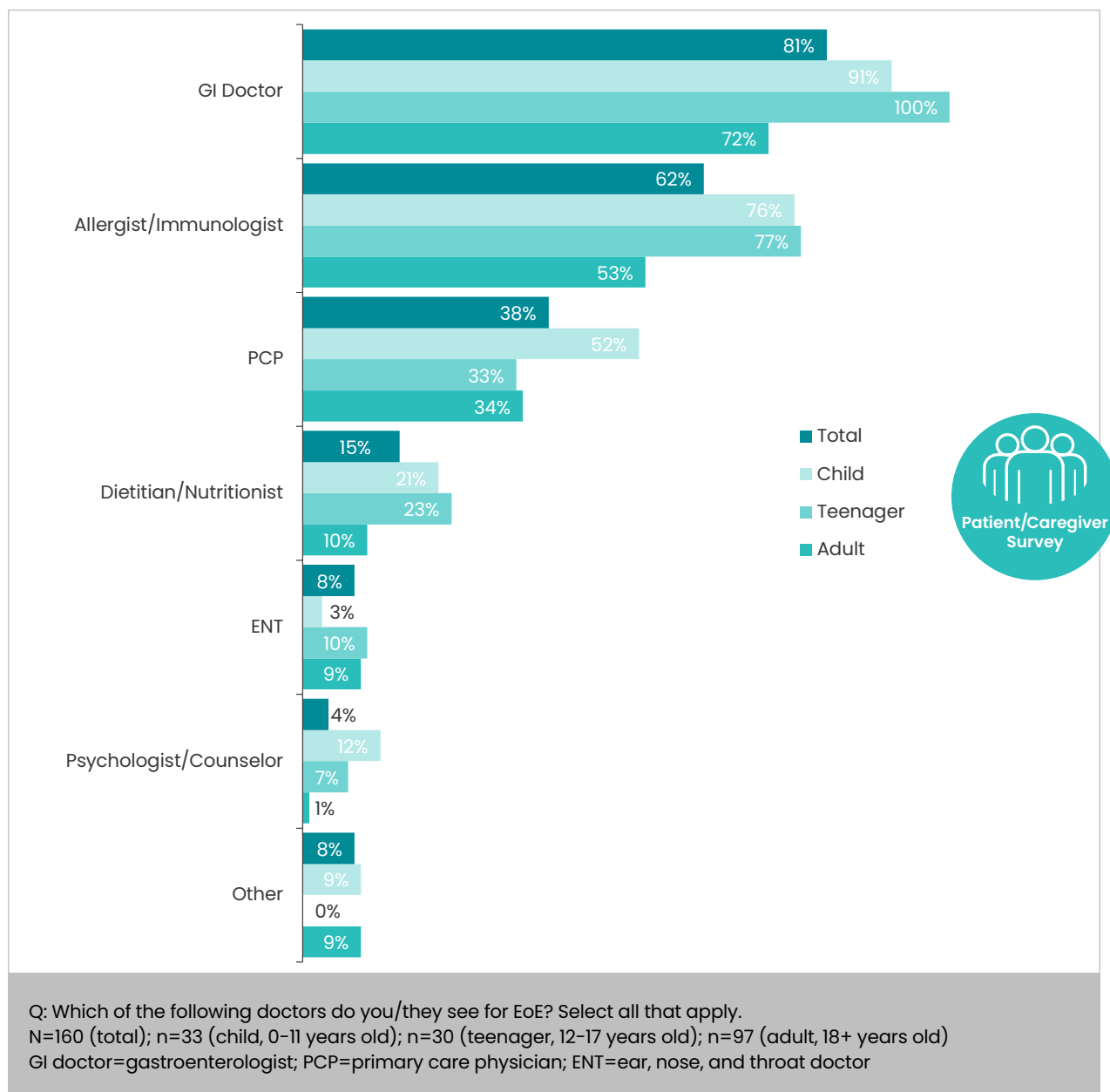
Allergists work with gastroenterologists, or GI doctors, who specialize in the diagnosis and treatment of allergic conditions like EoE. While GI doctors confirm a diagnosis, for patients with environmental triggers (such as pollen), allergists can help determine when a patient would benefit from an initial endoscopy due to symptoms concerning for EoE, and can also determine the best time to get an endoscopy for EoE monitoring. Given the landscape of emerging EoE treatment options, allergists can also work with patients to start, monitor, and reevaluate treatment plans.

It is important to include allergists in a patient’s care team due to their skills and expertise in managing allergic conditions. Experts suggest that the goals of EoE management (diagnosis, control, and remission) are best achieved through a multidisciplinary team of allergists, gastroenterologists, and other health care providers.

When looking at the different doctors patients see for EoE, four in five (81%) reported seeing a gastroenterologist, three in five (62%) reported seeing an allergist/immunologist, and two in five (38%) reported seeing a primary care provider. Patients/caregivers were less likely to see a dietitian or nutritionist (15%), ENT (8%), or psychologist or counselor (4%) for EoE. Among the 8% of patients/caregivers who indicated seeing “other” doctors, the most common response was a speech language pathologist.

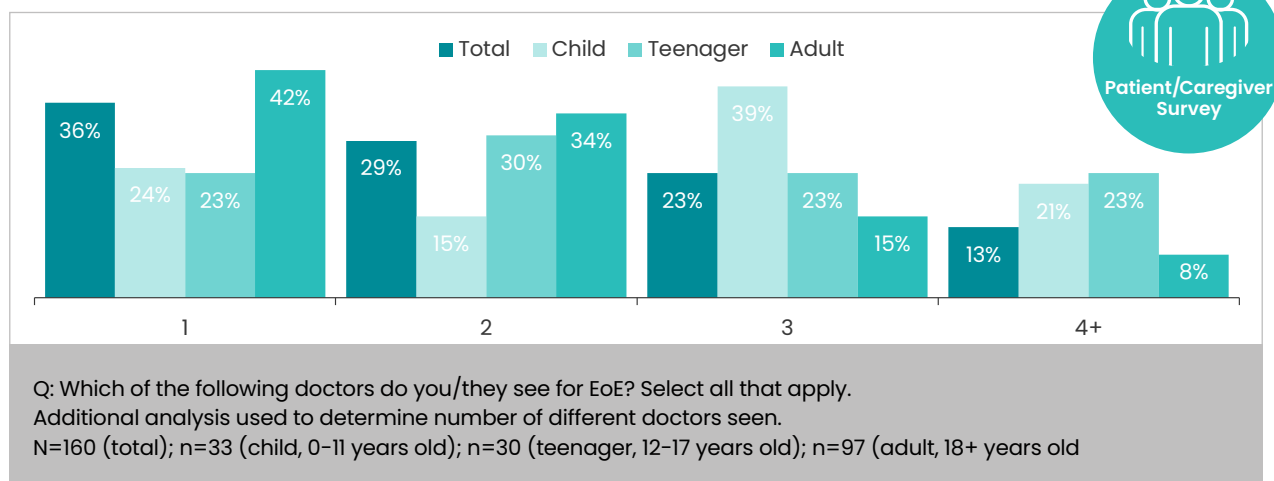
When broken down by age, all teenagers (100%) and nearly all children (91%) saw a gastroenterologist, compared to 72% of adult patients. Children and teens were also more likely to see an allergist/immunologist for EoE, with over three quarters of children and teens seeing one, compared to just over half (53%) of adults. Finally, over half (52%) of children see a primary care physician for EoE, compared to one third of teenagers (33%) and adults (34%).

Figure 22. Types of Doctors Seen for EoE by Patient Age



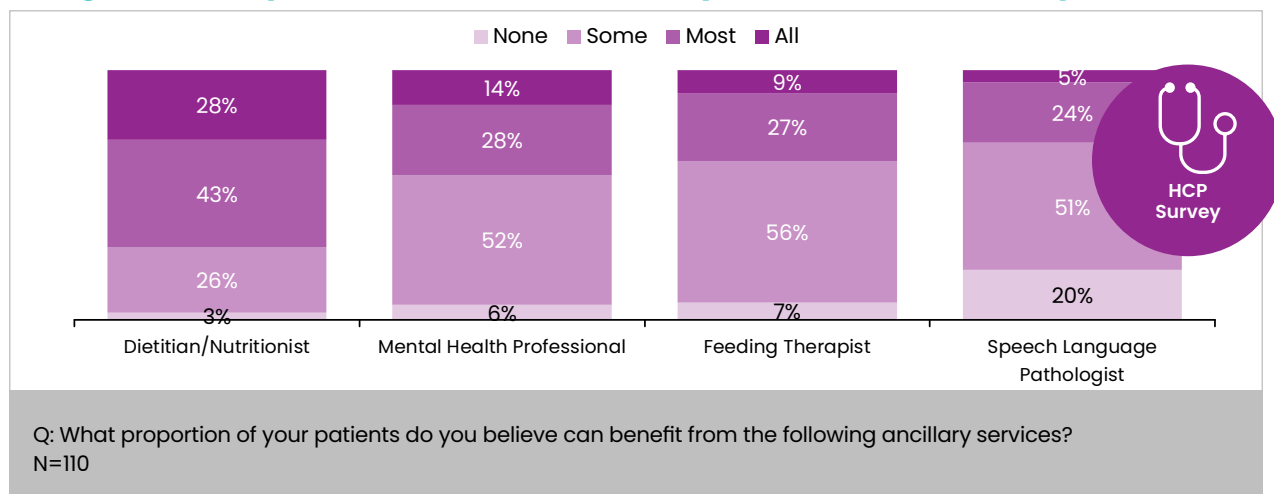
While just over one third of patients/caregivers (36%) reported seeing one type of doctor for their EoE management, most saw more than one type of doctor. One in eight respondents (13%) reported seeing four or more doctors for EoE. When broken down by age, children and teens were more likely to see multiple doctors for EoE. While two in five adult patients (42%) only saw one doctor for EoE, only one in four children (24%) and teenagers (23%) did. Children were more likely to see three doctors for EoE (39%), and teenagers were more likely to see two doctors (30%).

Figure 23. Number of Doctors Seen for EoE by Patient Age



Though patients/caregivers reported seeing dietitians, nutritionists, and psychologists less frequently than other providers for EoE, HCPs generally believed patients could benefit from using ancillary services for nutrition, mental health, and swallowing/feeding services. Around seven in ten (71%) HCPs believed “most” or “all” of their patients would benefit from seeing a dietitian or nutritionist who can help patients and caregivers navigate things like elimination diets, food reintroduction, reading food labels, and recipe modifications to avoid triggers. Acknowledging the social, emotional, and mental impacts of EoE, two in five (42%) HCPs also said “most” or “all” of their patients could benefit from seeing a mental health professional such as a psychologist, therapist, or psychiatrist. HCPs were slightly less likely to think “most” or “all” of their patients could benefit from providers who help with swallowing and feeding, such as feeding therapists (36%) and speech language pathologists (29%).

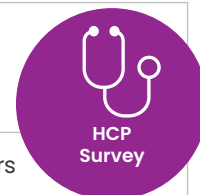
Figure 24. Proportion of Patients Who May Benefit from Ancillary Services



Health care providers may also collaborate with other HCPs for patient care. Gastroenterologists are the most common doctors that are looped into an EoE patient's care team—all allergists/immunologists and primary care physicians surveyed reported consulting with GI specialists as part of EoE patient care, and nearly half (44%) of GI specialists reported consulting with others in their field. This is unsurprising given that GI doctors are able to diagnose EoE and conduct tests such as endoscopies and biopsies. Four in five (82%) GI specialists and seven in 10 (69%) PCPs also reported collaborating with allergists/immunologists. More than three in five GI doctors, allergists/immunologists, and primary care physicians also collaborate with dietitians and nutritionists for EoE patient care.

Figure 25. HCP Collaboration on Patient Care by Provider Specialty

Among GI Doctors % who collaborate with... for EoE care	Among Allergists/Immunologists % who collaborate with... for EoE care	Among PCPs % who collaborate with... for EoE care
82% Allergists/Immunologists	100% GI Doctors	100% GI Doctors
62% Dietitians/Nutritionists	62% Dietitians/Nutritionists	69% Allergists/Immunologists
44% Other GI doctors	33% PCPs	65% Dietitians/Nutritionists
28% PCPs	24% Other Allergists/ Immunologists	23% ENTs
18% Psychologists	24% Pediatricians	19% Psychologists
10% ENTs	14% Psychologists	8% Pediatricians
5% Pediatricians	14% ENTs	4% Other PCPs

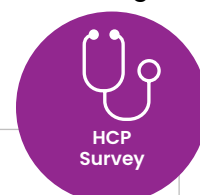


Q: Which of the following specialists do you consult/collaborate with for EoE patient care? Select all that apply.
If your own specialty is listed, select if you consult with peers in your medical discipline.
N=110; n=39 (GI doctor); n=26 (PCP); n=21 (allergist/immunologist)
GI doctor=gastroenterologist; PCP=primary care physician; ENT=ear, nose, and throat doctor

The vast majority of gastroenterologists (GI doctors) in the study (82%) reported receiving referrals for EoE patients from primary care physicians, and 69% reported receiving referrals from allergists/immunologists. More than half of GI doctors reported receiving EoE referrals from ENTs (56%) and emergency room physicians (51%). Around one third of GI doctors reported receiving referrals from pediatricians (38%) and from other GI doctors (36%).

Figure 26. EoE Referrals to GI Doctors

Among GI Doctors % who receive EoE referrals from:					
82% PCPs	69% Allergists/ Immunologists	56% ENTs	51% ER Physicians	38% Pediatricians	36% Other GI Doctors



Q: What type of doctor(s) do you receive EoE referrals from?

n=39*

*Question displayed only to GI doctors.

GI doctor=gastroenterologist; PCP=primary care physician; ENT=ear, nose, and throat doctor; ER=emergency room

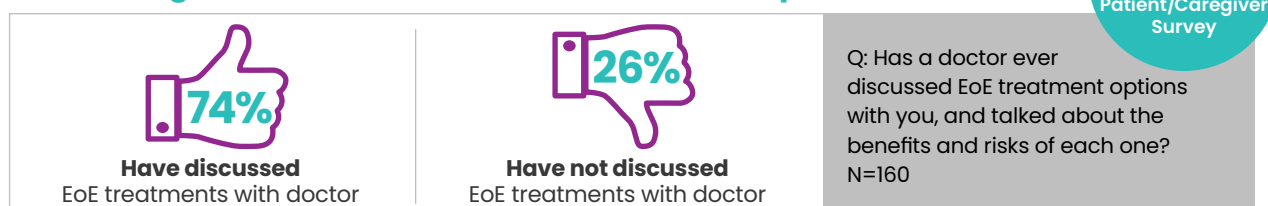
EoE Treatments

EoE is treated through a combination of diet changes and medicines. EoE treatments can help manage and reduce symptoms associated with EoE. Some treatments also target the underlying inflammation that causes EoE.²⁴ Current treatment options for EoE include:

- **Elimination diet** – A diet that removes suspected or known food triggers from the diet. Often, this includes removal of common allergy-causing foods such as milk, wheat, eggs, soy, peanuts/tree nuts, fish/shellfish. There are different versions of this diet which may involve removing several foods from the diet.
- **Elemental diet** – A liquid, formula-based diet. This special formula (an amino acid formula) does not include any food-based sources of protein and does not elicit an allergic response. Examples of the formula include Neocate®, EleCare®, PurAmino™, Alfamino.™ EssentialCare™ Jr, and EquaCare™ Jr. Elemental nutrition may be recommended for full or partial nutrition. If a patient cannot consume a sufficient amount of formula and/or the doctor determines it is necessary for other reasons, there may be the need for placement of a temporary feeding tube (nasogastric, or NG-tube) or a more long-term alternative (gastronomy tube, or G-tube).
- **Proton pump inhibitor (PPI)** – A pill or liquid that reduces acid in the stomach tract, reduces inflammation, and helps keep eosinophils from collecting in the esophagus. Some examples include, but aren't limited to omeprazole (Prilosec®) and esomeprazole (Nexium®).
- **Corticosteroids** – Topical corticosteroids are a commonly used drug treatment for EoE. Inhaled corticosteroids from asthma inhalers (fluticasone or budesonide) can be taken using a “puff and swallow” technique. Another technique may be to mix the corticosteroid (budesonide) with a carrier agent, making a “slurry” to swallow and coat the esophagus. Corticosteroids help control inflammation; the dose can be lowered to the smallest amount necessary once EoE is under control.
- **Biologic therapy** – A type of treatment that targets the underlying inflammation causing EoE. Biologics are given by injection or infusion and target a cell or protein to help manage this inflammation. They are commonly used as treatment for certain types of persistent asthma, moderate-to-severe eczema, and more recently, EoE. Dupilumab (DUPIXENT®) is approved by the U.S. Food and Drug Administration (FDA) for people 12 and older with EoE weighing more than 88 pounds.
- **Esophageal dilation** – A procedure that enlarges the esophagus in adults with EoE-related strictures to make swallowing easier. Over time, EoE can cause scarring in the lining and narrowing of the esophagus, making swallowing difficult and leading to strictures. Dilation is usually well-tolerated. It results in symptom improvement but does not change or improve the underlying inflammation. Dilations are not intended as a long-term treatment for EoE.

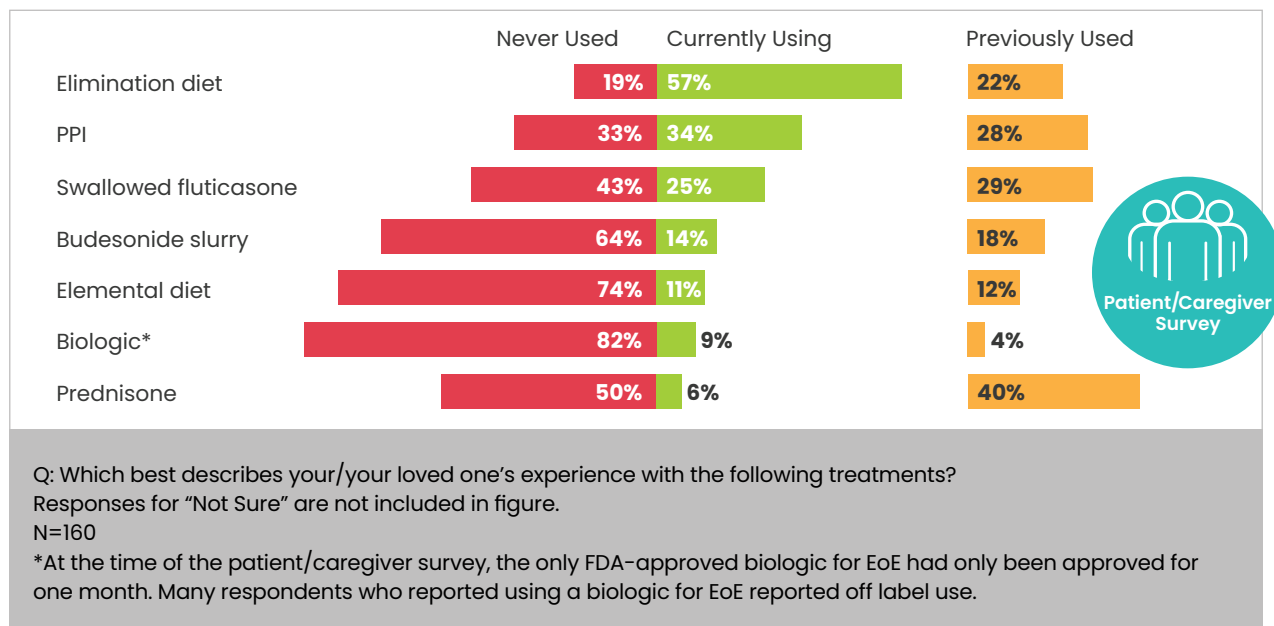
Given the landscape of treatment options for EoE patients, it is important for physicians to work with patients/caregivers to develop and monitor a treatment plan specific to patients' needs. Among patient/caregiver respondents, three quarters (74%) reported that their doctor has discussed EoE treatment options and talked about benefits and risks of each one.

Figure 27. Discussion of EoE Treatment Options with Doctor



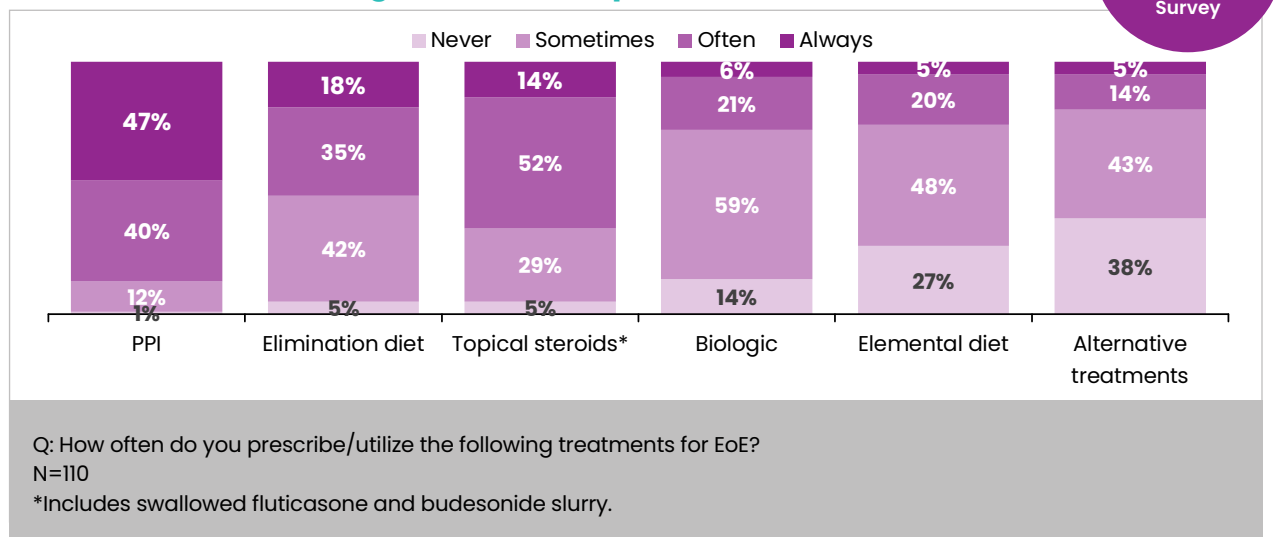
Most patient/caregiver respondents (57%) reported currently being on an elimination diet to help relieve symptoms. However, many patients/caregivers reported using medication to relieve symptoms, including one third (34%) who reported current uses of PPI, and one quarter (25%) who reported current use of swallowed fluticasone. Patients were less likely to use budesonide slurry (14%), elemental diet (11%), biologics (9%), and prednisone (6%). At the time of the patient and caregiver survey, the only biologic approved by the FDA for EoE had only been approved for one month. Many respondents who reported using a biologic for EoE reported off label use.

Figure 28. Experiences with Treatments



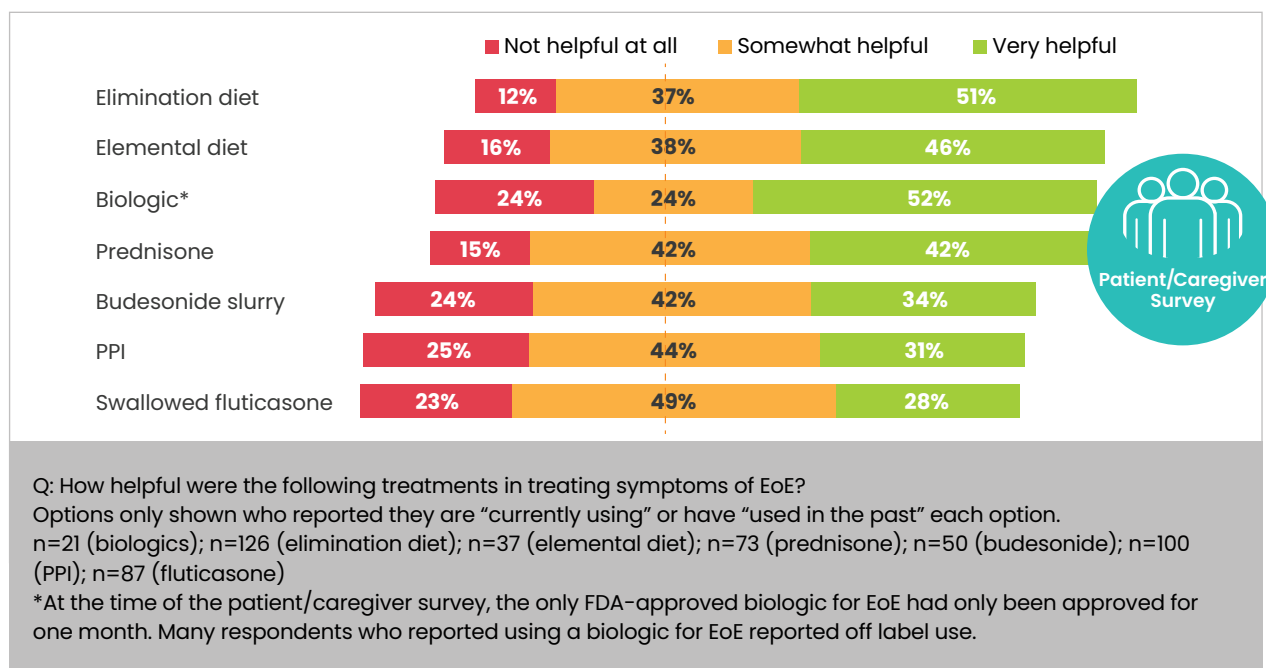
Physicians were more likely to report prescribing PPI – a vast majority (87%) indicated they “often” or “always” prescribe PPI for EoE patients. The most commonly used treatment according to patients, elimination diets, were also frequently prescribed by physicians. Over half (53%) of HCPs reported “often” or “always” prescribing elimination diets. Topical steroids such as budesonide and fluticasone were also frequently prescribed.

Figure 29. Prescription of Treatments



Among all treatment options, dietary treatments were reported to be the most helpful in treating symptoms of EoE among patients/caregivers who used them. Over half (51%) of those who had experience with elimination diets found them to be “very helpful” in treating EoE symptoms, and just under half (46%) found elemental diets to be very helpful. Though very few participants indicated they had used biologics for EoE, and most were used off label, over half (52%) who had used them found them to be very helpful. In most cases, patients reported different treatment options as at least being somewhat helpful in treating EoE symptoms.

Figure 30. Utility of Treatments



However, even when treatments are helpful in treating EoE symptoms, they may come with unexpected challenges. This can present another process of trial and error for patients and caregivers in finding a treatment option that works best for them. Patient and caregiver interviews revealed that sometimes prescribed treatments may not work as effectively as they want them to or may work for a time before reaching a plateau. Patients and caregivers also described how effective treatments that work can still be unpleasant to take or require additional time in an already busy schedule.

“The bolus feeds were difficult because he needed so much. He had to be on overnight drip feeds, which only last six hours and then you’ve got to refill them. I still wasn’t sleeping. And no kid likes to sleep with something sticking down their throat and taped to their cheek. My son would pull his NG tube out in the middle of the night, and all of the formula drains all over the bed and then you have to change sheets and refill and set them all up again. But if he pulled the NG tube out, then it was once a week we were going to the ER to get an NG tube placed again.” – Lauren

“We were mixing the budesonide with the [carrier agent]; it was gross. Asking him to put something in his mouth that he doesn’t like—he’s already picky—was a real challenge at the beginning. Because we were doing twice a day doses, and you can’t eat or drink after, it was always on our brain.” – Eva



Nearly half (44%) of patients/caregivers reported having concerns about current treatments. The most commonly-cited concerns included side effects and impacts of long-term use of medicine. Concerns around dietary treatments were also mentioned, including the long-term impacts of restricting diets, emotional or behavioral changes, and the impact on social life. Finally, patients/caregivers echoed a need for sustainable, effective treatment, indicating current treatments may not work, or do not address the underlying causes of EoE. HCPs in our survey stated that their patients' top three concerns about treatment were efficacy (how well it works), how easy it is to use or stick to, and cost.

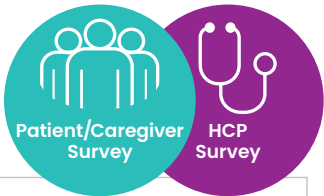
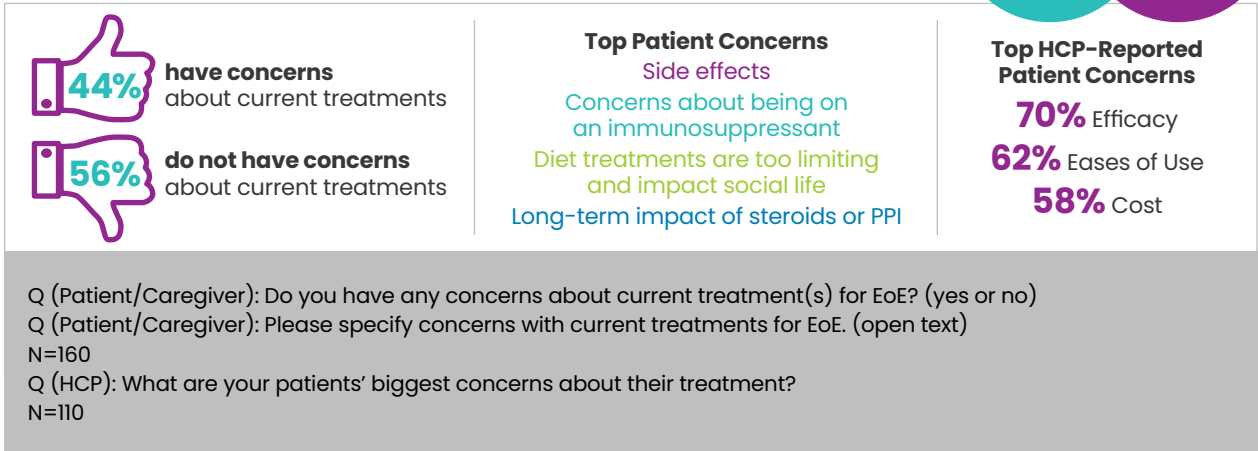
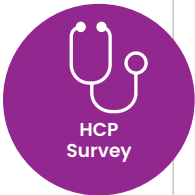
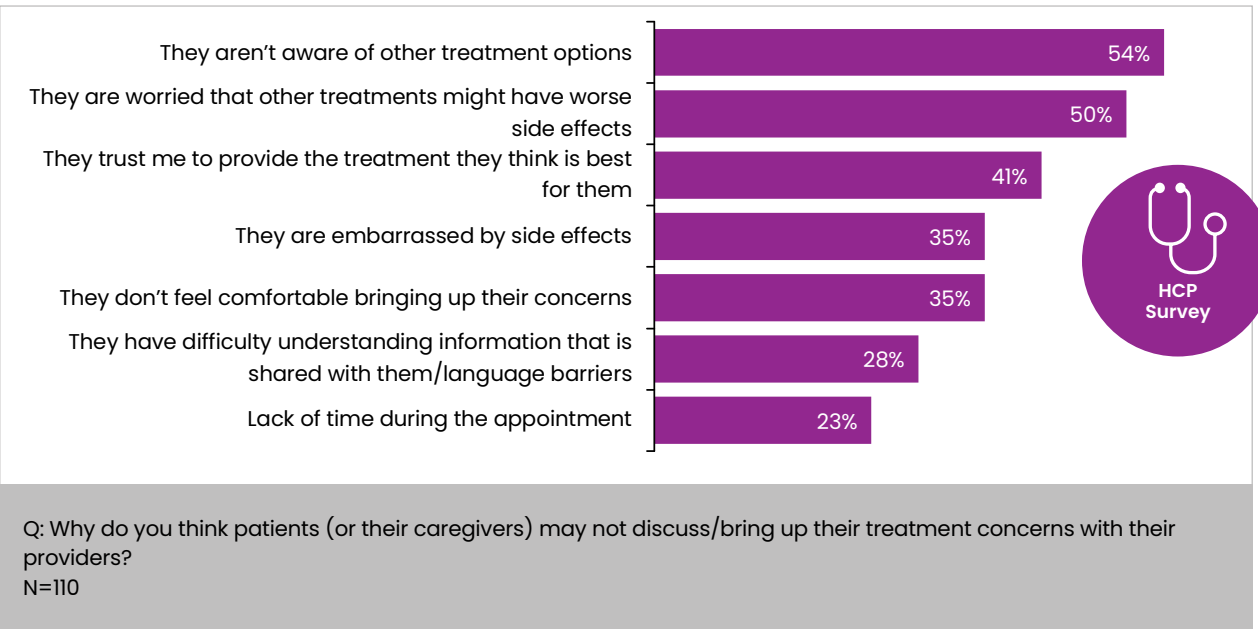


Figure 31. Concerns About Treatments



Most patients/caregivers with concerns about treatment reported discussing their concerns with their doctor. However, one in 10 (11%) said they have not discussed these concerns. When asked why patients/caregivers might not bring up treatment concerns with their doctor, most physicians reported that patients/caregivers may not be aware of other treatment options (54%), or they may be aware but concerned that other treatments might have worse side effects than their current treatment (50%). Two in five (41%) indicated patients/caregivers are likely to trust their doctors in providing the treatment they think is best.

Figure 32. Potential Barriers to Discussing Treatment Concerns



When it comes to making decisions about a treatment path, patients/caregivers and physicians agreed the most important factor is the efficacy of the treatment, or how well it works. However, physicians tended to underestimate the importance of side effects. While over two thirds (68%) of patients/caregivers said side effects were an important factor to consider when making treatment decisions, only one in five (19%) physicians said the same. Physicians also underestimated the power of their own advice. While nearly half (43%) of patients/caregivers consider their doctor's advice as an important factor, only one in ten (11%) physicians believed doctor's advice was an important factor for patients.



Figure 33. Factors Impacting Treatment Decisions

Patients/Caregivers		HCPs	Discrepancy with Patients/Caregivers
79%	Efficacy	63%	-16%
68%	Side effects	19%	-49%
43%	Advice from doctor/ doctor's experience	11%	-32%
36%	Convenience	50%	+14%
25%	Cost	37%	+12%
Not asked	Severity of disease	68%	N/A

Q (Patient/Caregiver): When deciding on a treatment for EoE, what impacts your decision the most?

N=160

Q (HCP): When deciding on a treatment plan for EoE, what impacts the decision the most?

N=110

"It's been really rough for [my son] when he was on the budesonide slurry. The couple of times he's had to do it, he gets really angry." – Rebecca

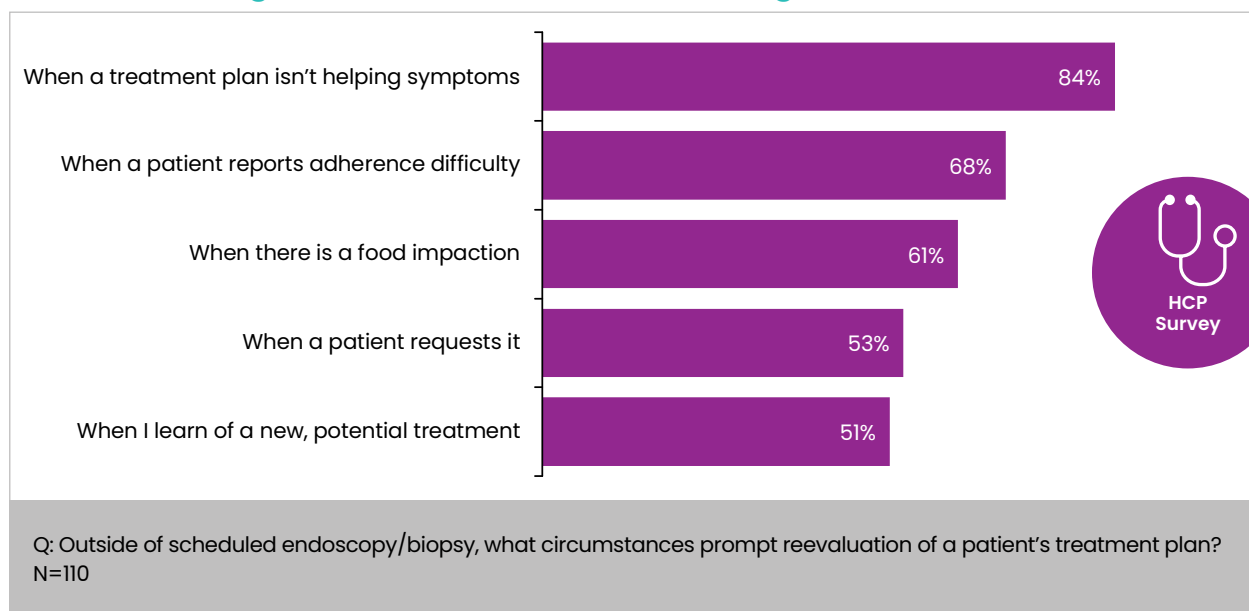
"We tried an elimination diet first, but [my son] still didn't get better. His eczema became a big comorbidity for him. They put him on budesonide and he had an allergic reaction. We stopped using budesonide, but the EoE and the eczema continued. He is now on the biologics which has helped immensely for him." – Lisa

"We just immediately the medication route because the scope itself was a whole other piece of anxiety for my son. The idea of being scoped more frequently [in order to] check whether the elimination diet was working was very stressful." – Eva



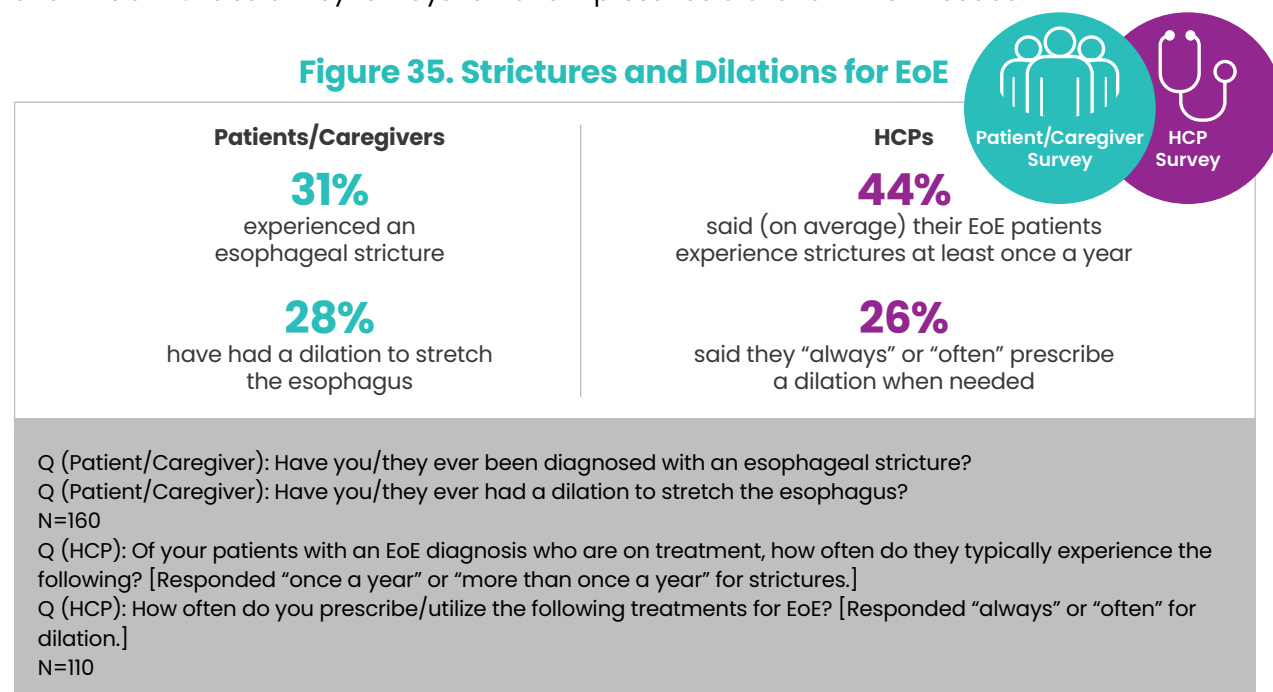
In some cases, treatment plans need to be reevaluated outside of a scheduled endoscopy or biopsy. Most physicians (84%) reported reevaluating treatment plans when current treatments are not helping symptoms. Patient feedback is also an important factor; over half (53%) of physicians reported they will reevaluate a patient's treatment plan if requested, and over two thirds (68%) said they will reevaluate a patient's treatment plan if the patient reports difficulties with adherence.

Figure 34. Reasons for Reevaluating Treatment Plan



About one third of patients/caregivers (31%) reported being diagnosed with an esophageal stricture, or an abnormal tightening of the esophagus. About the same number (28%) reported having a dilation to stretch the esophagus, a procedure not intended as a long-term treatment for EoE. About half of HCPs (44%) said their EoE patients experience strictures at least once a year, and 26% of HCPs said they "always" or "often" prescribe a dilation when needed.

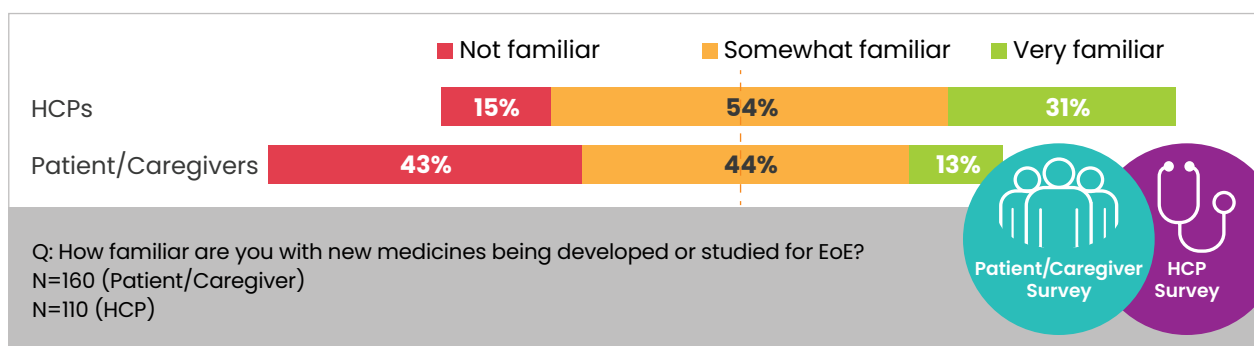
Figure 35. Strictures and Dilations for EoE



Potential therapeutic options for EoE are an area of ongoing study. At the time of this publication, clinical trials are exploring the efficacy and safety of several potential treatments, including a selective sphingosine 1-phosphate (S1P) receptor modulator, fluticasone propionate, a peptide derived from a natural immune-regulatory protein, an angiotensin receptor blocker, and monoclonal antibodies targeting TSLP and IL-13 (biologics).²⁵

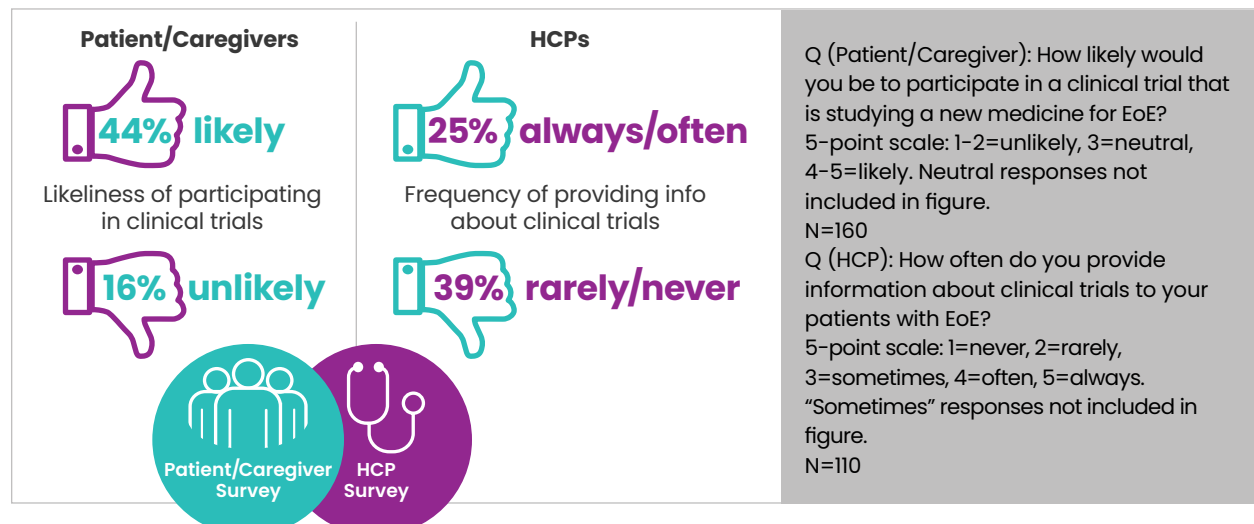
Unsurprisingly, physicians were much more familiar with new treatments for EoE than patients. While nearly one third (31%) of physicians indicated they were “very familiar” with new treatments, only about one in eight (13%) patients and caregivers said the same. In fact, nearly half (43%) of patients and caregivers said they were not familiar with new treatments at all. Awareness of emerging treatment varied by physician type; 48% of allergists/immunologists, 36% of gastroenterologists, and 12% of primary care physicians reported being “very familiar” with emerging treatments for EoE.

Figure 36. Awareness of Emerging Treatments



Patients and caregivers also expressed interest in participating in clinical trials studying new medicines for EoE. Nearly two-thirds (63%) of patients and caregivers said they were “very likely” or “somewhat likely” to participate in clinical trials, and only one in six (16%) said they were “very unlikely” or “somewhat unlikely” to participate. However, it may be difficult for patients and caregivers to find relevant clinical trial opportunities to participate in. Only one quarter (25%) of physicians indicated they “often” or “always” share clinical trial opportunities with their patients, and two in five (39%) say they “rarely” or “never” do. The remaining patients/caregivers (21%) responded neutrally regarding willingness to participate in clinical trials, and the remaining HCPs (35%) indicated that they “sometimes” share information about clinical trials with patients.

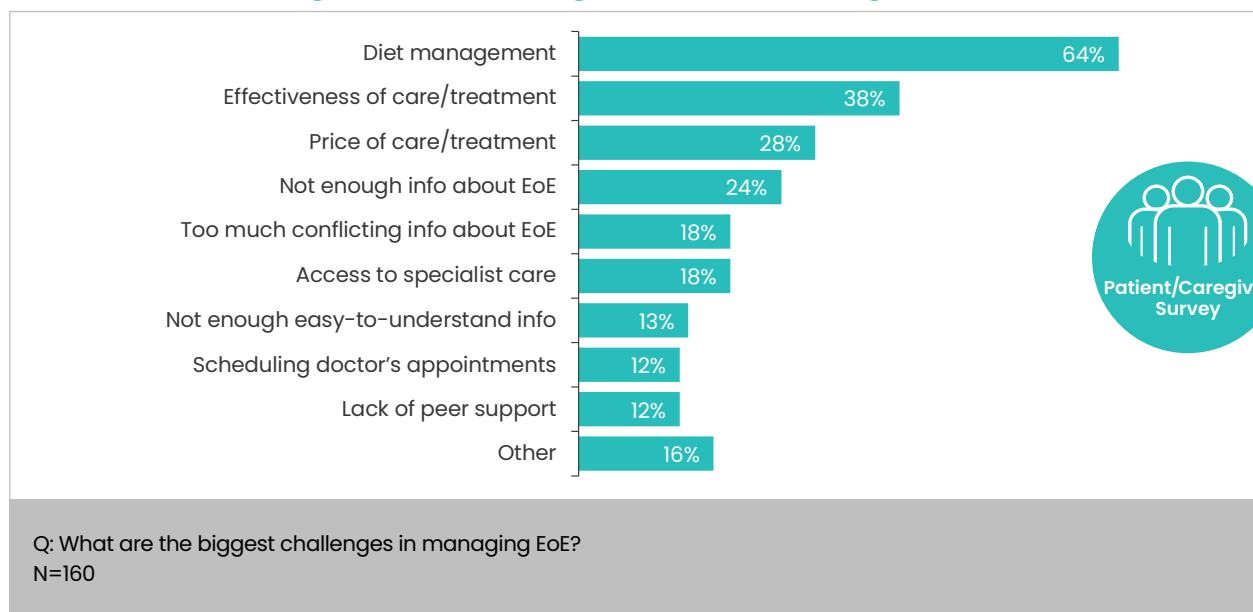
Figure 37. Clinical Trials for EoE



Challenges with Managing EoE

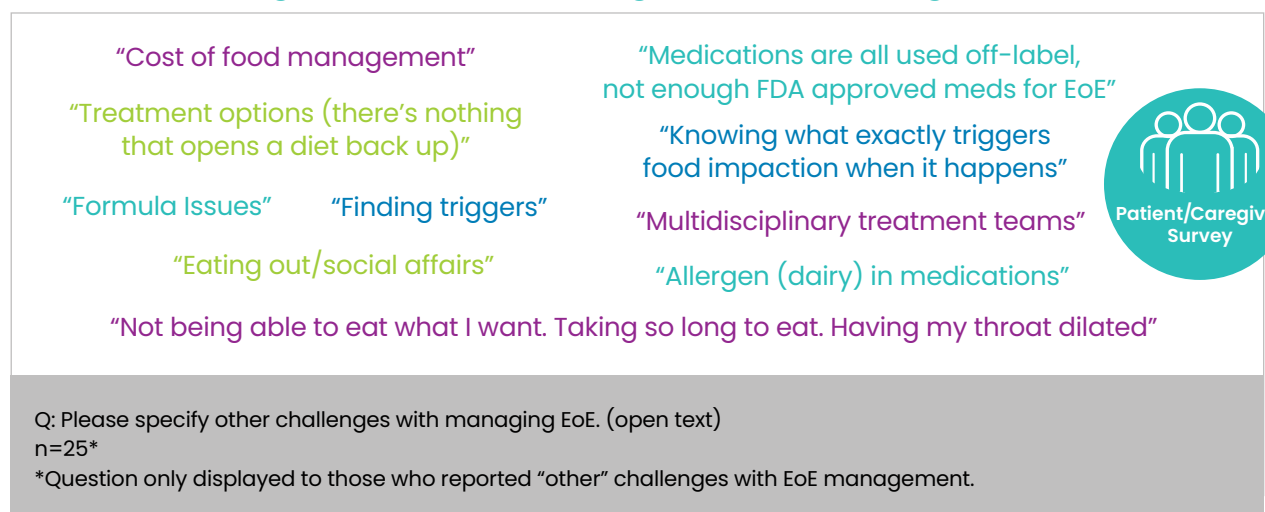
While many patients with EoE find relief after diagnosis, having a name for their condition, and working through a treatment plan, unexpected challenges can still arise. Nearly two thirds (64%) of patients and caregivers indicated diet management as one of the biggest challenges in managing EoE. Two in five (38%) also cite the effectiveness of care and treatment as one of the biggest challenges.

Figure 38. Challenges with EoE Management



One in six (16%) patients and caregivers listed challenges that were outside of the answer options provided. When asked to specify, patients and caregivers reported challenges such as the lack of treatment options, having to limit social activities due to restricting diets, effectively figuring out EoE triggers, and navigating trigger avoidance.

Figure 39. Other Challenges with EoE Management



The adjustments made to daily life, and the challenges that come along with them, were salient in patient and caregiver interviews. Patients and caregivers reported a sense of “mourning” following diagnosis, in recognition of the impact that an EoE diagnosis can have on diet, eating habits, and social life.

“It’s okay to mourn. You’re going to go through the mourning process because it’s going to be different. I just don’t think people are prepared for the emotional impact of this, especially at the beginning, which is quite massive.” – Lisa

“I think it can take a toll on a family of the patient. I think it can take a toll on the mental health. And I think there’s a period of coming to terms with it, and then grieving what it means, and then learning to live with it. The whole process of acceptance and all of that.” – Eva

“I was the only person that I knew with this for a long time until my son got diagnosed, and then it was him and me. We’d never met other people. So there’s a lot of social isolation and a lot of shame, because it sometimes feels like a really dumb disease. I just can’t swallow.” – Rebecca



The challenges of effectiveness of care and finding triggers were also reflected in patient and caregiver interviews. Patients and caregivers describe a long process of trial and error in figuring out triggers, getting the timing of scopes right, and finding treatment options.

“You get a good scope and you’re like, ‘Oh, we found the solution,’ and then six months later you get a bad scope. And you’re like, ‘Okay, what did we do wrong this time?’ And so, lots of up and down at first. And it took probably a good year, at least, for me as a caregiver to not take it so personally.” – Melissa

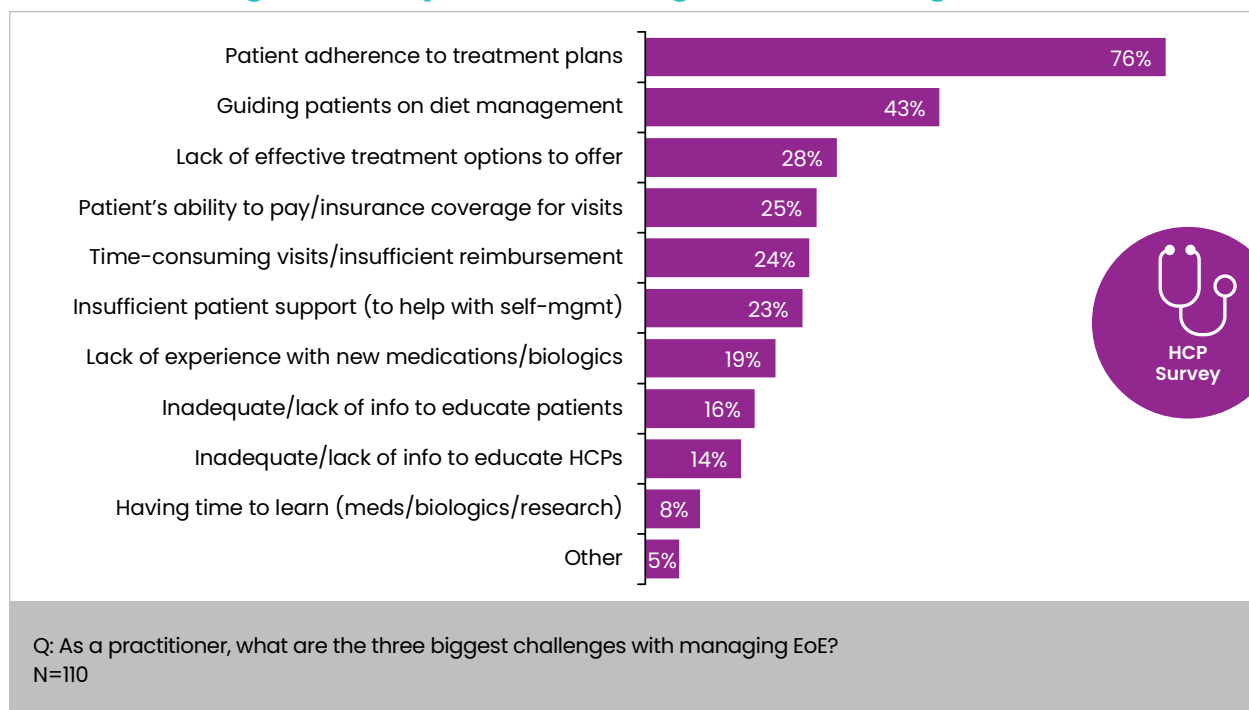
“Her scopes were about every six weeks apart, but it was easy to make sure she had no questionable food for that period of time. Whereas before, when we were looking at three or four months, you start second guessing.” – Ellie

“I wanted to just eliminate with foods and not have medications...[my son’s eosinophils] numbers got lower, but not into remission. He tried the budesonide swallow for a while. It just did not have as good results as the doctors were hoping. And then we went back to the PPI and that brought him back to remission.” – Melissa



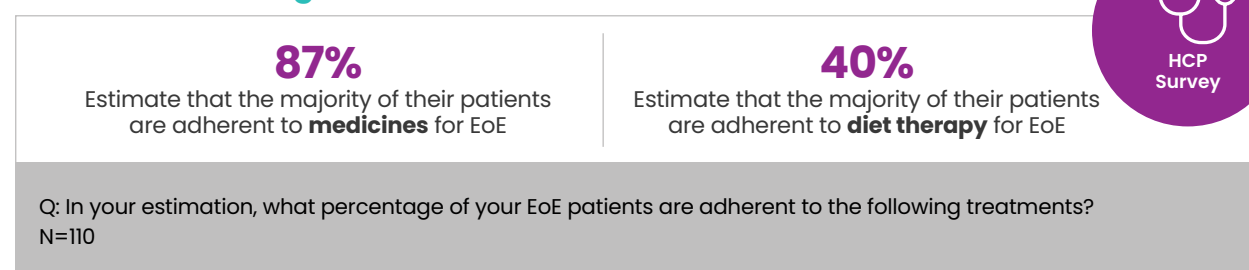
From the physician perspective, patient adherence to treatment plans is the biggest challenge with EoE management (76%). Particularly with the trial-and-error process described by patients, it may be a challenge to find treatments for patients that are both effective and feasible for patients to adhere to. Related, two in five (43%) HCPs also indicated diet management was a big challenge for patients' EoE management. Though selected less often, about one quarter of physicians cite insufficient support systems (23%), appointment times and reimbursement challenges (24%), cost and insurance coverage (25%), and lack of effective treatment options (28%) as challenges. Among those who indicated "other", the most identified challenges were insurance coverage for medication, and age restrictions on some medications.

Figure 40. Physician Challenges to EoE Management



The majority of HCPs (76%) stated that adherence to a treatment plan was the biggest challenge with managing EoE. When asked to estimate the percentage of their patients that are adherent to treatments, HCPs believed that patients were more adherent to pharmacological treatments (medicines) rather than dietary therapies. Most HCP respondents (87%) estimated that more than half of their EoE patients are adherent to EoE medicines, while only 40% of HCP respondents estimated that more than half of their EoE patients were adherent to diet therapy. Given that patients/caregivers reported that dietaries therapies were relatively helpful in treating symptoms of EoE (page 33), it is important to understand the barriers that patients and caregivers might face that can impede adherence to diet therapy.

Figure 41. Estimated Adherence to Treatments

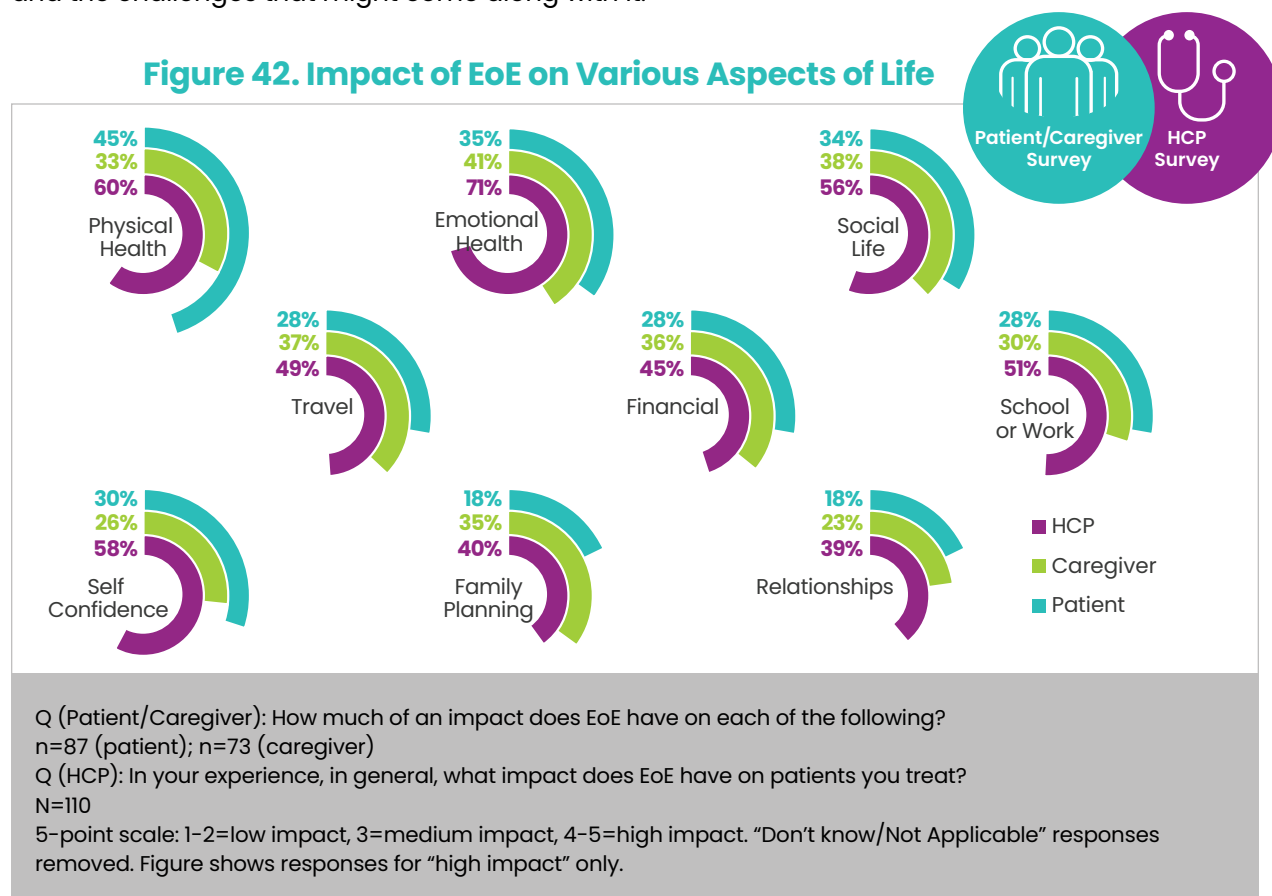


Impact of EoE

EoE can have a salient impact on many aspects of patients' and caregivers' lives. Beyond the physical impacts like EoE symptoms, inflammation, and esophageal damage, patients and caregivers experience social, emotional, and financial impacts as well. Studies have shown that EoE has been associated with anxiety and depression²⁶ and has an impact on quality of life.^{6,27}

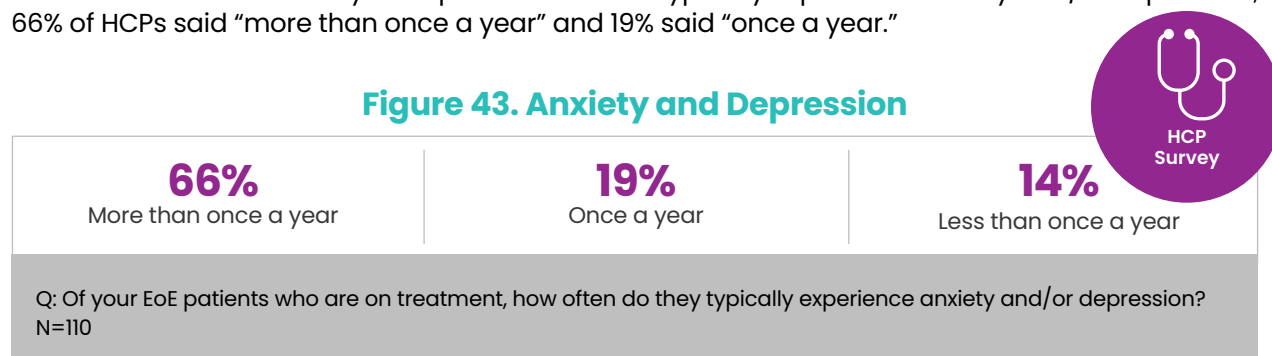
In this study, patients and caregivers said that EoE has the biggest impacts on physical health, emotional health, and social life. Patients' and caregivers' insights differ from HCP insights; HCPs said EoE has the biggest impacts on their patients' emotional and mental health, physical health, and self-confidence. In general, HCPs perceive that EoE has a bigger impact on patients than patients own self-report. It may be that patients consider EoE to be just one of many factors impacting their lives, whereas HCPs solely see patients within the context of EoE management, and the challenges that might come along with it.

Figure 42. Impact of EoE on Various Aspects of Life



When asked how often they think patients with EoE typically experience anxiety and/or depression, 66% of HCPs said "more than once a year" and 19% said "once a year."

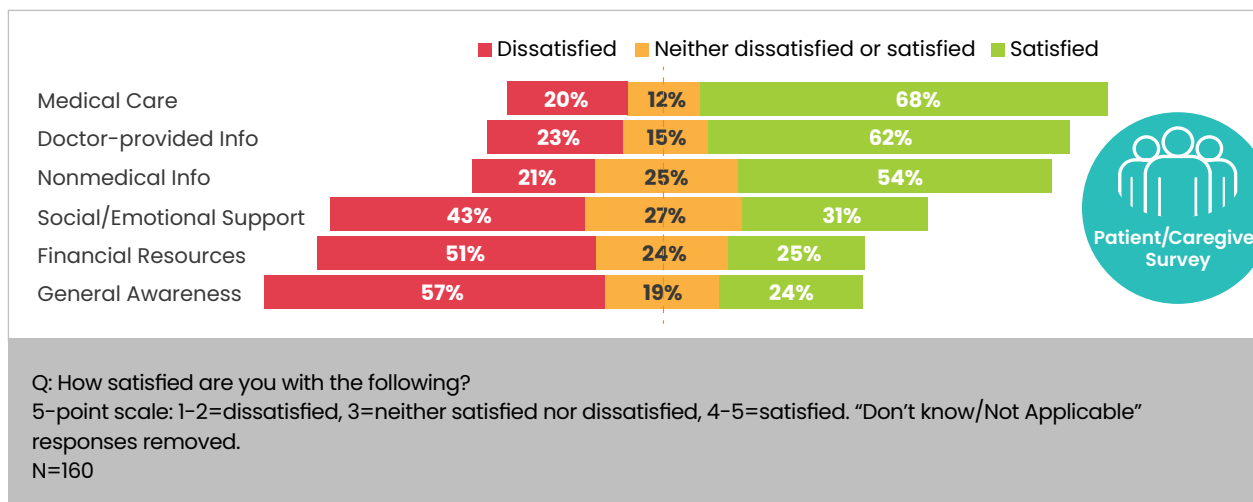
Figure 43. Anxiety and Depression



Resource Needs

When looking at satisfaction with resources that are currently available, a majority of patients and caregivers are satisfied with their medical care, as well as information around EoE. These results highlight the importance of appropriate and informative care; though patients experience challenges with diagnosis and management, finding the right doctor to navigate these challenges can be instrumental. Areas where patients and caregivers are less satisfied include general awareness of EoE (57% dissatisfied), financial resources to support medical care (51% dissatisfied), and social and emotional support (43% dissatisfied).

Figure 44. Patient/Caregiver Satisfaction with Resources



Mixed satisfaction with social and emotional support was a theme that came up in patient and caregiver interviews as well. Patients and caregivers described how invaluable it was to receive interpersonal support, especially from others who are managing EoE. At the same time, patients and caregivers described how support given in EoE support groups can be difficult to interpret depending on where in the EoE journey someone was. Given the increased presence of online support groups following the COVID-19 pandemic, these discussions stressed the need for systems and resources that support a broad range of EoE experiences.

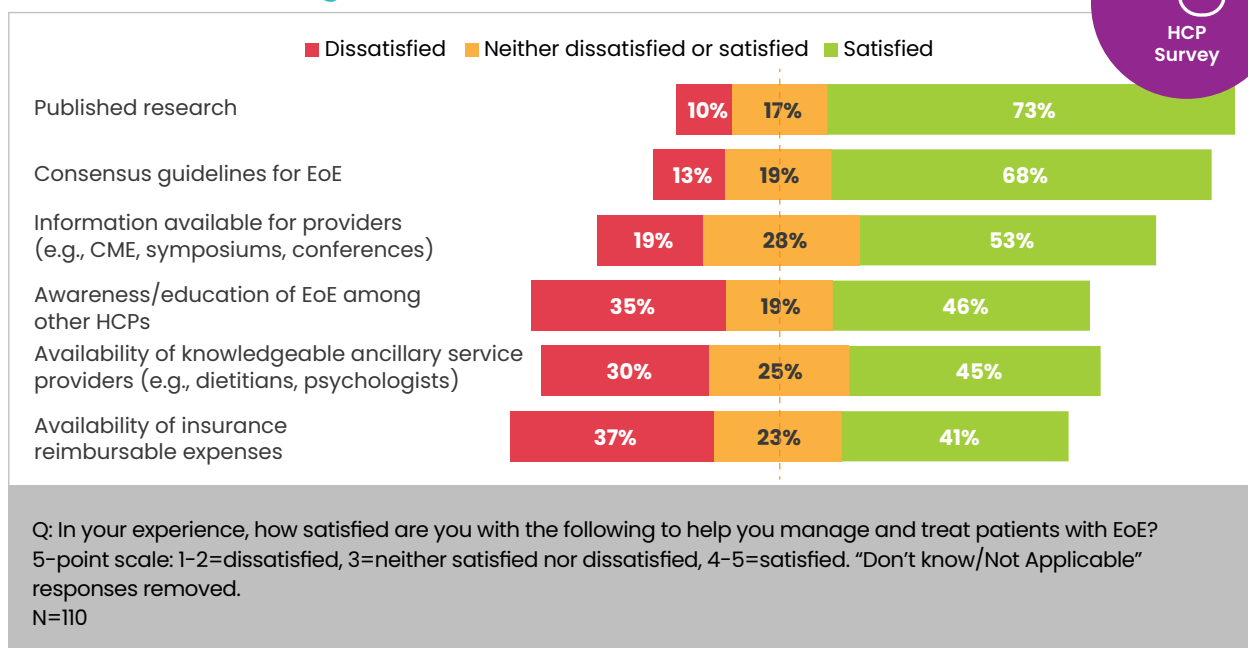
"One lady in our neighborhood has two kids who have it [EoE] and her husband just got diagnosed, too. So it's nice because we're sharing how to cope with it together." – Lisa

"We got a book, came to school, and we did a story time and question and answer with this class about what food allergies are and EoE and why some people can't eat certain kinds of food...And the kids are just surprisingly so helpful about wanting to make sure he felt included and not excluded because of things he could or couldn't eat. I think that helped his confidence going forward." – Melissa

"I found that often when you're in a support group situation online or in-person, there are the people that need the most help, that are struggling the most and have the scariest stories to tell. And so it's often skewed negatively. Like in terms of EoE, EoE is such a little part of our lives [now]. But there's probably a whole lot of people out there dealing with EoE that's a little part of their life. It's valid, too." – Ellie

On the HCP side, more than half of the providers were satisfied with the information about EoE available to them (53%), and about two thirds were satisfied with the consensus guidelines. However, when asked about their awareness of consensus guidelines, 14% indicated they were not aware of guidelines for EoE, including 23% of primary care physicians. The area with the second-lowest level of patient/caregiver satisfaction, financial resources, was echoed by HCPs. Nearly two in five (37%) HCPs indicated they were dissatisfied with the availability of insurance reimbursable expenses for patient diagnostics or treatments.

Figure 45. HCP Satisfaction with Resources



These sentiments were echoed in open-ended responses from physicians. Even though doctor-provided EoE information was an area of high satisfaction among patients, physicians expressed a need for more handouts, pamphlets, and other resources they could provide to patients about EoE. Other needs include standard guidelines, specifically as more treatments become available (at the time of the HCP survey, dupilumab had been approved for EoE by the FDA for approximately eight months). HCPs also noted the need for ancillary services such as nutrition, psychological, and social support.

Figure 46. Physician Resource Needs

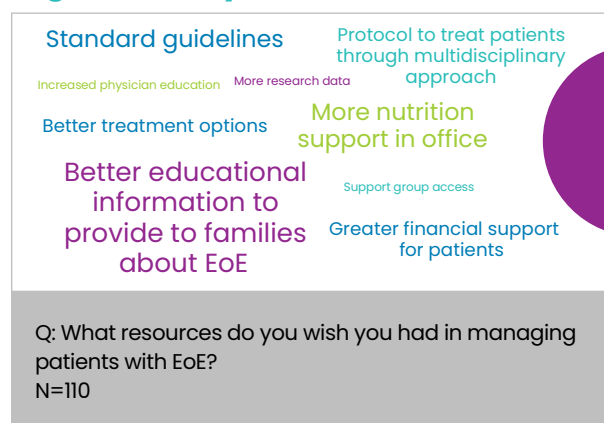
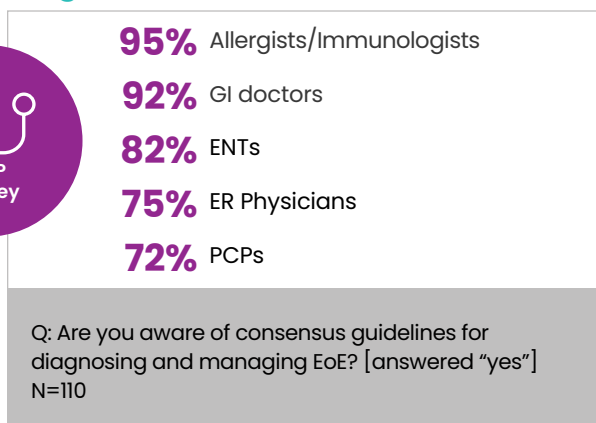


Figure 47. Awareness of Guidelines



Dissatisfaction with insurance coverage and financial resources was also apparent in the open-ended responses from the patient and caregiver survey. When asked to identify resources that are needed, patients and caregivers often expressed better insurance coverage of diagnostic tests and treatments.



"I wish the insurance companies would cover more of the cost for repeated endoscopies. This has been a huge issue for us."

"Better insurance coverage; just because my kid CAN eat, doesn't mean he does. We need elemental formula to make a nutritional shake so he consumes something but can't get coverage for it and it's expensive."

"I wish insurance companies were more knowledgeable and overall supportive of maintenance that works best for individual patients and not just an overall preferred treatment plan for the class of patients. Some treatments work better for others; everyone is different."

"Advocate for insurance reimbursement for complex care and travel to specialty centers when needed."

Some disparities exist in patient/caregiver and HCP satisfaction with awareness around EoE. While patients and caregivers are generally satisfied with medical care and doctor-provided resources around EoE, only 24% were satisfied with general awareness of EoE. On the HCP side, nearly half (46%) indicated they were satisfied with awareness and education of EoE among health care providers. Patient and caregiver interviews highlighted areas of the highest need when it comes to HCP awareness. In addition to general awareness, patients and caregivers stress the importance of relevant practical knowledge, and being able to develop treatment plans and recommendations that align with individual patient needs.



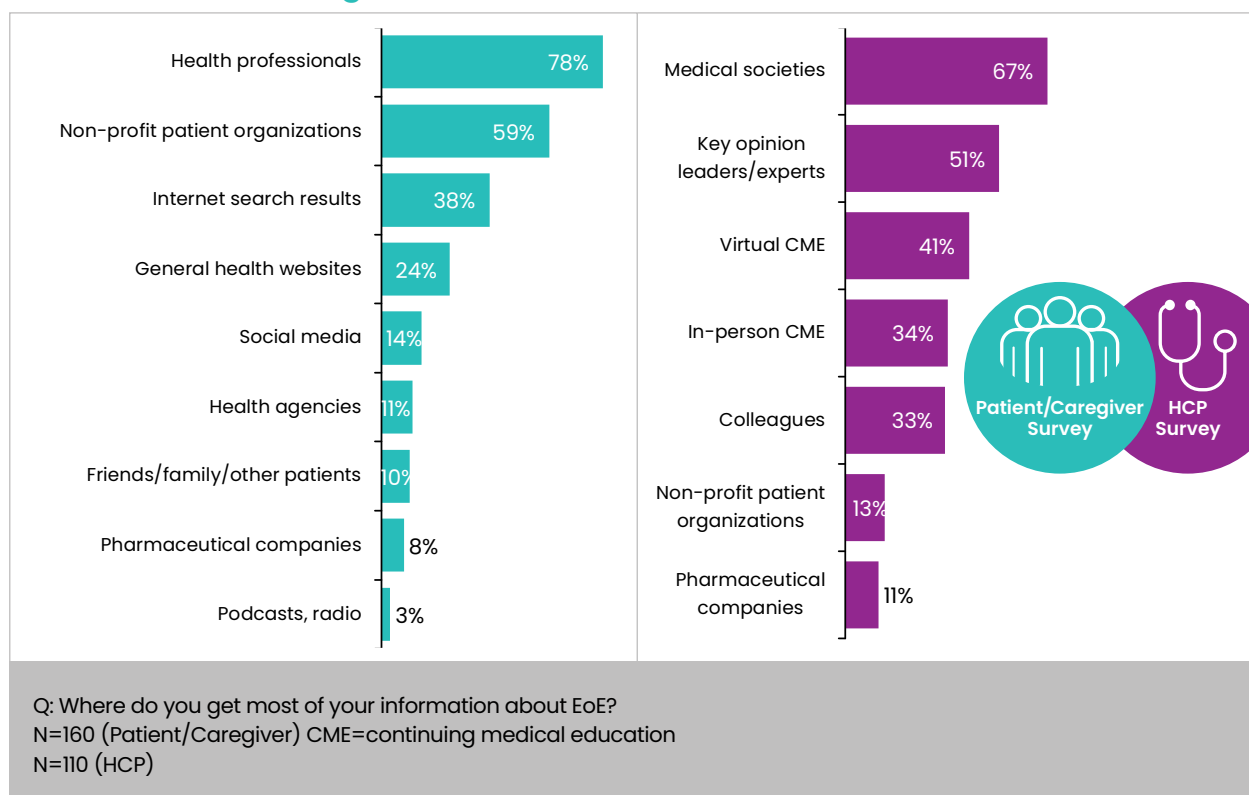
"I really think there needs to be a lot more attention paid to allergies, asthma, and things like this, the esophageal problems in medical school. I think there needs to be a lot more focus on it, because I'm not the only one." – Charlotte

"I feel like sometimes the doctors don't know the practical. Often, unless it's like the nutritionist in the EoE clinic, they don't understand multiple restrictions, so they can tell you, 'leave out butter', but they don't realize that you're going to have to look for a very specific margarine that doesn't also have soy and corn and everything else in it, and how to cook when none of those work." – Ellie

"I've run into so many [doctors] who don't know what it even is or how to begin to treat it. So, they go and they look up how people have been treated in the past, and it may not be the newest information...just having access to the educational material and being up to date on what the best practices are." – Rebecca

HCP awareness and knowledge of EoE is particularly important, as over three quarters of patients and caregivers get their information from health professionals. Additionally, a majority of HCPs get their EoE information from known field experts (51%) and medical societies and professional organizations (67%). Therefore, it is critical to raise awareness and education around EoE across the medical field.

Figure 48. Sources of Information for EoE



AAFA and APFED offer EoE resources for patients, caregivers, and health care providers (page 61)

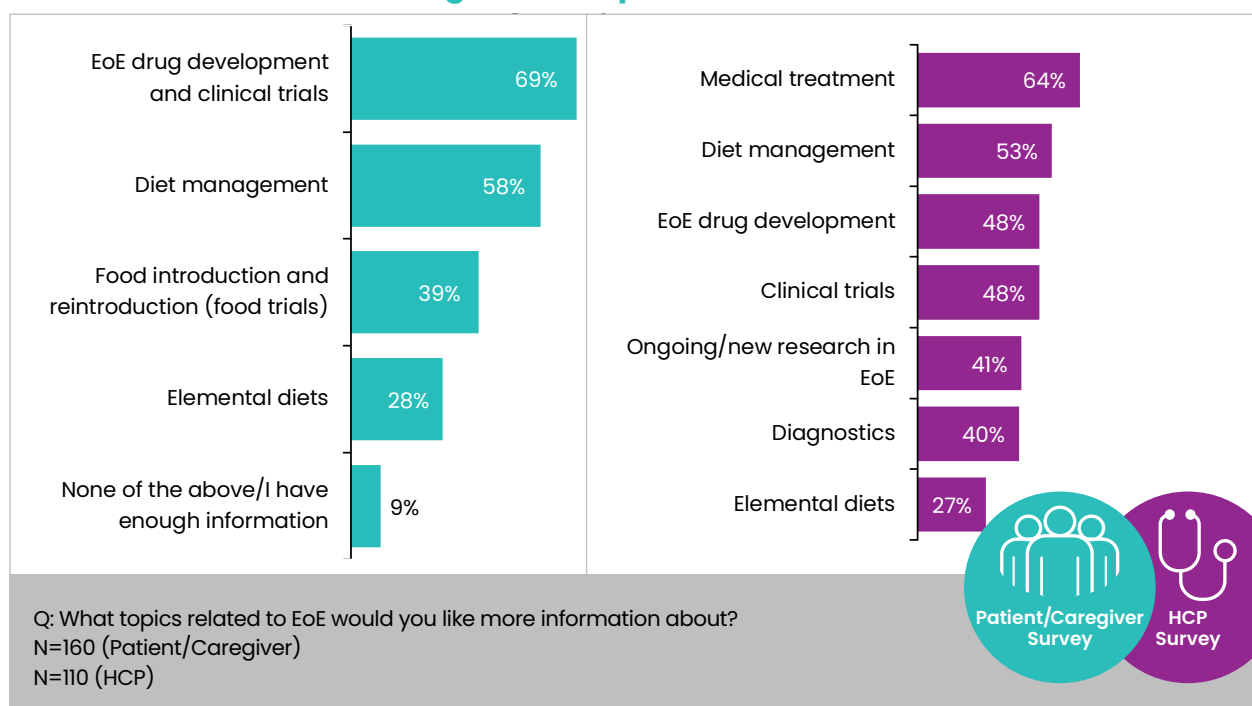
"On the APFED website or the Kids with Food Allergies online community, reading other people's stories [was helpful]. Or asking questions and reading through suggestions and stories from other people just helps to get a better idea of other kids' and other parents' experiences...I think that empowered me more as a parent to be curious, because I'd read something and then I'd go look for more information about it. I think that [helped to have] a better conversation with the GI doctors about next steps, and what was working and what wasn't working." – Melissa

"I was a volunteer with Kids with Food Allergies [AAFA's food allergy division] for a while, so I knew all of the 'starting out' tricks when the doctor came to me and said, 'Here, take this out of your diet.' I told him, 'Oh, I've been eavesdropping in the EoE [forums]. I know what to do. I'm not scared.'" – Ellie



Patients and caregivers and HCPs tend to differ in the topics they are interested in learning more about. While over two thirds (69%) of patients and caregivers are interested in learning more about EoE drug development and clinical trials, less than half (48%) of HCPs are interested in the same topic. However, there is some overlap in interests – over half of patients and caregivers (58%) and HCPs (53%) are interested in learning more about diet management, and roughly one quarter of both patients and caregivers (28%) and HCPs (27%) are interested in learning more about elemental diets. In these instances, it is important to have resources that are informative and appropriate for both audiences.

Figure 49. Topics of Interest



Patient and caregiver interviews highlighted these interests, expressing a need for comprehensive resources that cover everything from symptoms to treatment options. Patients and caregivers also stress the need for resources that cover a broad range of experiences.

"I really think that having a place that talks about all the symptoms, a place that talks about the emotional portion of this...and it isn't just the person with EoE, it is anybody who loves the person with the EoE, and especially caregivers." – Lisa

"It would be helpful if discharge papers had some resources and suggestions for food substitutions that were culturally sensitive and account for those who already have multiple diet restrictions because of health" – Charlotte

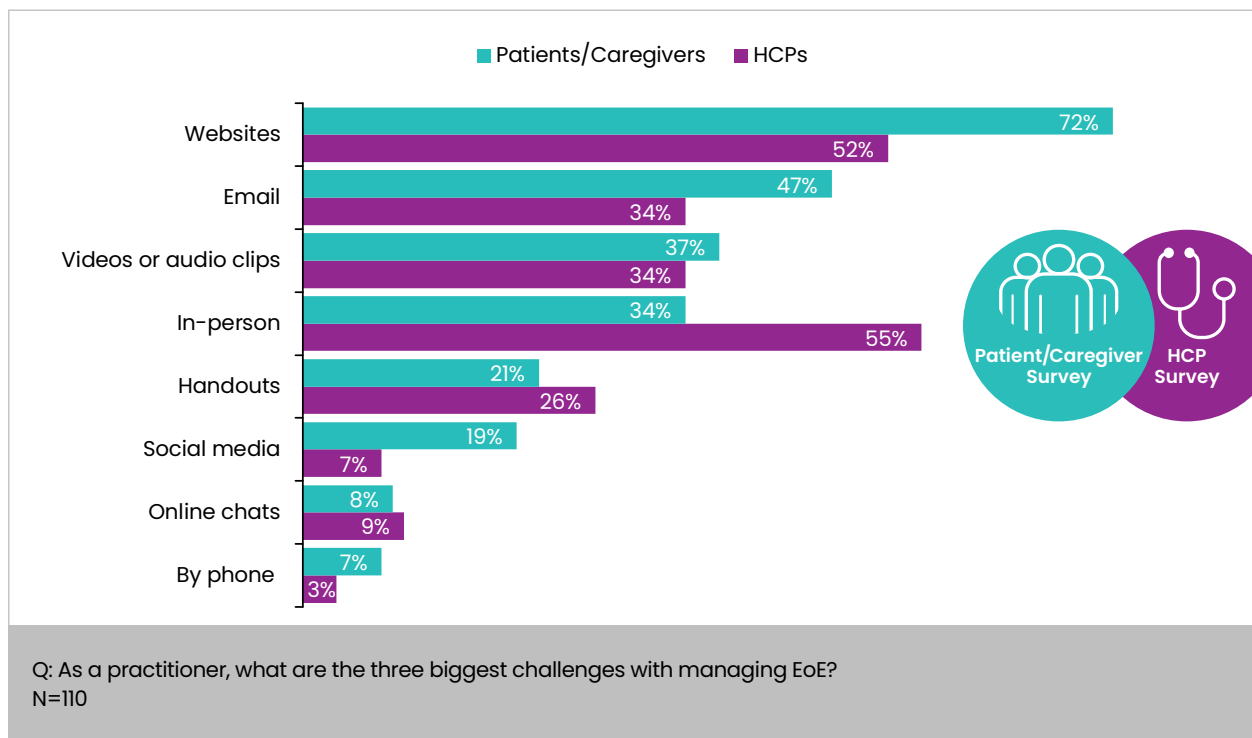
"I really think just providing as much information as possible, and maybe like a spectrum of care, if that makes sense. Putting out all the options." – Eva

"I think it would be helpful if there were a place that shared all of the different potential treatments. I haven't found one place that has that...I would love a place where we can look at efficacy for treatments and different ones that are available." – Lisa



In terms of how EoE information is delivered, patients and caregivers largely prefer to receive information through websites. Patients and caregivers are more likely than HCPs to want to receive information through virtual delivery such as websites (72% vs. 52%) and email (47% vs. 34%), whereas HCPs prefer more in-person delivery, such as through in-person meetings and conferences (55% vs. 34%) and handouts (26% vs. 21%). These differences highlight areas in which resources can be developed for different audiences.

Figure 50. Preferred Method of EoE Information Communication



In addition to resources for patients and caregivers and HCPs, patient and caregiver interviews also reflected a need for resources to others in patients' support system, such as other family members, friends, and school staff. Developing resources for a wide range of audiences can help raise awareness of EoE and ensure EoE patients feel supported outside of their direct care team.

"I think the other piece for me was the people around us. When he started feeling better, in their minds, they're like 'Well, he's better. He's fine.' But I know this is something he's living with. And the reason he's feeling better is because he's on a regular medication. He's not just fixed, and we can't just stop. We can't just say he's done. Having resources to share with family members too, about the fact that this is a chronic thing that he's living with." – Eva

"You are optimistic with your kid; you educate your kid. You show them videos, read books, make it normal for your kid and help them advocate for themselves, making other people aware, classmates or sports mates, or other people like that. Because if other people are aware, they're going to be more cognizant in general." – Melissa

"At the school level and creating a 504 and an IEP and all of that, things have gotten much better since we started this journey. I think there's much more training. I think there's much more understanding as more and more kids have food allergies and eosinophilic issues. But there's still a long way to go." – Lisa



Unmet Needs and Opportunities to Improve Care

In the 30 years since eosinophilic esophagitis (EoE) was first recognized as a disease, the prevalence and incidence of EoE has increased significantly. Research helped improve the understanding of etiology, pathophysiology, clinical manifestation, and burden of disease for EoE. As the landscape of EoE care in the U.S. continues to evolve, the Asthma and Allergy Foundation of America (AAFA) and the American Partnership for Eosinophilic Disorders (APFED) recognize the need to better understand current challenges and barriers to timely diagnosis, quality medical care, effective treatments, and access to resources for EoE.

This report provides an overview of the EoE journey from the patient, caregiver, and health care provider (HCP) perspectives using data gleaned from a multi-component needs assessment study. By analyzing data and common themes from the study, AAFA and APFED identified several unmet needs and areas of opportunity for improving EoE care.

In this section, we summarize unmet needs that emerged from the study as well as opportunities for EoE stakeholders to address needs in the following domains:

- Clinical care and HCP education
- Treatments and patient-centered research
- Patient education and public awareness
- Psychosocial support
- Advocacy and financial support

Unmet Needs in Clinical Care and Health Care Provider Education

Patients and caregivers reported encountering numerous barriers to accessing appropriate care for EoE. The process of diagnosis can be lengthy and frustrating. Proper and timely diagnosis for EoE is important to facilitate prompt treatment to halt damage to the esophageal tissue. Treatment delays contribute to irreversible fibrosis of the esophagus. The majority of patient and caregiver respondents indicated that it took a year or more for them to receive an accurate diagnosis for EoE after first noticing symptoms (Figure 8). Lengthy diagnosis was correlated with factors such as being misdiagnosed (or spending time ruling out other diseases), challenges accessing a specialist, and barriers to diagnostic testing (Figure 9). Patients and caregivers also report seeing multiple specialists or waiting long periods of time to see the right specialist (Figure 14). Patients cited low symptom awareness and knowledge of EoE among health care providers among the contributors to a delayed diagnosis (Figure 17).

Symptoms may not be readily recognized by people experiencing them or by the HCPs they go to for initial consultation. When medical care is sought, a person may experience dismissal of symptoms by their doctor, multiple clinic visits with different specialists, and misdiagnoses. Many patients/caregivers reported encountering HCPs who were not knowledgeable in EoE symptoms and diagnosis.

Awareness of EoE symptoms, in both primary and specialty care, remains a critical unmet need. HCP education—which can be delivered through lectures at medical conferences, continuing medical education programs, curriculum for medical students and fellows, visiting fellowships/ grand round programs, awareness campaigns on platforms that clinicians use for information, etc.—can improve knowledge and awareness of EoE symptoms. This is critical to improving the diagnostic journey for people with EoE.

Opportunity: Build educational programs for health care providers that focus on improving recognition of EoE symptom awareness among different age groups and differentiating between EoE and other masqueraders, such as gastroesophageal reflux disease. Develop and disseminate resources for HCPs (e.g., patient conversation guide, screening tools) to better identify adaptive behaviors that may be indicative of EoE.

In addition to recognizing symptoms, alignment with clinical guidelines for the management of EoE can help reduce the barriers to timely and accurate EoE diagnosis. Expert consensus guidelines for the management of EoE were published in 2007²⁰ and updated in 2011²¹. Updated again in 2018¹⁴ and 2020²⁸, diagnostic criteria evolved to recommend that proton pump inhibitors (PPIs) be used as a treatment for EoE rather than a diagnostic tool. Although the vast majority of HCPs surveyed said they were familiar with the guidelines for EoE management (Figure 47), the vast majority said that non-response to PPI would prompt them to refer a patient to a GI doctor to pursue an EoE diagnosis (Figure 16). While this aligns with the 2007 and 2011 consensus report, it is contradictory to the 2018 updated consensus recommendation to remove PPI as a diagnostic tool.

These guidelines also acknowledge the role of endoscopy in diagnosing EoE. Timely referral to a gastroenterologist to perform needed procedures may reduce the time it takes for patients to be diagnosed with EoE and ultimately offered treatment. However, some non-GI health care providers reported that they did not refer a patient to a GI specialist, even if EoE was suspected, because symptoms were vague and/or because patients were reporting symptom decrease with the treatment plan initially prescribed (Figure 15).

There is a need for physicians to be aware of consensus guidelines—particularly when it comes to diagnostic criteria and the need to refer a patient for endoscopy and biopsy services. Additionally, more than one third of HCPs reported dissatisfaction with current awareness and education of EoE among other HCPs (Figure 45).

Opportunity: Increase awareness of current consensus guidelines to support prompt and accurate diagnosis of EoE. Develop and utilize clinical care algorithms in tandem with consensus guidelines so that health care providers can better understand when to refer a patient to a specialist. Support development of reliable biomarkers and advancements in less-invasive clinical testing to detect and monitor EoE, reducing the number of endoscopies and biopsies that are performed under anesthesia.

While there is a need to improve awareness of existing guidelines, it is also important to acknowledge advances in EoE diagnostic methods, understanding of disease pathophysiology, and treatment modalities. Updated consensus guidelines can ensure these advances are accounted for in the diagnosis and evidence-based clinical management for EoE.

Opportunity: Update expert consensus guidelines to consolidate current recommendations for both diagnostics and clinical management to help ensure people with EoE are offered evidence-based treatment plans. These guidelines should include current diagnostic and monitoring methods available for EoE, including emerging unsedated techniques. Medical societies, health care groups, and patient advocacy organizations must support increased awareness and adoption of these guidelines as recognized best practices.

Following diagnosis, clinical management of EoE often involves repeated endoscopies, ongoing testing, and treatment evaluations. People with EoE often have more than one doctor or specialist involved in their care (Figure 23). Initial consultation may begin with a primary care provider, specialist, or in an acute care setting. Patients are then referred to a gastroenterologist to conduct testing required for EoE diagnosis. Once the diagnosis is determined, the ongoing care team may include allergists/immunologists, gastroenterologists, primary care physicians, and ENT doctors. HCPs acknowledged that many patients with EoE may also benefit from ancillary services such as dietitians, speech or occupational therapists, and mental health professionals (Figure 24). However, patients may not have access or be referred to appropriate specialists and ancillary services.

A multidisciplinary care team is important for effective EoE management; particularly for patients with allergic comorbidities and patients experiencing anxiety and/or depression. The establishment of protocols to refer patients to specialists may support improved care for EoE patients. Multidisciplinary care models and treatment algorithms that include evaluation for other specialty services, such as psychology, can improve EoE patient care. Additionally, embedding services related to nutrition and diet within allergy or gastroenterology practices may provide better care coordination and support for patients with EoE.

Opportunity: Develop models of multidisciplinary care teams for both public and private practice settings to help health care providers ensure people with EoE have access to appropriate, comprehensive care.

Expansion and awareness of referral resources, such as APFED's Specialist Finder (see Resources on page 61), can help patients find specialty services and improve EoE care.

In addition to a multidisciplinary team of HCPs, the patient is a critical part of the health care team. For optimal patient-centered clinical care, ongoing education for HCPs should incorporate the patient perspective. Educational programs for HCPs can be offered through their preferred methods, such as in-person conferences, websites, and continuing medical education programs (Figures 48 and 50).

Opportunity: Develop and disseminate models for referral, diagnostic, and treatment algorithms to both clinicians and patients. Treatment algorithms should include referring patients to reputable patient advocacy organizations for patient education and support. HCP education programs incorporating patient perspectives would elevate symptom awareness, and in turn, help reduce diagnostic and treatment delays. Patient perspectives can also help inform HCPs about the struggles people face at different points of their journey and improve patient-provider communication.

Unmet Needs in Treatments and Patient-Centered Research

Treatment of EoE is often a long process of trial and error. Most patients/caregivers reported trying various pharmacological treatments for EoE at some point during their journey (Figure 28). Patients cite a number of concerns about current treatments, including side effects and long-term impacts of pharmacological interventions (Figure 31). The lack of FDA-approved medications for EoE* and the common practice of medications being used off-label for EoE cause challenges in managing EoE (Figure 39).

Patients/caregivers reported effectiveness of EoE care/treatment as one of the biggest challenges with EoE management (Figure 38). Similarly, HCPs reported a lack of effective treatment options to offer as one of the top challenges in managing EoE (Figure 40). For example, proton pump inhibitors—the most commonly-prescribed treatment by HCP respondents (Figure 29)—had the second lowest patient-reported utility for treating EoE (Figure 32).

Patients/caregivers and HCPs acknowledged the need for better, sustainable, and more effective treatment options for EoE, expressing that commonly-used treatments like PPI and topical steroids may not work or may not address the underlying causes of EoE. In 2022, the approval of dupilumab (a biologic) for EoE marked the first FDA-approval of a treatment for EoE. Limited options in drugs approved for EoE remains a barrier to treatment. Topical corticosteroids that are often prescribed to treat EoE are used off-label and cause variability with dosing due to compounding, a practice which often involves patients/caregivers mixing their own “home brews” with various carrier agents.

Opportunity: Develop new safe, effective, convenient, and affordable therapies indicated for the treatment of EoE. The FDA, researchers, patient advocacy groups, drug developers, and patients must all support pipeline developments to bring to market new therapies indicated for the treatment of EoE.

Patient/caregivers and HCPs also expressed concerns about dietary therapies, one of the recommended treatments for EoE. Dietary restriction is burdensome to patients and their family members, particularly without access to ancillary services such as a registered dietitian. Food is an integral part of life and dietary restrictions due to EoE can negatively impact activities such as dining out, holidays, family gatherings, social or professional engagements, and travel. Patient/caregiver concerns around dietary therapies included the long-term impacts of restricting diets, emotional or behavioral changes, and the impact on social life.

Most patient/caregiver respondents reported currently being on an elimination diet (Figure 29), and patients/caregivers also reported diet management as the biggest challenge in managing EoE (Figure 38). Similarly, HCPs report guiding patients on diet management as one of the top challenges in managing EoE (Figure 40). Though elimination diets are commonly used and prescribed to treat EoE (Figures 28 and 29), HCPs estimate that adherence to dietary therapies for EoE is significantly lower than adherence to pharmacological treatments (Figure 41). Additionally, patients/caregivers identified diet management as one of the top EoE topics they'd like more information about (Figure 49).

Opportunity: Expand practical strategy resources to help improve adherence to dietary therapy. Increase awareness among HCP of resources to help implement and manage a patient who utilizes dietary therapy.

*At the time of the patient/caregiver survey, the only FDA-approved treatment indicated for EoE (a biologic) had only been approved for one month.

The majority of HCP respondents believed that patients' lack of awareness of existing treatment options may be a barrier to discussing treatment options (Figure 30). Additionally, the factors impacting patients' treatment decisions do not always match the factors that HCPs believe to drive treatment decision-making (Figure 33). HCPs reported that they most often reevaluate patient treatment plans when they learn of new potential treatments for EoE (Figure 34). HCPs identified medical treatment as the top EoE topic they would like information about (Figure 49).

Shared decision-making tools can help improve patient/caregiver awareness—as well as HCP awareness— of current treatment options and support patient-centered treatment for EoE.

Opportunity: Develop shared decision-making tools for patients and providers to facilitate discussion about treatment options and determine an appropriate course of therapy that the patient can reasonably access, afford, and adhere to. Patient's lifestyle and treatment preferences need to be considered as this is highly likely to influence adherence to the treatment plan.

There is also a lack of awareness in emerging treatments among patients and caregivers (Figure 36). Patients/caregivers identified EoE drug development and clinical trials as the top topic they'd like more information on (Figure 49). Though there is greater awareness of emerging treatments among HCPs (Figure 36), HCPs also identified drug development as one of the main topics of interest (Figure 49).

Opportunity: Elevate awareness of current and pipeline treatments for EoE among health care providers, patients, and caregivers.

Patient involvement in clinical trials is crucial for the development of new therapeutic options. However, patient and health care provider responses showed disparities with regard to awareness of treatments in the development pipeline and willingness to participate in clinical trials. More than half of patient respondents indicated they are somewhat or very likely to participate in clinical trials, whereas health care providers indicated they were less likely to provide information about clinical trial opportunities to patients (Figure 37).

Opportunity: Increase awareness of clinical trial and research survey opportunities among patients and health care providers.

Clinical trials for EoE are challenging, as clinically significant endpoints must address what is meaningful to patients. This is difficult for a condition like EoE because patients experience a variety of symptoms that can differ between individuals. Therefore, what is considered a meaningful outcome for patients is varied.

Opportunity: Incorporate the patient voice in clinical trial design so that endpoints are meaningful, and protocols aren't overly burdensome or financially challenging for patients to participate. Consider factors related to diversity, equity, inclusion, and accessibility of research studies. Expand, improve, and validate patient reported outcome tools to use in clinical trials.

As new treatments for EoE become available, it is also critical that patients' and caregivers' voices and preferences are incorporated throughout the research process. Patients are more likely to adhere to a treatment regimen if they are satisfied with the therapy. Organizations like AAFA and APFED can serve as a bridge between patients/caregivers, researchers, clinicians, and regulatory agencies.

Opportunity: Prioritize patient voice in research by presenting patient insights to drug developers and the FDA to address patient-reported burdens and treatment needs and preferences. Expand opportunities to connect patients and researchers so that they may learn from one another.

Unmet Needs in Patient Education and Public Awareness

To ensure that patients are active participants in their health care, people with EoE need to have access to updated information about seeking appropriate care and taking an active role in determining best treatments to match their needs.

Conflicting, confusing, and incomplete information about EoE can lead to challenges in managing EoE (Figure 38). Patients indicated a need for a learning “center” specifically for the newly diagnosed and/or resources to better manage diagnosis. Preferred methods of EoE information for patients/caregivers included digital communications, such as websites, email, and videos (Figure 46).

Opportunity: Develop easy-to-understand resources for patients to help them acclimate to a new diagnosis. Provide learning “centers” that house curated lay-friendly content with a specific aim of educating families about EoE etiology, treatment options, and practical strategies for daily living. Elevate awareness of these resources among providers that treat EoE so that they may share with their patients.

From the HCP perspective, the most common factor leading to a delay in timely diagnosis was that patients learned to self-cope with their symptoms (Figure 11). This highlights a need to improve public awareness of symptoms in addition to HCP understanding. Additionally, patients/caregivers reported dissatisfaction with general awareness of EoE (Figure 44). Broad awareness and education around EoE signs and symptoms may help undiagnosed patients recognize potential signs of EoE, prompting them to speak with a health care provider. Education and awareness campaigns can also help increase overall awareness of EoE and communicate to patients/caregivers that they are not alone. This can potentially reduce social isolation and increase social acceptance of the EoE diagnosis.

Opportunity: Develop and launch public awareness campaigns to teach people common symptoms, and to help them to recognize adaptive behaviors (such as eating smaller bites, coating foods in sauces to lubricate them, drinking a lot of liquids with meals, avoiding dry foods, etc.) to prompt initiation of clinical care. Campaigns may focus on the most common symptoms in various age groups (e.g., feeding difficulties in infants/toddlers, trouble swallowing for teens and adults, etc.).

In addition to public awareness campaigns, there is also a need to develop patient-facing materials for HCPs. This is especially important because patients/caregivers reported getting most of their EoE information from HCPs (Figure 48), and HCPs requested better educational information to provide to patients and families (Figure 46). Patient-facing materials provided to HCPs for use at point of care can help improve patient awareness, ability to self-manage EoE, and patient-provider communications.

Patient education materials should be culturally appropriate and address various patient experiences, such as comorbidities and age at diagnosis. Both patient/caregiver and HCP respondents reported high overlap of allergic comorbidities (Figures 5–6). Additionally, age at diagnosis varied significantly (Figure 7). Materials that consider factors such as comorbid conditions and patient age can support improved self-management of EoE.

Opportunity: Develop and distribute easy-to-understand, culturally relevant patient education materials to health care providers with information about EoE symptoms, management, treatment, and comorbid conditions to share with their patients to promote self-care, health literacy, and shared-decision making.

Unmet Needs in Psychosocial Support

EoE can have a salient impact on many aspects of patients' and caregivers' lives. Beyond the physical impacts such as EoE symptoms, inflammation, and esophageal damage, patients and caregivers experience social, emotional, and mental health impacts as well. Studies have shown that EoE has been associated with anxiety and depression and has an impact on quality of life.

Patients/caregivers and HCPs reported that EoE has a high impact on emotional health, social life, self-confidence, and relationships (Figure 42). HCPs reported that EoE patients typically experience anxiety and/or depression more than once a year (Figure 43). Finding appropriate support is often difficult and patients/caregivers reported dissatisfaction with social/emotional support for EoE (Figure 44). Existing resources available through AAFA, APFED, and other organizations can support patients through the daily challenges of managing EoE.

Importantly, patients face different challenges and have different needs based on the stage of their journey. Patients reported that they are looking for support appropriate to where they are in their journey (for example, someone who is newly diagnosed has different support needs than a caregiver or someone who has lived with EoE for a long time).

Opportunity: Promote availability of existing social/emotional resources to HCPs who can share with patients, and develop new resources that are relevant to various stages of the patient journey (e.g., newly-diagnosed patients).

Most HCPs believed that at least some of their patients with EoE would benefit from access to a mental health professional (Figure 24), though less than one fifth of GI doctors, allergists/immunologists and PCPs indicated that they consult with psychologists for EoE care (Figure 25). Increasing referrals and access to services for anxiety and depression and education about EoE impacts for mental health providers are an area of unmet need. Simplifying and facilitating easier referrals to mental health professionals can ensure patients have access to mental health services as needed.

Opportunity: Encourage HCPs to screen EoE patients for needed psychosocial support and professional services. Encourage mental health professionals to list their clinic contact information on referral platforms. Disseminate information to mental health professionals about EoE and the patient burden to help improve services for patients who seek their care.

While not covered in this study, there are other areas of social needs assessment for EoE. Future areas of research in EoE can further explore the impact of EoE on various aspects of life.

Opportunity: Conduct additional studies to explore the impact of EoE on schools and the workplace. Assess impact of EoE on caregivers to provide additional insights into other areas of unmet needs.

Unmet Needs in Advocacy and Financial Support

Patients/caregivers face financial barriers in accessing timely and effective care for EoE. They indicated that EoE has a high impact on finances (Figure 42) and reported dissatisfaction with financial resources for EoE (Figure 44).

Patients and caregivers grapple with the health care costs of EoE. Nearly one third of patients/caregivers reported the price of health care and EoE treatment as one of the biggest challenges with managing the disease (Figure 38). EoE is a condition that requires recurring medical procedures and available treatments are often used off-label. Costs for medicines and formulas used for dietary therapy can be exorbitant. Biologic treatments are expensive and insurance providers usually require a fail-first or step therapy approach that requires patients to try and fail other therapies before approving reimbursements for a more expensive therapy.

More than one third of HCPs reported dissatisfaction with the availability of insurance reimbursable expenses (Figure 45). Over one fourth of HCPs cited financial barriers for out-of-pocket expenses as a factor that leads to delays in diagnosis and access to treatment for their patients (Figure 11).

Opportunity: Develop and advocate for policies that aim to improve step therapy or “fail-first” protocols and promote insurance coverage of medical foods so that patients may better access the treatments prescribed by their doctors.

Patients also reported challenges with insurance coverage for diagnostics and treatments. To shorten the diagnostic timeline and ensure timely access to treatments, there is a clear need for payer education. Insurers need a better understanding of current diagnostic and treatment options for EoE, the necessity of multiple specialists for ongoing clinical care, related healthcare utilization for EoE, and the impact of not treating the condition.

Further, patients report a lack of insurance reimbursement for dietitian services to oversee dietary management of EoE, and for elemental formula that is prescribed for full or partial nutrition.

Opportunity: Facilitate ongoing discussions with payers to increase their understanding of EoE, diagnostic and treatment barriers, and estimated health care utilization for EoE, including the need for repeat endoscopy and multiple specialists for ongoing care and the impacts of untreated disease. Increase awareness of expert consensus guidelines for diagnostic and clinical management of EoE among payers. Educate payers about factors that influence adherence rates and the impacts of untreated disease.

In addition to removing barriers to insurance coverage, patients/caregivers and HCPs also highlighted the need for better patient assistance programs for many EoE treatments, such as medicines and formulas used for dietary therapy. Pharmacological treatments that are indicated for asthma but used off-label for EoE (such as budesonide and fluticasone) may have available patient assistance programs for treatment of asthma, but patients who must rely on off-label use of these treatments for EoE may not be eligible for assistance.

Opportunity: Expand eligibility of assistance program qualifications to reduce financial barriers related to out-of-pocket costs for formula and pharmacological treatments.

While dietary therapy is often a highly effective treatment, it is burdensome for patients to follow and patients report negative impacts on quality of life. Amino acid formulas—medical foods that can be administered orally or enterally—are often not covered by insurance companies due to payers’ refusal to cover orally-administered formulas or because of age limitations for coverage. Access to formula for those who need it is critical because these formulas serve as full/partial nutrition in addition to resolving EoE symptoms and reducing the number of eosinophils. Access to quality formula and medical food is paramount. The 2022 formula recall and supply shortage put a spotlight on weaknesses in the supply chain and put patients at risk.

Amino acid formulas can be costly for supplemental or total nutrition, especially for adults (who often require larger volumes) and households that may have more than one person requiring formula. Patients often struggle to get these formulas covered under their pharmacy or durable medical equipment benefits coverage. These formulas qualify for tax deductions, but the process is convoluted. Special medical foods can get reimbursed on HSA plans as they are used to treat disease, but they are only covered for the excess difference in cost compared to commonly available same products. The claims must have a letter of medical necessity and include proof of the “normal cost” of comparable products.

Additionally, families who qualify for the Women, Infants, and Children (WIC) program may obtain their elemental formula through WIC, however each state’s formulary differs on which formulas are offered, and some do not offer elemental formula at all. Elemental formula may be the sole source of full nutrition for some patients.

Opportunity: Adopt nationwide legislation to facilitate insurance coverage of medical foods, such as amino acid formulas, whether consumed for full or partial nutrition, regardless of oral or enteral delivery. Costs of medically-restricted diet (elimination or elemental diet) should be mitigated and addressed in the U.S. federal tax code so patients can easily access deductions for these medically-necessary expenses or get reimbursed by an HSA, FSA, Archer MSA, or HRA.

People with EoE who have difficulty maintaining full-time work due to EoE can apply for benefits through two programs at the Social Security Administration (SSA)—Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Parents of children with EoE may also be eligible to apply for SSI. Financial criteria and medical eligibility for these programs are determined by SSA. To be medically eligible, you must have a condition that has lasted at least 12 months and may also prevent you from being able to perform any type of work activity. However, definitions of EoE may vary; for example, Veteran Affairs has a disability rating for EoE, where a veteran may be rated at 10, 30, or 60% disability based on severity of EoE.

Opportunity: Increase awareness for patients about their rights and potential pathways for benefits or accommodations.

Summary of Unmet Needs and Opportunities

Domains of Unmet Needs	Opportunities
Clinical Care and Health Care Provider Education	<ul style="list-style-type: none"> • Build educational programs for health care providers that focus on improving recognition of EoE symptom awareness among different age groups and differentiating between EoE and other masqueraders, such as gastroesophageal reflux disease. Develop and disseminate resources for HCPs to better identify adaptive behaviors that may be indicative of EoE. • Increase awareness of current consensus guidelines to support prompt and accurate diagnosis of EoE. Develop and utilize clinical care algorithms in tandem with consensus guidelines so that health care providers can better understand when to refer a patient to a specialist. Support development of reliable biomarkers and advancements in less-invasive clinical testing to detect and monitor EoE. • Update expert consensus guidelines to consolidate current recommendations for both diagnostics and clinical management to help ensure people with EoE are offered evidence-based treatment plans. These guidelines should include current diagnostic and monitoring methods available for EoE. Medical societies, health care groups, and patient advocacy organizations must support increased awareness and adoption of these guidelines as recognized best practices. • Develop models of multidisciplinary care teams for both public and private practice settings to help health care providers ensure people with EoE have access to appropriate, comprehensive care. • Develop and disseminate models for referral, diagnostic, and treatment algorithms to both clinicians and patients. Treatment algorithms should include referring patients to reputable patient advocacy organizations for patient education and support. HCP education programs incorporating patient perspectives would elevate symptom awareness, and in turn, help reduce diagnostic and treatment delays. Patient perspectives can also help inform HCPs about the struggles people face at different points of their journey and improve patient-provider communication.
Treatments and Patient-Centered Research	<ul style="list-style-type: none"> • Develop new safe, effective, convenient, and affordable therapies indicated for the treatment of EoE. The FDA, researchers, patient advocacy groups, drug developers, and patients must all support pipeline developments to bring to market new therapies indicated for the treatment of EoE. • Expand practical strategy resources to help improve adherence to dietary therapy. Increase awareness among HCP of resources to help implement and manage a patient who utilizes dietary therapy. • Develop shared decision-making tools for patients and providers to facilitate discussion about treatment options and determine an appropriate course of therapy that the patient can reasonably access, afford, and adhere to. Patients' lifestyle and treatment preferences need to be considered as this is highly likely to influence adherence to the treatment plan. • Elevate awareness of current and pipeline treatments for EoE among health care providers, patients, and caregivers. • Increase awareness of clinical trial and research survey opportunities among patients and health care providers. • Incorporate the patient voice in clinical trial design so that endpoints are meaningful, and protocols aren't overly burdensome or financially challenging for patients to participate. Consider factors related to diversity, equity, inclusion, and accessibility of research studies. Expand, improve, and validate patient reported outcome tools to use in clinical trials. • Prioritize patient voice in research by presenting patient insights to drug developers and the FDA to address reported burdens and treatment needs and preferences. Expand opportunities to connect patients and researchers so that they may learn from one another.

Domains of Unmet Needs	Opportunities
Patient Education and Public Awareness	<ul style="list-style-type: none"> • Develop easy-to-understand resources for patients to help them acclimate to a new diagnosis. Provide learning “centers” that house curated lay-friendly content with a specific aim of educating families about EoE etiology, treatment options, and practical strategies for daily living. Elevate awareness of these resources among providers that treat EoE so that they may share with their patients. • Develop and launch public awareness campaigns to teach people common symptoms, and to help them to recognize adaptive behaviors (such as eating smaller bites, coating foods in sauces to lubricate them, drinking a lot of liquids with meals, avoiding dry foods, etc.) to prompt initiation of clinical care. Campaigns may focus on the most common symptoms in various age groups (e.g., feeding difficulties in infants/toddlers, trouble swallowing for teens and adults, etc.). • Develop and distribute easy-to-understand, culturally relevant patient education materials to health care providers with information about EoE symptoms, management, treatment, and comorbid conditions to share with their patients to promote self-care, health literacy, and shared-decision making.
Psychosocial Support	<ul style="list-style-type: none"> • Promote availability of existing social/emotional resources to HCPs who can share with patients, and develop new resources that are relevant to various stages of the patient journey (e.g., newly-diagnosed patients). • Encourage HCPs to screen EoE patients for needed psychosocial support and professional services. Encourage mental health professionals to list their clinic contact information on referral platforms. Disseminate information to mental health professionals about EoE and the patient burden to help improve services for patients who seek their care. • Conduct additional studies to explore the impact of EoE on schools and the workplace. Assess impact of EoE on caregivers to provide additional insights into other areas of unmet needs.
Advocacy and Financial Support	<ul style="list-style-type: none"> • Develop and advocate for policies that aim to improve step therapy or “fail-first” protocols and promote insurance coverage of medical foods so that patients may better access the treatments prescribed by their doctors. • Facilitate ongoing discussions with payers to increase their understanding of EoE, diagnostic and treatment barriers, and estimated health care utilization for EoE, including the need for repeat endoscopy and multiple specialists for ongoing care and the impacts of untreated disease. Increase awareness of expert consensus guidelines for diagnostic and clinical management of EoE among payers. Educate payers about factors that influence adherence rates and the impacts of untreated disease. • Expand eligibility of assistance program qualifications to reduce financial barriers related to out-of-pocket costs for formula and pharmacological treatments. • Adopt nationwide legislation to facilitate insurance coverage of medical foods, such as amino acid formulas, whether consumed for full or partial nutrition, regardless of oral or enteral delivery. Costs of medically-restricted diet (elimination or elemental diet) should be mitigated and addressed in the U.S. federal tax code so patients can easily access deductions for these medically-necessary expenses or get reimbursed by an HSA, FSA, Archer MSA, or HRA. • Increase awareness for patients about their rights and potential pathways for benefits or accommodations.

Limitations

Data presented in this report have limitations that AAFA and APFED would like to acknowledge. Patients, caregivers and HCPs were offered a chance to receive honoraria, which may have contributed to selection bias. Patients and caregivers recruited for the one-on-one interviews and for the patient and caregiver survey were recruited through social media, newsletters, and emails to AAFA and APFED community members and followers. Therefore, this study population represents the demographics of AAFA and APFED followers, and may not be representative of all those affected by EoE. This impacts the generalizability of the results. For example, EoE is more prevalent in males than females. However, the participants of this study overwhelmingly self-identified as women. Research shows women are more likely to take online surveys than men, but nevertheless the patient voice of men impacted by EoE is needed in future studies. Similarly, respondents of the patient and caregiver survey largely identified as white. More research is needed to capture the diversity of EoE patient voices, as different populations may have different experiences with EoE diagnosis, management, and treatment, and therefore may have different resource needs.

Additionally, in much of the report, data are combined for caregivers and patients. Research looking at other conditions show distinct experiences and impacts for patients and caregivers. Future studies could separate the data to look at these differences more closely. Related, the caregiver survey asked caregivers to report on the impacts of EoE on their loved one with EoE. Additional research is needed to see the impacts on caregivers, such as the need to take off time from work to go to medical appointments or care for their loved ones, impacts on caregivers' personal relationships, and financial impacts on the family. While these themes were explored in the patient and caregiver interviews, supporting these findings with quantitative data would further validate the results.

While the survey asked about patients and caregivers experiences and satisfaction with treatments, the survey did not ask about treatment preferences, such as how they would prefer the treatment to be delivered, and what outcomes they would like to see from a treatment. Similarly, while the survey asked which doctors were seen for EoE and satisfaction with medical care, the survey did not ask about patient and caregiver preferences for who is a part of their care team. For example, few patients and caregivers reported seeing a dietitian or nutritionist for EoE care, but the survey did not ask if patients and caregivers would prefer to have these care providers managing their EoE. Collecting further data on these topics is important to understand the full landscape of unmet needs for the EoE community.

Regarding the HCP survey, more research is needed to look at differences by provider type. While we recruited providers from a wide range of specialties that treat patients with EoE, the low sample size made between-group comparisons difficult.

Physicians responded to questions about how they would manage a patient in a hypothetical clinical situation. The study did not attempt to verify actual clinical practice. Similarly, the HCP survey asked about awareness of and satisfaction with consensus guidelines. However, the survey did not specify the publication date of guidelines, nor did it attempt to verify knowledge and practice of current guidelines for diagnosis or treatment. Additional research on clinical practice is needed to further understand differences in patient and HCP perspectives, and identify ways in which clinical care falls short in meeting patient needs.

Finally, dupilumab became available as an EoE treatment for adults beginning in May 2022, and therefore wasn't available to patients and caregivers who took the survey. The HCP survey was launched just eight months after dupilumab was approved, and so there was not much time for their patients to receive drug and/or report on satisfaction compared to other treatments. While some patients reported taking biologics off-label, the sample size was not large enough to effectively compare satisfaction with this treatment to others. As more EoE treatment options become available, more research is needed on patient and HCP use and satisfaction with these treatments.

EoE Resources for Patients, Caregivers, and Health Care Providers

The Asthma and Allergy Foundation of America (AAFA), its Kids with Food Allergies (KFA) division, and the American Partnership for Eosinophilic Disorders (APFED) offer resources for patients, caregivers, and health care professionals.

Patient Education Resources

- **AAFA and KFA's "Your Guide to Managing EoE"** is a resource for patients and families to better understand EoE, the path to diagnosis, disease management strategies, and the importance of emotional support: aafa.org/eoe
- **APFED's EoE Patient Education Toolkit** helps patients and families navigate a new diagnosis. It provides answers to commonly asked questions, treatment options, strategies for daily living, and an overview of the research landscape: apfed.org/eoetoolkit
- **APFED's EoE resources in Spanish** – APFED offers a webpage, brochure, video, and a patient education toolkit in Spanish: apfed.org/acerca-de-las-eoe
- **APFED's annual patient education conference** provides an opportunity to learn from experts and connect with families: apfed.org/conference
- To register for upcoming educational **webinars** or to view recordings of past webinars, visit apfed.org/webinars
- **APFED's podcast series**, "Real Talk: Conversations about living with eosinophil-associated diseases": apfed.org/podcast.

Patient and Caregiver Support

- **APFED's Eos Connection Online Community** enables patients and caregivers to offer one another peer support: apfed.inspire.com.
- **AAFA's Online Patient Communities** offer patients and caregivers a chance connect with others who understand what it is like to live with EoE and other allergic conditions. Visit AAFA's community at community.aafa.org or the Kids with Food Allergies community for parents at community.kidswithfoodallergies.org

Nutrition and Diet

- **KFA's Safe Eats™ Recipes**: kidswithfoodallergies.org/recipes
- **KFA's Formula and Medical Foods Guide and Assistance**: kidswithfoodallergies.org/formula
- **KFA's Food Allergen Label Reading Guides**: kidswithfoodallergies.org/living-with-food-allergies/top-food-allergens/

Health Care

- **APFED's Specialist Finder** is a searchable database of specialists who treat EoE: apfed.org/specialist
- **AAFA's Guide to Drug Assistance Programs**: aafa.org/patient-assistance

Research

- **Patient registries** – to learn about patient registries for people with EoE, or to enroll, visit apfed.org/take-action/patient-registry
- **APFED's research grants** support investigators conducting studies related to eosinophilic diseases: apfed.org/research/grant-application-for-researchers/
- **AAFA's My Life with Food Allergy EoE Spotlight** research report: aafa.org/foodallergyife
- **AAFA's guide to understanding clinical trials**: aafa.org/clinical-trials

Additional Support

- **AAFA's resources for other allergic conditions** – AAFA provides information about food allergy, asthma, seasonal allergy, or eczema diagnosis: aafa.org
- **APFED's archive of available resources** – health care providers, patients and caregivers can find additional resources for EoE: apfed.org/resources

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