EoE Knowledge Exchange
Summary Report

29th November 2023

Meeting Overview

Sanofi and Regeneron's second EoE Knowledge Exchange brought together EoE patient advocacy representatives and experts from across the globe. The meeting aimed to build upon discussions initiated in 2021 by seeking insights to drive EoE advocacy and policy dialogue.

During the previous EoE Knowledge Exchange, participants had observed that EoE is an invisible, progressive, and lifelong condition, which few people recognize or understand. Sanofi and Regeneron undertook comprehensive research following the meeting to understand the EoE patient journey, and the real-life impact of the condition.

For this second EoE Knowledge Exchange, Sanofi and Regeneron used insights from the research to explore the unmet needs of people living with EoE and to determine ways in which to collaboratively address these in order to ensure a better quality of life for the EoE community.

This report summarizes the key takeaways and discussions from the EoE Knowledge Exchange.

Meeting Agenda

Welcome & Introductions
Session 1 – Understanding Perspectives to Address the Challenge
Session 2 – Prioritizing Unmet Needs to Mobilize Change
Session 3 – From Evidence to Action
Session 4 – Collaborating to Initiate Impact
Closing & Thank You

Session 1: Understanding Perspectives to Address the Challenge

In this session, insights from *The Emotional Journey of Patients with Eosinophilic Esophagitis*, which was published in *Advances in Therapy*, were presented by co-author Mary Jo Strobel from the American Partnership for Eosinophilic Disorders (APFED).

Participants were invited to reflect on the findings and provide their thoughts.

Key takeaways

1. Patient stories demonstrating real-life impact across different stages of the EoE journey can be an important tool in increasing awareness and understanding of the condition.
   - EoE patients often feel disappointed by the lack of recognition from the healthcare community, as their concerns are often dismissed as mental health issues, and HCPs often do not realize the broader impact of EoE beyond clinical manifestation.

2. A standardized definition and/or measure for disease control and treatment outcomes needs to be established
   - This would support a partnership approach towards a coming goal between patients and HCPs

"What patients consider a good outcome may not align with what the clinicians currently measure. This has been an ongoing problem, and while many studies now use patient-reported outcomes, it's not often uniformly implemented in clinic settings, and that's a real challenge." – PAG representative

   - It would help patients in understanding treatment outcomes, which would encourage engagement in care/compliance with treatment.
   - Patients do not know what 'normal' looks or feels like and often lack clarity on their desired treatment outcomes
   - Patients often feel anxiety, stress or experience social challenges due to not fully understanding triggers

"The disappointment isn't just about the healthcare service. People experience disappointment in themselves for not seeking care earlier or, when they did, finding it ineffective." – PAG representative

Session 2: Prioritizing Unmet Needs to Mobilize Change

This session delved into the unmet needs at each stage of the patient journey.

Pre-seeking Care stage of EoE patient journey

Identified Needs	Reasoning
EoE Disease Awareness	• Limited awareness makes it difficult for patients, parents, and carers to recognize EoE symptoms. • The adaptive behavioral nature of the condition adds further complexity, making it more difficult to identify and diagnose.
HCP Awareness/ Education	• EoE is frequently perceived exclusively as an atopic disease or type two inflammation. Recognizing the potential coexistence of other diagnosed comorbidities can serve as a catalyst for a faster diagnostic process. • Expert HCPs are needed in primary and specialty care to identify, address, and manage EoE. • GPs do not identify EoE cases early in their practice.
Patient Awareness/ Education	• This is needed to help people recognize the connection between symptom triggers and patients' coping strategies to manage their undiagnosed EoE.
Timely Diagnosis	• Early diagnosis can lower the burden of symptoms. • Timely referrals for endoscopy can help manage distress and complications arising from untreated EoE.
Pediatric EoE diagnosis	• Validated screening tools are needed for pediatric patients, especially in primary care settings. • Fear of visiting a doctor's office is a key issue associated with pediatric EoE that needs to be addressed.
Psychosocial Impact Research	• Research would help the development of targeted interventions, support services, and educational resources to address the needs of individuals and families affected by the condition from the point of seeking care onwards. • For example, understanding of the psychosocial impact of the chronic symptoms of EoE is limited.
Uncomplicated terminology	• New terminology may help EoE be easier to understand and increase public recognition.

Diagnosis stage of EoE patient journey

Identified Needs	Reasoning
HCP Awareness/ Education	• Inadequate communication and collaboration between physicians can impact effective action. • Better awareness is needed in primary care to improve patient journeys. • Earlier anticipation of referral for endoscopy. • Habit of labeling patients too early, often with a psychiatric condition, before considering EoE alongside a psychiatric comorbidity.

	• HCPs trusting patients' pain presentation, even when related to a psychiatric problem.
Timely Diagnosis	• There is often a delay in getting an endoscopy. • Need better diagnostic tools - endoscopy can be invasive.
Pediatric EoE diagnosis	• Non-invasive diagnostic tools are needed for pediatric patients.
Patient Awareness/ Education	• Confusion among some patients regarding food sensitivity testing, as they perceive working with an allergist to identify food triggers to be the definitive solution.

Treatment stage of EoE patient journey

Identified Needs	**Reasoning**
Optimized Disease Management Optimized Disease Management (continued)	• Insufficient time for HCPs to explain the nature of the disease to patients and foster an understanding of its chronic nature. • Shortage of expertise available to guide and support patients adhering to food-elimination diets. o For example, misunderstanding around delayed responses to dietary changes, where patients reintroduce eliminated foods prematurely when not seeing immediate improvement. • Lack of consensus on a standardized approach to treat the condition that takes into account its complexity. • Step therapy protocols impede patient eligibility for certain treatments, potentially delaying effective interventions. • Health disparities are a barrier to accessing care and treatment for EoE.
HCP Awareness/ Education	• Need for multidisciplinary teams, implementing a holistic approach to address both physical and mental health. • Provide patients with a better understanding of EoE treatment/ management options to manage expectations. • Problem differentiating EoE with food allergies, difficulty arises as many EoE patients have comorbid allergies.
Patient Awareness/ Education	• Low awareness of treatment options for EoE leads patients opting for food elimination diets as a primary approach. • Need for understanding around what to expect from treatment.
Joint Treatment Decision-Making	• Treatment decisions are predominantly led by HCPs.
Uncomplicated terminology	• Clear definitions to distinguish between food sensitivity, intolerance, and allergy.

Monitoring stage of patient journey

Identified Needs	**Reasoning**
HCP Awareness/ Education	• Poor understanding of the challenges that patients encounter during the transition from pediatric to adult care.
Patient Awareness/ Education	• Patients don't recognize the significance of monitoring EoE. • Need to explain histologic and endoscopic remission to patients early, ideally at their first visit with their treating physician.

Optimized Disease Management	• Standardized definition and/or measures for disease control needs to be established. • Patients should be routinely evaluated via endoscopy despite their apparent well-being, as there might be underlying disease activity that hasn't outwardly manifested. • A long-term study reviewing the burden of poorly managed patients is needed to demonstrate the increased cost impact on the healthcare system. • Cost and time for follow-up monitoring is a barrier to optimal care.

Session 3: From Evidence to Action

In this session, increased EoE education and patient advocacy were highlighted as core strategies to address identified unmet needs.

Key takeaways

HCP education

- Disease education for primary care physicians/GPs needs to address the importance of specialist referrals to speed diagnosis and clearly demonstrate the physical and mental impact of delayed diagnosis
- Suite of tools that support HCP education could include:
    - A pre-screening tool for physicians to identify the symptoms of common adaptive behaviors that are often overlooked
    - Screener to identify those in need of additional support for coping with the condition
    - Shared decision-making tool
    - Standardized definition for EoE control
- HCP education and awareness efforts could be amplified by congress/ conference activities and webinars.

Public awareness:

- Any public initiative needs to increase symptom awareness and urge individuals to seek help by:
    - Clearly demonstrating the invisible and silent nature of the condition, which may lead to undetected progression until significant symptoms manifest.
    - Empowering individuals with information about potential symptoms and encouraging them to seek help when certain indicators align with their experiences.

"At this moment in time, the public doesn't know what EoE is and the consequences of not receiving a diagnosis. The only time that it becomes apparent is when it actually really impacts their lives, such as difficulty swallowing food." – PAG representative

Pediatric EoE

- The education system could be a key setting to raise EoE awareness due to the pediatric manifestation of the condition, and to address the impact of adaptive behaviors that are learned during childhood.

"We need to identify the triggers that individuals are living with, leading them to develop these coping strategies. If we intervene earlier, we can help people understand that these adapted behaviors are a sign they should be seeking help." –PAG representative

Session 4: Collaborating to Initiate Impact

This session focused on potential approaches to increase understanding of EoE and its impact on patients.

Key takeaways

There was joint consensus that:

- Ahead of policy efforts, it was critical to advance EoE awareness.
- A simple, informative HCP education initiative could be ideal for a 'next steps' project.

Key approaches discussed

1. Awareness of EoE within a broader context:

- Increase understanding of EoE within a broader framework, including consideration of other potential atopic /type 2 inflammatory diseases.

"If we want to get people on board, we have to start looking at them as a collective… we know 80% of our community has one or more other atopic disease." – PAG representative

2. Interconnected health issues

- HCPs need to take a comprehensive and holistic approach, acknowledging that patients with EoE may also have other medical conditions. This is an important consideration as it provides more effective and personalized care that addresses the diverse needs of individuals with multiple comorbidities.
- Treatment discussions between patients and HCPs need to be better, especially concerning biologics with their broad potential to address various conditions.

"We have so many biologics coming in, and every biologic is talking about their one condition." – representative from GAAPP

3. Using outcome measures to improve recognition of EoE

- Potential economic consequences of EoE could be investigated, which could also demonstrate the value of improving access to biologics.
- EoE infographic that depicts the health and social impact and can be shared at key conferences.

Final Considerations:

- Collaboratively developed initiatives/assets are more engaging for audiences.
- Education materials developed from a global perspective provide a solid foundation, but they need localized figures and examples for organizations to use them effectively in their country
- Explore the possibility of hosting a patient organization conference during National Eosinophil Awareness Week.
- Potential of creating an EoE Awareness Day, but need to consider potential scheduling conflicts with other awareness days.

Conclusion

This Knowledge Exchange continued to build on the knowledge and understanding of EoE, a condition that requires greater awareness and priority on healthy policy and advocacy agendas across the globe.

There was a joint consensus that better awareness and understanding of EoE, especially within the HCP community, was a key unmet need. We look forward to further discussions later this year to agree next steps to address this critical need.

Sanofi and Regeneron want to thank everyone for their participation and for sharing valuable insights to support a better understanding of the challenges experienced by EoE patients. These insights are crucial in the development and implementation of guidelines and policies that ensure the best standards of care for people with EoE. In the meantime, we remain committed to the EoE community and appreciate any updates you would like to share with us.

With kind regards,

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Zoé Fumat
Global Public Affairs project specialist, Immunology

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APPENDIX

Meeting Participants

Knowledge Exchange Participants

- Prof Ahmed Madisch, Centrum Gastroenterologie Bethanien, Germany
- Amanda Cordell, Trustee and Chair, EOS Network, United Kingdom
- Jennifer Gerdts, Executive Director, Food Allergy Canada, Canada
- Mary Jo Strobel, Executive Director, American Partnership for Eosinophilic Disorders (APFED), United States
- Dr Salvatore Oliva, Associate Professor of Paediatrics, Consultant in pediatric Gastroenterology, Spapienza, University of Rome, Italy
    - **With support of Dr Roberta Giodice, President of the Italian Association of Families Against Eosinophilic Esophagitis (ESEO).*
- Sarah Gray, Founder & CEO, AusEE, Inc., Australia
- Susanna Palkonen, Director, European Federation of Allergy and Airways Diseases Patients Associations (EFA)
- Tonya A. Winders, President, Global Allergy & Airways Patient Platform (GAAPP)

Note: Dr Helen Larsson, from the Department of ENT/H&N Surgery at NU-hospital group, Sweden, who is also a co-author of *The Emotional Journey of Patients with Eosinophilic Esophagitis*, was invited and unfortunately could not participate in the meeting.

Sanofi & Regeneron Representatives

- Mary Ruth Brehmer, Director, Global Patient Advocacy, Respiratory/GI, Regeneron
- Miquel Diaz, Head Global Public Affairs, Respiratory and Gastroenterology Specialty Care, Sanofi
- Zoé Fumat, Global Public Affairs Project Specialist, Immunology, Sanofi

Weber Shandwick Representatives

The communication agency, Weber Shandwick, supported and facilitated the Knowledge Exchange.

- Satinder Phull, Senior Vice President, Health Policy and Advocacy
- Virginia Hasenmeyer, Vice President, Health Policy