



## Plain Language Summary of principles for improving the care of people with eosinophil-associated diseases

David J Jackson<sup>1,2</sup>, Praveen Akuthota<sup>3</sup>, Rebeca Andradas<sup>4</sup>, Albert J Bredenoord<sup>5</sup>, Amanda Cordell<sup>6</sup>, Sarah Gray<sup>7</sup>, Joyce Kullman<sup>8</sup>, Sameer K Mathur<sup>9</sup>, Ian Pavord<sup>10</sup>, Florence Roufosse<sup>11</sup>, Christian Rubio<sup>12</sup>, Irena Clisson Rusek<sup>13</sup>, Dagmar Simon<sup>14</sup>, Mary Jo Strobel<sup>15</sup> & Tonya Winders<sup>16,17</sup>

<sup>1</sup>Guy's Severe Asthma Centre, Guy's & St Thomas' NHS Trust, London, UK; <sup>2</sup>School of Immunology & Microbial Sciences, King's College, London, UK; <sup>3</sup>Division of Pulmonary, Critical Care, and Sleep Medicine, Department of Medicine, University of California San Diego, La Jolla, CA, USA; <sup>4</sup>Spanish Association of Eosinophilic Esophagitis-AEDESEO, Madrid, Spain; <sup>5</sup>Department of Gastroenterology and Hepatology, Amsterdam UMC, University of Amsterdam, Amsterdam, The Netherlands; <sup>6</sup>EOS Network Eosinophilic Diseases Charity, Colchester, England, UK; <sup>7</sup>AusEE Inc., Queensland, Australia; <sup>8</sup>Vasculitis Foundation, Kansas City, MO, USA; <sup>9</sup>Division of Allergy, Pulmonary and Critical Care Medicine, Department of Medicine, School of Medicine and Public Health, University of Wisconsin, Madison, WI, USA; <sup>10</sup>Oxford Respiratory NIHR BRC, Nuffield Department of Medicine, University of Oxford, Oxford, UK; <sup>11</sup>Department of Internal Medicine, Hôpital Erasme, Université Libre de Bruxelles, Brussels, Belgium; <sup>12</sup>Global Genes, Boston, MA, USA; <sup>13</sup>Association Pour l'Information sur les Maladies à Eosinophiles-APIMEO, Bourg-la-Reine, France; <sup>14</sup>Department of Dermatology, Inselspital, Bern University Hospital, University of Bern, Bern, Switzerland; <sup>15</sup>American Partnership for Eosinophilic Disorders, Atlanta, GA, USA; <sup>16</sup>Allergy and Asthma Network, Vienna, VA, USA; <sup>17</sup>Global Allergy & Airways Patient Platform, Vienna, Austria.

\*Corresponding author: DJ Jackson; David.Jackson@gstt.nhs.uk

First draft submitted: 22 December 2022; Accepted for publication: 6 April 2023; Published online: 17 May 2023

### Summary




#### What is this summary about?

Eosinophil-associated diseases (EADs) are a group of conditions in which eosinophils (a type of white blood cell) are thought to play a key role in the disease and how it develops. Some EADs are common, such as atopic dermatitis (also called eczema) and a subtype of asthma called eosinophilic asthma, while others are rare, such as

hypereosinophilic syndrome (a condition in which a person has a very high number of eosinophils in both the blood and one or more organs). People with EADs face many problems related to their conditions. Symptoms such as severe abdominal pain, itch, or shortness of breath impact both the patient as well as their friends and family. Patients with EADs also experience delays to diagnosis and treatment as well as financial barriers. Healthcare professionals sometimes fail to recognize the complex set of symptoms that characterize an EAD, and this may cause delays in reaching a correct diagnosis. As a result, it may take longer for a patient to get the best care and the most effective treatments, which may contribute to poor health. The goal of this charter is to describe the key elements of good quality care, which all people with EADs deserve, as well as to present an action plan to improve health and overall well-being for people with EADs.

**Proposed use of this patient charter:** The principles described in this charter (a written guide to achieve an outcome) show the core elements of quality care that people with EADs must receive. They also describe clear steps to reduce the burden on patients and their caregivers and to improve patient health outcomes. We urge healthcare professionals, hospitals, and policymakers around the world to adopt these principles quickly. By doing this, people with EADs will be more likely to receive an accurate and timely diagnosis and have access to quality care and treatment in the right setting.

#### How to say (double click to play sound)...

- **Eosinophil:** ee-oh-sin-uh-fil 
- **Eosinophilic:** ee-oh-sin-uh-fil-lic 
- **Hypereosinophilic:** hai-per-ee-oh-sin-uh-fil-lic 

### Who should read this summary?

This summary was written for people with EADs and their caregivers (for example, family and friends), as well as anyone who wants to know more about EADs. It may also be helpful for healthcare professionals who treat people with EADs.

## Who sponsored this summary?

This summary, the Rapid Service Fee, and the Open Access fee were funded by AstraZeneca (Gaithersburg, MA, USA).

## What diseases does this summary cover?

- Eosinophil-associated diseases, or EADs, are a group of diseases that are associated with high numbers of eosinophils in the body and that are characterized by symptoms relating to this type of inflammation
- EADs can involve many organs, including but not limited to the lungs, skin, or digestive tract, and may affect several organs at once
- EADs include common illnesses such as eosinophilic asthma (a subtype of asthma) and atopic dermatitis (also called eczema) and rare conditions such as hypereosinophilic syndrome (a condition in which a person has a very high number of eosinophils in their blood and one or more organs), eosinophilic gastritis or duodenitis, and eosinophilic esophagitis

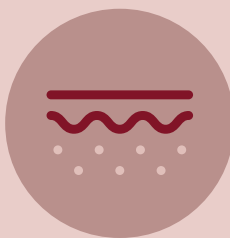
### Body systems affected by EADs



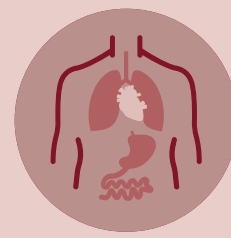
Lungs



Digestive tract



Skin



Across the body

## What problems do people with EADs face?

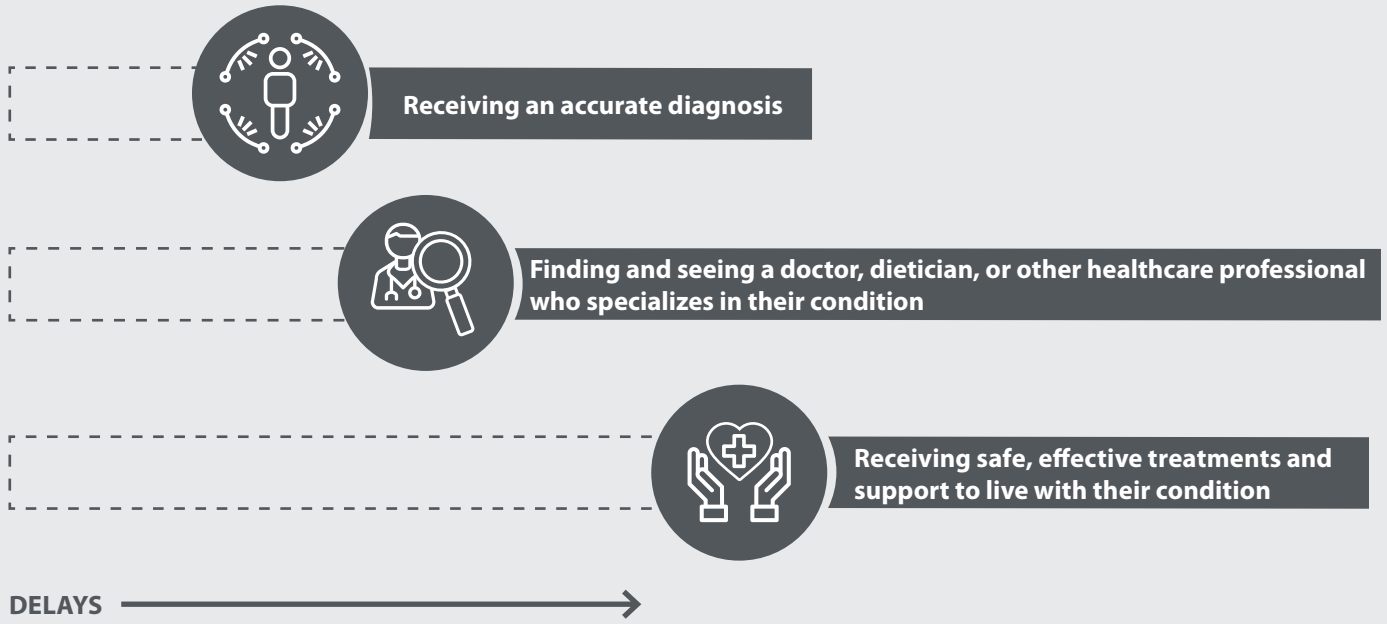
- Chronic symptoms such as abdominal pain, itch, or difficulty breathing that may get worse or flare up over time and may impair the patient's ability to perform daily activities
- Reduced quality of life affecting school or work, social activities, and mental health
- High monetary costs
- Frequent visits to different healthcare professionals, the emergency department, and/or the hospital
- Lack of effective treatment options and side effects from long-term use of corticosteroids

### Problems faced by people with EADs



## What causes many of the problems faced by people with EADs?

• Some healthcare professionals may fail to diagnose an EAD correctly due to the complex symptoms that patients experience, and as a result, people may have delays in the following:



## Why was this patient charter created?

This charter was created to identify and address the multiple barriers and challenges faced by people with EADs to ensure that each person with an EAD has access to high-quality care and leads a fuller life.

## What is the purpose of this patient charter?

- Outline key elements of good quality care, which all people with EADs deserve
- Define a strategy to effectively treat EADs and improve the overall well-being of patients
- Inspire policymakers around the world to reform healthcare practices for people with EADs

## Why was this patient charter created?

01



**Principle 1**  
Greater awareness  
about EADs

02



**Principle 2**  
Timely and  
accurate diagnosis

03



**Principle 3**  
Access to a  
multidisciplinary team

04



**Principle 4**  
Safe and effective  
treatment options

01



**People with EADs and their caregivers, healthcare professionals, and the public must have greater awareness and education about EADs**



### Challenges

- Many healthcare professionals and people with EADs do not know a lot about EADs because many of these conditions are rare, and they are not familiar with the associated role of eosinophils in these diseases
  - This leads to delays in accurate diagnosis and optimal treatment
- People with EADs may visit many different healthcare professionals because their symptoms are varied and may overlap with symptoms of other diseases



### Recommendations

- Create educational materials about eosinophils and associated diseases aimed at healthcare professionals who work in primary or specialty care, including respiratory, dermatology, allergy, gastroenterology, hematology, nutrition, pediatrics, and emergency medicine
- Provide accurate information for people with EADs and their caregivers, including materials related to specific subsets of EADs, to support patients in playing an active role in managing their condition and deciding on the right treatment for them
- Increase public awareness about EADs and their impacts, how to recognize EAD symptoms, and what medical care is needed for patients with EADs



## People with EADs must receive a timely, accurate diagnosis



### Challenges

- Patients experience a long and difficult journey, sometimes lasting years, from when symptoms of an EAD begin to when a correct diagnosis is made
- Knowledgeable specialists are needed to provide a complete patient assessment that considers all symptoms a patient may experience. Specialized tests may also be needed, such as those for lung or heart function. These specialists and specialized testing are critical for a formal diagnosis of an EAD, and when one or both are not available, doctors may fail to recognize and diagnose a patient with an EAD



### Recommendations

- When patients approach their primary care doctor or the emergency department with signs and symptoms of an EAD, physicians must recognize the importance and need for testing that includes bloodwork to understand the number of eosinophils present in their blood
- Create clear guidelines and criteria for diagnoses, treatments, and patient referrals to specialists
- Refer the patient to a relevant specialist if the signs and symptoms are consistent with an EAD, even when blood eosinophils are not high
- Identify recognized experts in different countries who have access to clear and up-to-date tools for diagnosis and treatment options
- Develop accurate, less invasive ways to diagnose and monitor EADs



## Principle 2 example

### Hurdles to a timely diagnosis of eosinophilic gastritis or duodenitis

This example illustrates the barriers and challenges to care that patients with EADs face. The average time from the first symptom to the diagnosis of these disorders is over 3 years. Of note, this average does not consider the large number of patients who are undiagnosed or misdiagnosed.

### What leads to a delayed diagnosis of eosinophilic gastritis or duodenitis or to a misdiagnosis?



**Common symptoms of eosinophilic gastritis or duodenitis, including abdominal pain, nausea, diarrhea, and an early feeling of fullness, overlap with other digestive conditions.**

- Almost 40% of patients are misdiagnosed with conditions such as irritable bowel syndrome, chronic indigestion, or food intolerance
- Misdiagnosis may further delay accurate diagnosis and optimal treatment, as well as lead to repeated invasive procedures, the development of irreversible damage to tissues, and side effects from unnecessary treatments



**People can be shuffled between many doctors.**

- Patients visit an average of 7 doctors, some of whom may not have experience treating their condition, before being properly diagnosed



**Limited disease awareness may result in unnecessary tests and errors in samples or test results.**

- It can take over 2 years before the first endoscopy is performed
- When tissue samples are taken to confirm a diagnosis, there may be errors in taking the sample or reporting the results of the test
- Some of these tests are not necessary and add to patient healthcare and financial burden



**Developing a standardized guideline for diagnosing eosinophilic gastritis or duodenitis, as well as better educational tools, can greatly improve the recognition and diagnosis of these conditions.**



**All people with EADs must have access to an appropriate multidisciplinary team, when necessary**



**Challenges**

- People with EADs may see several doctors who each treat the different components of their disease separately rather than treating the whole patient and considering the symptoms as a group, which may result in the patient having more than one treatment plan
- People with EADs may lack access to evidence-based education that would empower patients to advocate for themselves
- It also may be hard for some people with EADs to access specialists because of high costs, limited economic resources, language barriers, lack of access to information, or the distance between specialists and where the patient lives



**Recommendations**

- Provide access to the following resources:
  - Expert care centers available locally and nationally for patients with EADs
  - Multidisciplinary teams developed in these centers for the diagnosis, management, and treatment of EADs
  - An EAD coordinator (for example, a nurse specialist) who can facilitate the patient journey among all the relevant specialties involved in managing EADs
  - Monetary support to cover the costs of these resources
- Improve communication between patients and all specialists involved in their care
- Use a best practice model of long-term care based on shared decision-making between healthcare professionals and patients and their caregivers that focuses on a personalized approach



**Principle 3 example  
Use of a multidisciplinary team for people with eosinophilic esophagitis**



Eosinophilic esophagitis is driven in part by an allergic response to food in the esophagus; one treatment option is dietary therapy, which can often help to improve symptoms and induce remission in people with eosinophilic esophagitis.



Dietary therapy requires people to eliminate certain food groups from their diet, such as milk, eggs, wheat/grains, legumes (which include soybeans and peanuts), tree nuts, fish, and shellfish.



Although this kind of dietary therapy can be effective for many people with eosinophilic esophagitis, it is not effective for all patients and may be difficult to manage, and more than one-third of adults stop following the diet.



In order to help patients manage this dietary therapy effectively, their treatment should be managed by a multidisciplinary team that includes both a dietician and a gastroenterologist specializing in eosinophilic esophagitis who know how to best adapt the diet for each individual patient.

04



## People with EADs must have access to safe and effective treatment options without unnecessary regulatory delays



### Challenges

- A lack of understanding of newer treatment options and the key role of eosinophils in driving inflammation in many EADs can lead to limited treatment choices and the overuse of steroids
  - Systemic steroids, including oral and injectable forms, are associated with many risky and life-changing short and long-term side effects
- There is limited access to new therapies for EADs, particularly biologic therapies, that target the eosinophils contributing to these diseases
- People with EADs may feel compelled to manage their conditions on their own and may make changes to their diet or lifestyle or take medication without HCP supervision to relieve their symptoms



### Recommendations

- Increase access to affordable, non-invasive tests and tools among healthcare professionals to improve the diagnosis and management of EADs to help identify the right treatment at the right time for each patient
- Make sure that around the world, disease guidelines are up to date to reflect the latest evidence for current and future treatment options and their importance in the management of EADs
  - Share these guidelines with healthcare professionals, as well as patients and their caregivers
- Ensure patients receive regular treatment evaluations to best manage their EADs and that healthcare professionals proactively modify treatment when appropriate
- Provide simple, relevant information to people with EADs about their disease(s)
  - This should be the responsibility of healthcare professionals and patient advocacy groups
- Provide an action plan for all people with EADs to help them manage their disease(s)

## What are the conclusions related to this patient charter?

- The principles described in this patient charter highlight the key elements of good quality care to which people with EADs are entitled
- EADs place a heavy burden on millions of people around the world who live with these diseases
- Clear steps can be taken to help reduce this burden and improve patient outcomes
- Best practice recommendations for both the diagnosis and treatment of specific EADs must be regularly updated and made available to healthcare professionals and patients and their caregivers around the world
- Healthcare professionals, hospitals, and policymakers are urged to promptly adopt these principles to ensure people with EADs receive an accurate and timely diagnosis and have access to high quality care in the right setting



## Where can you find more information?

Read the original article by Jackson *et al.* "[Improving Care in Eosinophil-Associated Diseases: A Charter](#)" in *Advances in Therapy*.

Other *Advances in Therapy* articles that readers might find useful include the following:

"[A Renewed Charter: Key Principles to Improve Patient Care in Severe Asthma](#)"

"[Global Quality Standard for Identification and Management of Severe Asthma](#)"

## Acknowledgments

Medical writing support was provided by Dan Jackson, PhD, CMPP, of CiTRUS Health Group (USA) and was funded by AstraZeneca (Gaithersburg, Maryland, USA) in accordance with Good Publication Practice (GPP 2022) guidelines. We thank JK for providing feedback on the readability of this publication.

## Financial & competing interests disclosure

Full author disclosure information can be found in the original article.