



Nathan's story of undiagnosed eosinophilic oesophagitis (EoE) causing food bolus obstruction (FBO)

A costed integrated patient scenario (CIPS)

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Foreword	2
Introduction	3
What is eosinophilic oesophagitis?	3
Clinical presentation of EoE	3
Epidemiology of EoE	4
Burden of EoE and impact on quality of life	5
Diagnosis of EoE	6
Management of EoE	7
Unmet need/learning points	8
Rationale for this document	11
Analysis style	11
Meet Nathan	12
Nathan's history	12
Overview: Nathan's EoE care pathways	13
Suboptimal/typical management pathway	16
Optimal management pathway	25
Costs and workforce implications	31
Learning points	34
For clinicians	35
For service providers	36
For service transformation	37
Conclusion	38
Abbreviations	39
Contributors	40
Consensus group	40
Facilitators	40
References	41
Appendix	43
HES disclaimer	43
Additional tables and figures	45

Foreword



It is becoming clear that failure to diagnose eosinophilic oesophagitis (EoE) in patients presenting to accident and emergency (A&E) is a serious barrier to optimal patient care, resulting in a cycle of persistent episodes of food bolus obstruction (FBO), sometimes leading to repeat attendances at A&E and delays before appropriate treatment.

By far the most common cause of FBO is EoE. New EoE guidelines developed jointly by the British Society of Gastroenterology (BSG) and British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and published in *Gut* in June 2022,¹ give clear guidance on what should be done for these patients. If this could be achieved, the quality of patient care would be dramatically improved, providing clear diagnosis, effective treatment and cost efficiency for both the health service and the patient.

This document sets out the effects, both in human and economic terms, of the current average standard of care and recommended best practice. It behoves clinicians in each hospital trust to put this into practice – the sooner the better, as the incidence of EoE is rising.² Indeed, the frequency of FBO is increasing to the point where it is now one of the most common gastrointestinal emergency admissions, although many patients with FBO are still admitted to ear, nose and throat services, which are not set up to diagnose EoE.

The collaborative expertise involved in creating this pathway is impressive and unanimous. The patient voice, represented by EOS Network (eosinophilic diseases charity), was a key input. Wilmington Healthcare's guidance around the process was enormously valuable due to their experience in pathway development. I thank all involved, and I look forward to seeing significant improvement in the timely diagnosis of EoE in patients with FBO in the future, which will lead to improved therapeutic outcomes, prevention of complications of stricture and reduced A&E attendances.

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What is eosinophilic oesophagitis?

Eosinophilic oesophagitis (EoE) is a chronic allergy-/immune-mediated inflammatory condition of the oesophagus,²⁻⁶ in which the body overproduces eosinophils in the oesophagus, leading to inflammation.⁷ It is characterised clinically by symptoms related to oesophageal dysfunction and histologically by eosinophil-predominant inflammation.^{2,4,8}

Clinical presentation of EoE

Clinical presentation of EoE differs between children and adults (Table 1).^{3,9} Children may present with failure to thrive, choking, regurgitation or vomiting after eating, and food refusal.^{2,8,9} Children may be labelled as picky eaters.² Adolescents and adults typically present with retrosternal discomfort/chest pain, dysphagia to solids, food bolus obstruction (FBO) and intractable dyspepsia, which is typically not or only partially responsive to proton pump inhibitors (PPIs).^{5,8,9} An FBO describes food getting stuck in the oesophagus – patients may describe a feeling of food sticking in the chest after swallowing and that food is moving slowly.² Immediately when food becomes stuck, patients may feel a pain or sensation of squeezing in the chest, which can be frightening.¹⁰ Some people feel pain in their oesophagus, and patients often feel the need to spit out saliva or may start to drool because the saliva will not go down.¹⁰ Patients may develop abnormal eating habits to compensate for symptoms, such as eating small pieces of food, chewing excessively, avoiding foods that are likely to be difficult to swallow, eating only soft foods or softening food with sauces and fluid, or vomiting after eating.^{2,9} Older girls may be labelled as having eating disorders.² Symptoms are often chronic and may be intermittent, but patients may present after a short history or even an acute event, especially if FBO is the predominant feature.^{2,9}

Table 1. Clinical symptoms of EoE in children and adults^{2,3,5,8,9}

Children	Adults
Failure to thrive	Dysphagia
Vomiting/regurgitation	FBO
Choking	Vomiting
Food refusal	Intractable dyspepsia, unresponsive/ partially responsive to PPIs

FBO, food bolus obstruction; PPI, proton pump inhibitor.

Immunoglobulin E (IgE)-mediated food allergies, rhinitis, asthma and eczema are significantly more common in EoE patients compared with the general population,^{4,11} and up to three quarters of patients have a personal or family history of allergy.⁹ Three quarters have positive skin prick tests to at least one food allergen – typically dairy, eggs, peanuts, fish, wheat and soy – or aeroallergens such as dust mite, pollen and grass.⁹

The underlying pathogenesis of EoE involves remodelling of the oesophageal wall with fibrosis.² Left untreated EoE is likely to progress to stricturing disease.² Spontaneous oesophageal perforation is a rare complication.^{2,8,9}

Epidemiology of EoE

Eosinophilic oesophagitis is an increasingly common cause of dysphagia and FBO in children and adults.^{1,11} It is the most prevalent cause of chronic oesophagitis after gastro-oesophageal reflux disease (GORD) and the leading cause of dysphagia and FBO in children and young adults.²⁻⁴

Male sex is a strong risk factor for EoE in children and adults, with a male:female ratio of 3:1.^{2,4,9,11} It is also more common in white patients than those from other ethnic groups.¹ A history of EoE in a first-degree relative increases the risk of a person developing EoE.¹

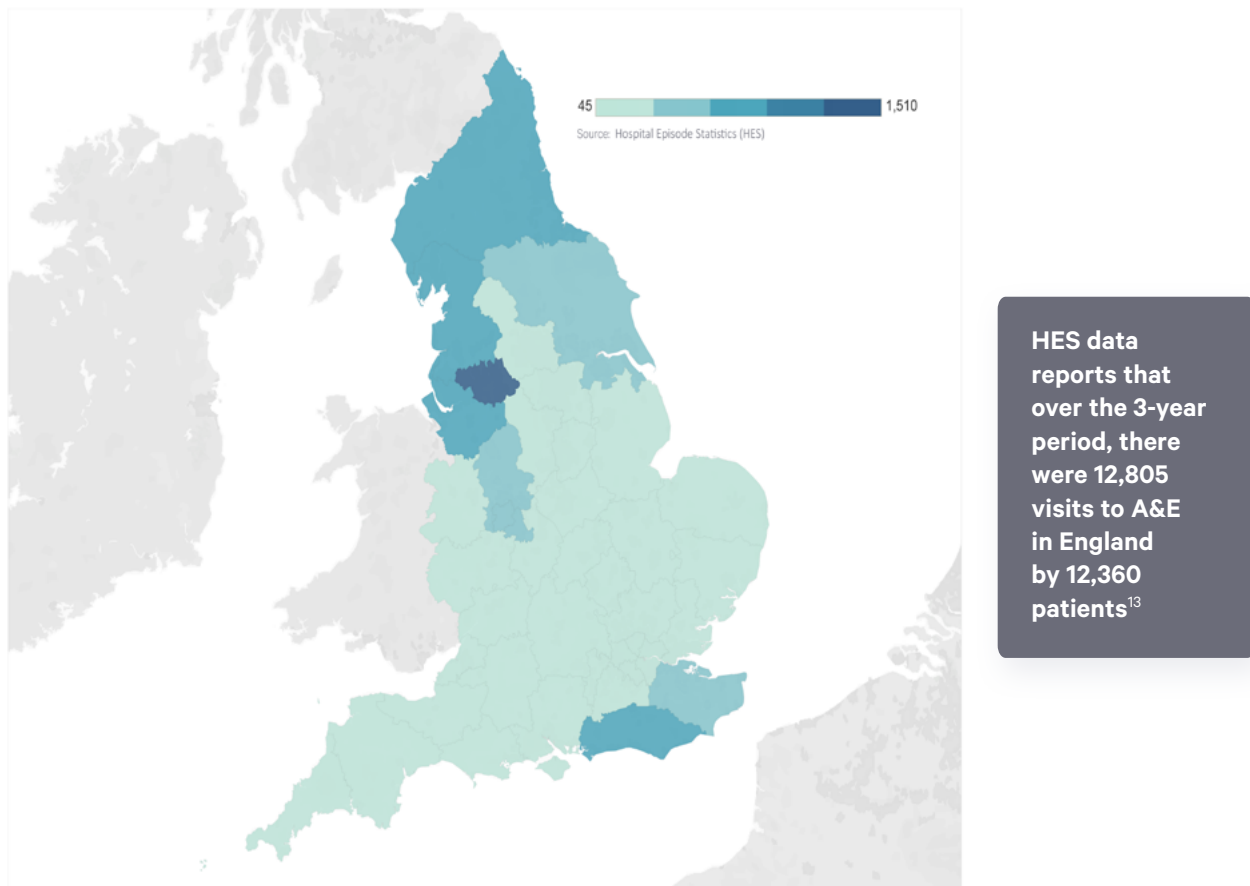
Eosinophilic oesophagitis may occur at any age, starting from childhood, but the incidence increases during adolescence and peaks during early adulthood.^{1,3,4,9} Estimates of the incidence vary widely, depending on the method of data collection and populations studied, ranging from 1 to 20 (mean 7) new cases per 100,000 population per year.^{3,4} Based on an estimated annual incidence of approximately 10 per 100,000 population according to a paper from the USA,³ the UK, which has a population of about 60 million people,¹² has an incidence of about 6,000 cases per annum. The estimated incidence of EoE by integrated care system (ICS) based on local population figures can be found in the Appendix. Prevalence ranges between 10 and 57 cases per 100,000 population and is higher among symptomatic patients.^{3,4}

The frequency of EoE is 7% in adults with oesophageal symptoms undergoing an upper endoscopy⁴ but as high as 23% and 50% in patients with dysphagia and FBO, respectively.^{4,6,11} Based on Hospital Episode Statistics (HES) data, Figure 1 shows the number of patients that visited accident and emergency (A&E) with a foreign body in the throat, including FBO, per ICS during 2016–2019.¹³ The Appendix - Table 4 provides the estimated incidence at the ICS level based on the local population size.

EoE statistics

- Allergy-/immune-mediated food allergy^{3,4}
- May occur at any age, but increasing incidence in children with age and a peak in adults at 30–50 years^{3,4}
- Male sex is a strong risk factor for EoE in children and adults¹
- Incidence varies widely: mean 7 (range 1–20) new cases per 100,000 population per year⁴
- Prevalence: 10–57 cases per 100,000 population⁴

Figure 1. Number of patients visiting accident and emergency (A&E) with a diagnosis of foreign body in the throat, including food bolus obstruction (FBO), per integrated care system (ICS) in England during fiscal years 2016–2019 according to Hospital Episode Statistics (HES).¹³



Burden of EoE and impact on quality of life

Eosinophilic oesophagitis significantly impacts health-related quality of life (HRQoL), impairing physical, social and psychological functioning.^{1,4,14, 15} Patients with EoE are at higher risk of psychiatric disease than siblings and the general population, with the highest risks in the first five years of follow up and in patients diagnosed in childhood.¹⁶ The impact on mental health tends to be more pronounced in male patients, while physical and emotional impacts tend to be greater in female patients.¹⁷

Symptoms of EoE can be unpleasant, socially embarrassing and distressing.^{1,4,7,14} Patients may have negative experiences dining out or attending work interviews and worry about having a choking episode in public and having to hide attacks from others.¹⁴ Embarrassment and shame may contribute to perceived or internalised illness stigma, which can negatively affect anxiety and depression symptoms in patients with EoE.¹⁴ Anxiety may be related to uncertainty about the long-term consequences of this chronic illness; fears of disease progression; the need for long-term medication; highly restrictive dietary modifications; swallowing difficulties; and choking hampering social interactions.⁴ Indeed, although patients experience impairment across all domains of the disease-specific Adult Eosinophilic Esophagitis Quality of Life (EoE-

QOL-A) measure, the 'disease anxiety' and 'eating/diet impact' as in subdomain is significant, especially in female patients.¹⁷ Both sexes are affected in terms of social impact and swallowing anxiety.¹⁷ The 'disease anxiety' subdomain of the EoE-QOL-A is most affected by female gender, younger age, severe clinical disease activity, higher number of food bolus extractions, and more recent EoE diagnosis,¹⁷ with age 18–35 years an independent risk factor for anxiety.¹⁸

Quality of life in patients with EoE is worse in those with more severe symptoms and active disease.⁴ Severe clinical disease activity (i.e., daily dysphagia and food impaction), younger age and female sex are associated with impairment on most subdomains of the EoE-QOL-A.¹⁷ Patients with EoE have significantly more active problem solving, palliative reaction, avoidance, passive expectancy and social support seeking compared with the general population.¹⁷ Less effective coping strategies are related to poor perception of general and disease specific HRQoL, particularly in males.¹⁷

For children, EoE may have profound effects on daily life, including mood disorders such as anxiety and depression, sleeping difficulties, attention-deficit hyperactivity disorder, and social difficulties, including effects on schooling, after-school activities and social events.^{4, 16, 19} They often experience frustration, negative moods and anger about symptoms, treatment, dietary and social restrictions and feel 'different'.¹⁹ HRQoL is significantly worse in children with more pronounced oesophageal symptoms, those with active histological disease and those treated with dietary restrictions.⁴ Children with EoE often do not report symptoms at a time when they often face particular difficulties transitioning from paediatric to adult services and around self-management of diets and medication.¹

Impairment improves during the course of treatment, but the condition is chronic and relapsing requiring lifelong treatment.⁴ Patients with lower symptom severity scores achieve the largest improvements in HRQoL scores.⁴ A proactive approach towards screening for anxiety and depression, excessive restrictive behaviours around eating, coping mechanisms, and provision of sufficient mental care is needed to help patients adjust to living with EoE and improve their HRQoL.^{14, 17} Patients may be reassured that their physical health should not be greatly affected and mental health issues are typically minor.¹⁵

Diagnosis of EoE

Diagnosis and treatment of EoE early in its natural history may prevent long-term complications of fibrosis and strictures requiring subsequent endoscopic intervention.¹ However, patients with EoE typically suffer for a mean of 3–10 years before they are diagnosed with EoE, with diagnostic delay longer in men than in women and in adults than in children.^{20–23} Inflammatory features are more common early in the course of EoE (62% of patients with diagnostic delay ≤ 2 years versus 20% in patients with diagnostic delay of >21 years), while fibrotic features and food impaction events increase with increased length of diagnostic delay (56% and 24%, respectively, with diagnostic delay ≤ 2 years and 92% and 57%, respectively, with diagnostic delay ≥ 21 years).²¹

Eosinophilic oesophagitis cannot be diagnosed on clinical history alone, and examination is usually unremarkable, with no identified oropharyngeal manifestations.⁹ Other systemic and local causes of oesophageal eosinophilia (Table 2) should be excluded, as many other oesophageal disorders can present in a similar manner.^{2, 4, 9} Proton pump inhibitor (PPI)-responsive oesophageal eosinophilia was previously considered a separate entity but is now widely accepted as a different point along a continuum of EoE.^{9, 24}

Table 2. Diseases other than EoE associated with oesophageal eosinophilia⁹

Disease	
GORD	Hypereosinophilic syndrome
Eosinophilic gastrointestinal diseases not isolated to the oesophagus	Drug hypersensitivity
Crohn's disease	Churg-Strauss syndrome and other vasculitides
Coeliac disease	Graft versus host disease
Atopic disorders	

GORD, gastro-oesophageal reflux disease.

Endoscopy is an essential tool in the diagnosis of EoE.^{8,9} Anatomical features seen on endoscopy are not diagnostic for EoE, so diagnosis is confirmed histologically from oesophageal biopsies taken during endoscopy showing ≥ 15 eosinophils/high power field (hpf).^{2,8,9}

In patients with FBO, urgent referral to gastroenterology and an endoscopy on the next available endoscopy list or as an immediate emergency is recommended depending on clinical presentation.¹ Patients with spontaneous resolution of FBO should be booked for endoscopy and outpatient review.¹ All adults undergoing endoscopy should have oesophageal biopsies if they have endoscopic signs associated with EoE or symptoms of dysphagia or FBO with a normal looking oesophagus.¹ This should include at least six biopsies from different anatomical sites within the oesophagus.^{1,25} Where possible, PPIs should be withdrawn for at least three weeks prior to endoscopy and biopsy to enable accurate diagnosis of EoE.¹ For patients with a high index of suspicion for EoE but whose initial histology is not diagnostic, repeat endoscopy with adequate biopsies should be considered, if there are suggestive endoscopic features or typical symptoms of eosinophilic oesophagitis.¹

Management of EoE

The aim of treatment in patients with EoE is to induce long-term clinical and histological remission.¹ However, one of the biggest challenges has been the lack of a treatment pathway as, until recently, there was no standard care for inducing remission in EoE.

Treatment has included the use of PPIs (e.g. omeprazole or lansoprazole), corticosteroids (e.g. off-label use of inhalers such as fluticasone, budesonide), with or without dietary restrictions.^{7,8}

- Although some clinicians find PPIs useful, NICE states that they are not effective for EoE in most people.⁷
- Off-label corticosteroids are effective when used properly but dosing and delivery is difficult and imprecise because it involves swallowing formulations designed for inhalation, which is counterintuitive and poorly understood by patients and clinicians.⁷

- Dietary interventions – including a six-food elimination diet that involves cutting out milk, eggs, nuts, wheat, soy and seafood^{1,7} – are challenging, resulting in low adherence; professional support is often difficult to access; and specialist diets can be expensive and unaffordable for many people with this disease.⁷

In 2018, a licensed orodispersible tablet (ODT) containing 1 mg budesonide for the treatment of EoE in adults aged ≥ 18 years – was licensed by the European Medicines Agency.^{26,27} The licence was extended with the addition of a 0.5 mg strength ODT in March 2020.²⁸ In September 2020, the Scottish Medicines Consortium (SMC) recommended use of budesonide ODT for the treatment of EoE in adults (older than 18 years) who have been unsuccessfully treated with PPIs.²⁹ In June 2021, National Institute for Health and Care Excellence (NICE) technology appraisal 708 recommended the use of this product as an option for inducing remission of EoE in adults.⁷ NICE noted that clinical trial evidence shows that budesonide ODT improves the signs and symptoms of EoE compared with placebo, although there is no direct evidence for budesonide ODT compared with fluticasone or the six-food elimination diet.⁷ Although budesonide ODT has a marketing authorisation for induction and maintenance of remission in EoE, it was only licensed for induction when the technology appraisal began and so NICE currently recommends it only for induction of remission.⁷ The British Society of Gastroenterology (BSG) and British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) joint consensus guidelines on the diagnosis and management of EoE in children and adults support the use of budesonide ODT over other swallowed steroid formulations in the induction treatment of EoE given its regulatory approval in both the UK and Europe.¹

After initiation of therapy, it is essential to check clinical response with improvement in symptoms of dysphagia, retrosternal discomfort or vomiting/regurgitation and histological remission by endoscopy and biopsy – usually 8–12 weeks after starting treatment and depending on waiting times for endoscopy,¹ which have increased due to the backlog following COVID-19. Patients require ongoing care, as the disease can return if it is not treated or well managed.

Unmet need/learning points

Awareness and understanding of EoE

Lack of awareness and understanding of EoE is an issue in the community and the acute sector.

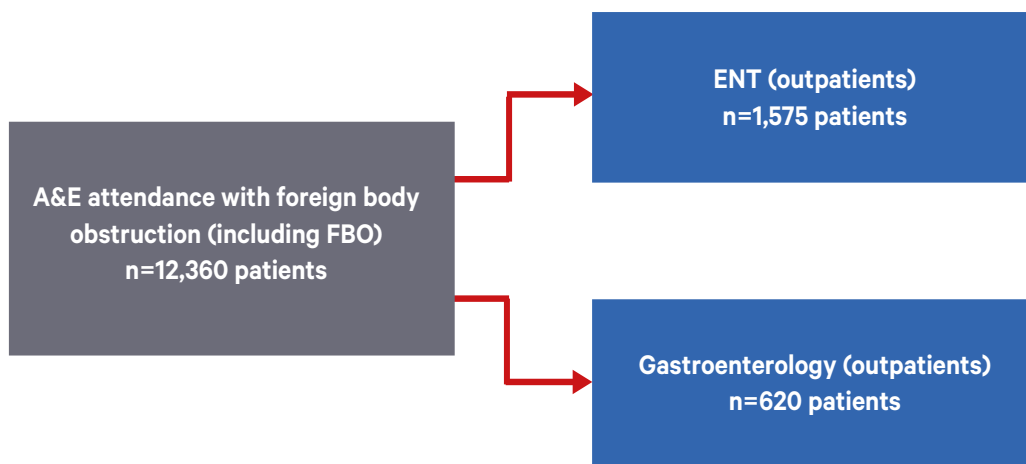
- Patients typically suffer for 3–10 years before they are diagnosed with EoE.²⁰⁻²³
- They may have repeated A&E and hospital attendances for FBO during this time and are often managed inappropriately until they receive the correct diagnosis.
- All of this impacts on their physical, mental and social quality of life.
- Delays in correct diagnosis are largely due to local A&E guidelines signposting or referring these patients to ear, nose and throat (ENT) specialists rather than gastroenterologists (Figure 2).
- EoE is very likely underdiagnosed in patients with dysphagia or FBO due to lack of awareness of the diagnostic requirements for the condition leading to no or insufficient biopsies taken when endoscopy is ordered.

- A study in a district general hospital in the UK found that only 42.2% of patients presenting with dysphagia or FBO over 1 year had oesophageal biopsies and only 9% of these had the required six biopsies, with 3.7 biopsies on average across the study population.³⁰
- A study from Dundee in 2019 also highlighted sporadic and unpredictable adherence to the clinical guidelines available at the time for the investigation, diagnosis and management of EoE, with wide variation in practice among admitting specialties.⁶ The authors advocated a formal FBO protocol that involves management by a single specialty, flexible oesophago-gastro-duodenoscopy (OGD), multiple oesophageal biopsies (with standardisation of oesophageal biopsy reports and a formal eosinophil count) and routine outpatient follow-up.

Since the BSG/BSPGHAN guidelines for diagnosis and management of EoE were published in 2022,¹ there has been clear guidance on the appropriate management of these patients.

- While these guidelines are being adopted and implemented, communication to increase awareness and suspicion of EoE in patients with FBO and highlight the optimal management of these patients needs to continue.

Figure 2. Most patients with foreign body obstructions in the throat, including food bolus obstructions (FBOs) during 2016–2019 were referred to ENT according to Hospital Episode Statistics (HES)¹³



- The 2022 BSG/BSPGHAN guidelines¹ need to be shared and cascaded within:
 - the community to improve appropriate referrals and diagnosis
 - the acute sector to ensure A&E clinicians make prompt referrals to gastroenterology for endoscopy with appropriate biopsies instead of referring patients to ENT.

Prescribing

Despite budesonide ODT now being licensed for initial and maintenance therapy of EoE, NICE approval and dose recommendations in the British National Formulary (BNF) are only for initial treatment for 6–12 weeks under specialist initiation.^{7,31}

With lack of a recommendation on maintenance treatment from NICE, current access to treatment beyond the initial course can differ greatly from patient to patient, from clinician to clinician and from trust to trust.

- Patients may have to wait for their next appointment or even their next endoscopy before the consultant prescribes another 6–12-week course, or patients have to contact their consultants' secretaries or administration staff to obtain simple repeat prescriptions for ongoing treatment.
- This puts immense pressure on hospitals to book regular 6-monthly consultant appointments, creates an extra burden for hospital staff, and requires patients to come into hospital every six months to obtain long-term therapies that could be managed in primary care.

General practitioners (GPs) often prescribe steroid inhalers 'as directed' (that is, as per the specialist's instructions to swallow the dose), this is because these formulations are on their formulary for inhalation and they are less likely to be questioned about the prescription if marked 'as directed'.

- By stating 'as directed' they are less likely to be asked to complete 'off-licence use' documentation.

Patients are also often confused about using inhalers to swallow the drug, leading to subtherapeutic dosing due to poor adherence to the treatment regimen and poor technique when using the device for administration for which it was not designed.

If prescribing can be addressed across the system, there would be benefits to the patient through:

- reduced appointments
- clinicians not having to see stable patients for prescriptions
- administrative staff not having to arrange prescriptions between clinical appointment
- reduced system savings through fewer clinical appointments for maintenance therapies.

Rationale for this document

This journalistic-style case of a patient with EoE aims to highlight the current suboptimal/typical pathway of a patient versus the optimal pathway. It demonstrates the impact of the condition on the personal and clinical journey of the patient, highlighting the positives and negatives of both pathways and the cost implications of each over a five-year period.

Analysis style

This case study uses a Delphi-style consensus process involving experts in this specialist field alongside an economic analysis methodology. This has been developed using fictitious, but realistic, patient journeys which are compared to highlight potential care improvement opportunities.

Use of behavioural methods drives engagement through the combination of objective clinical data, clinical expertise and financial analysis wrapped in a journalistic style. The study includes prompts for commissioners and service transformation leads to consider when evaluating their local health economy.

The goal is to inspire more stakeholders to take note and act towards positive change by thinking strategically and collaboratively about engagement, education and designing optimal care for people with undiagnosed EoE.

Based on consensus of clinical practice the boxes below highlight suboptimal/typical or optimal practice.

Red boxes highlight suboptimal/typical pinch points in many pathways throughout the country.

Yellow boxes highlight standard/reasonable practice based on a consensus of specialists.

Green boxes highlight best practice points that are above and beyond current recommended optimal practice and that are already being trialled in some care pathways across the country.

Meet Nathan

- Nathan is a 30-year-old information technology (IT) banking consultant who lives with a flatmate in central London. He has a well-paid job but works long hours
- Since the coronavirus disease 2019 (COVID-19) pandemic hit, Nathan has been working from home and is looking to move out of London with his girlfriend, who is a chef.
- Nathan is a healthy, active and social individual; he loves cycling, running and playing the saxophone with his band at weekends.
- Nathan's ambition is to join an IT firm outside of London, maintain an outdoors lifestyle and continue playing with his band.



Nathan's history

Nathan has been a fussy eater since childhood. According to his mum, he often left food on his plate. As a teenager, he began to complain of discomfort and something that sounds like reflux when eating, which his mum put down to indigestion or him eating too quickly.

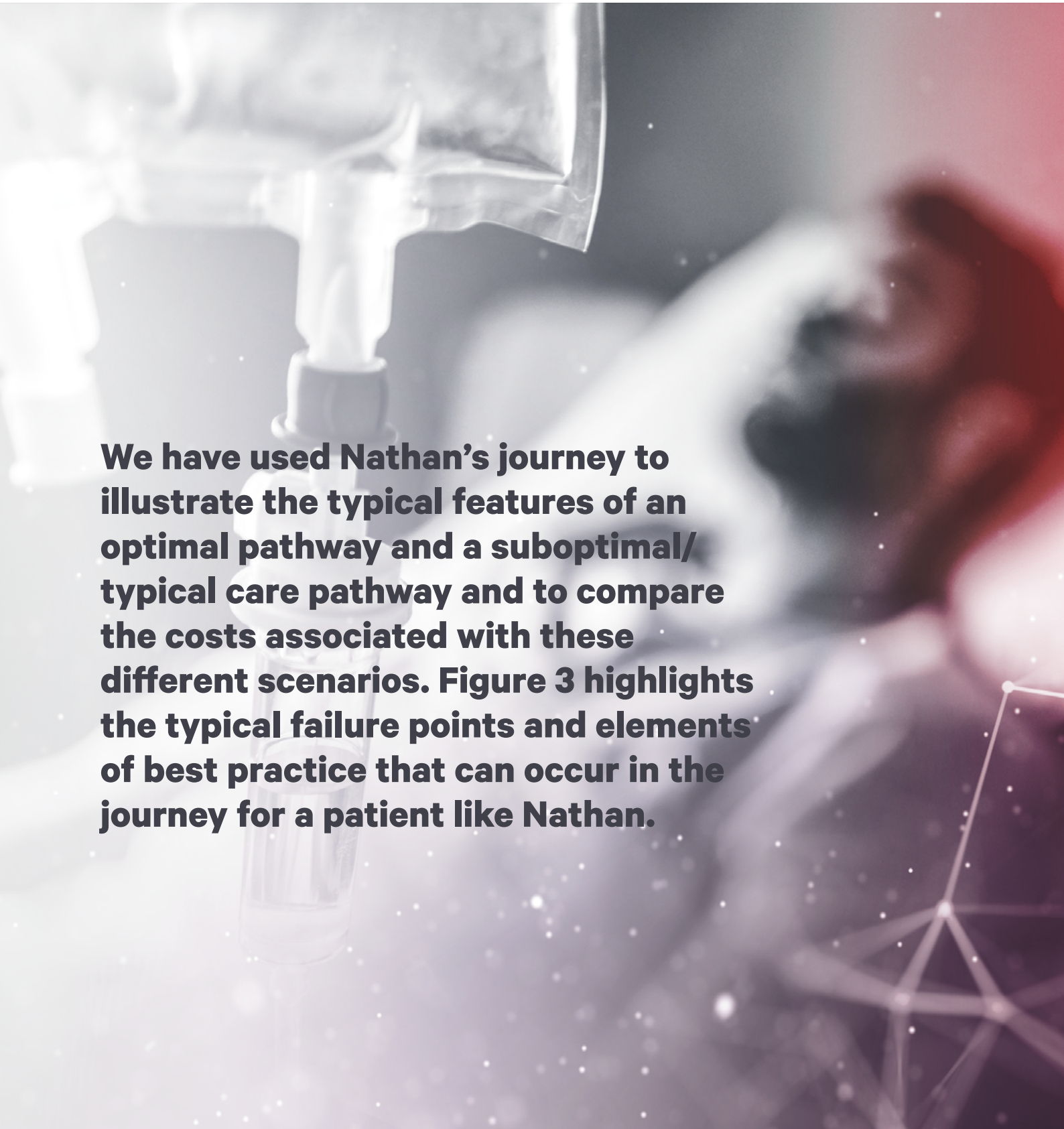
Since Christmas 2014, Nathan had been experiencing discomfort after eating. He carried antacids, as he thought it was due to his preference for spicy soups and curries. In March 2015, Nathan realised that his food preferences had been changing. He had been avoiding pizza and steaks and had become accustomed to drinking lots of water when eating to help his food go down. As part of his fitness routine, he had been drinking protein shakes.

Nathan has had multiple consultations with his GP, complaining of a feeling of food stuck in his throat, but no further action has been taken.

About Nathan

- BMI 20 kg/m²
- Waist circumference 71 cm
- Blood pressure 119/79 mmHg
- Non-smoker
- Occasional drink with friends in the bar/pub (4 units over the weekend)
- No relevant familial risk factors
- No significant previous medical history other than a tendency to asthma during childhood and hay fever during summer

Overview: Nathan's EoE care pathways



We have used Nathan's journey to illustrate the typical features of an optimal pathway and a suboptimal/typical care pathway and to compare the costs associated with these different scenarios. Figure 3 highlights the typical failure points and elements of best practice that can occur in the journey for a patient like Nathan.

Figure 3. Overview: Nathan's EoE care pathways

Suboptimal/typical care pathway

Optimal care pathway

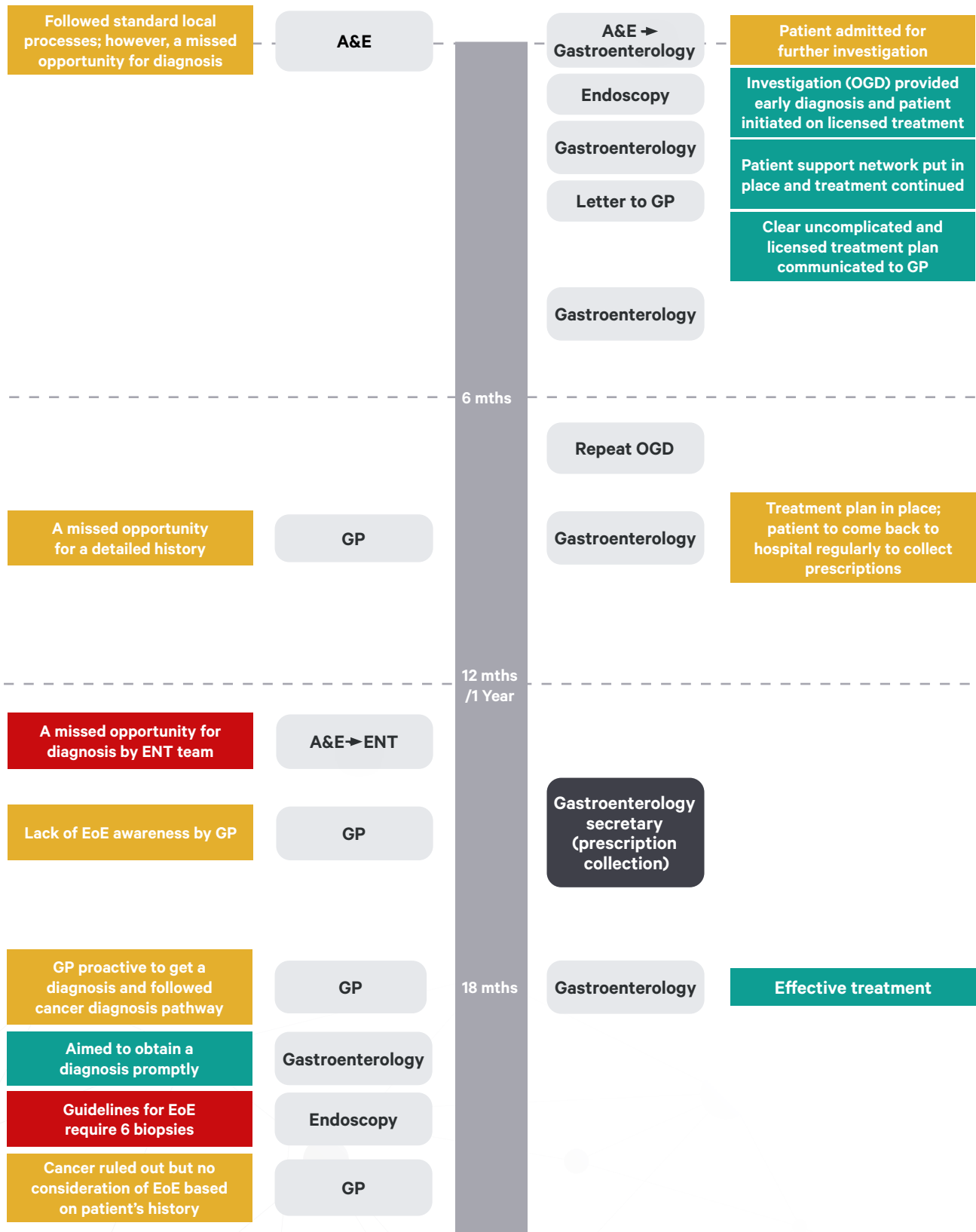
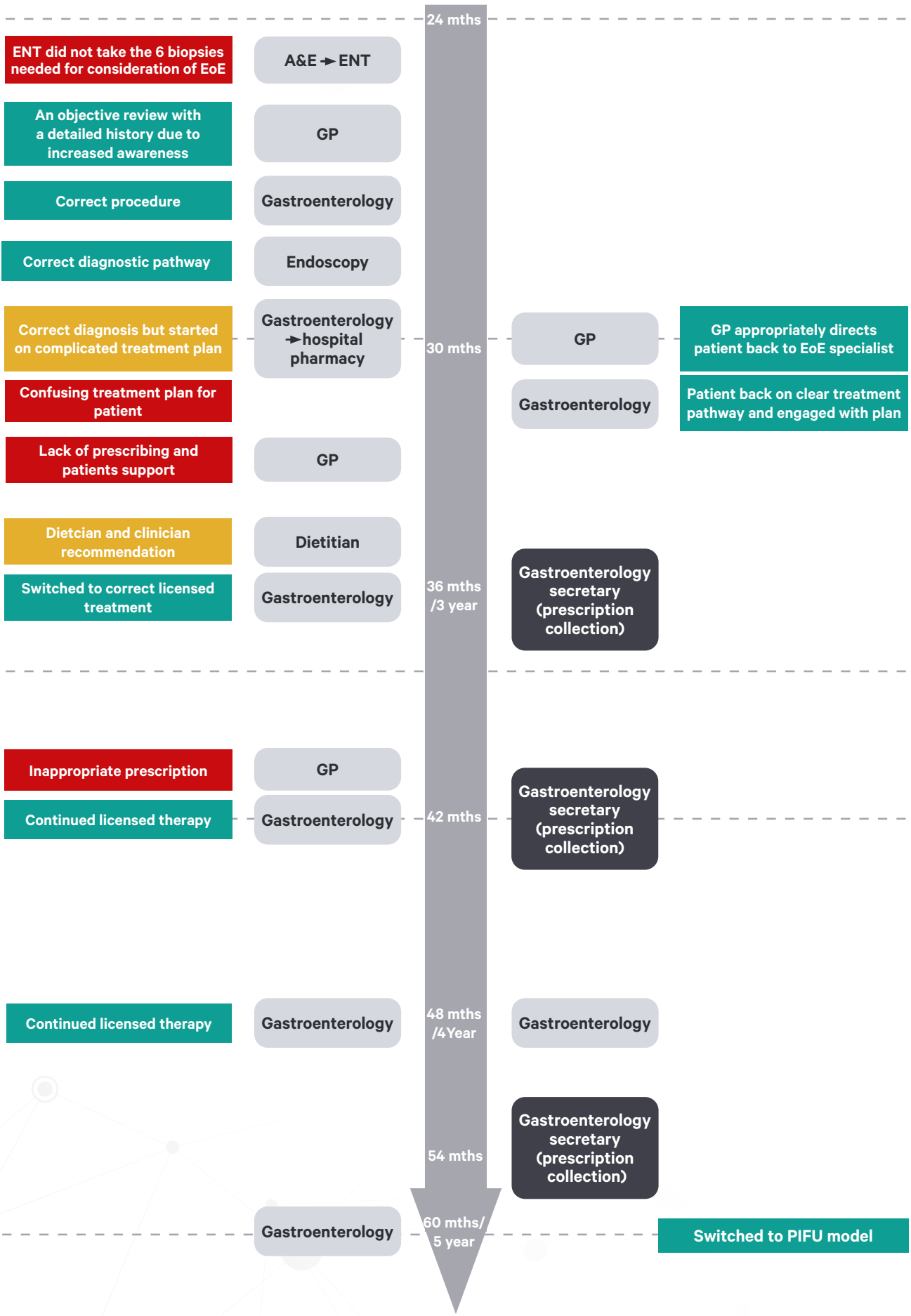


Figure 3. Overview: Nathan's EoE care pathways



Suboptimal/typical management pathway

At his brother's graduation celebration BBQ, Nathan had an episode that felt like choking and couldn't swallow his own saliva. He ended up at A&E. Nathan thought it was because he was not chewing his food properly.

A&E attendance (Month 1)

Nathan presented to A&E, where he waited nearly 6 hours to be seen. As he had food stuck in his throat, he was given a diet cola, then three doses of intravenous (IV) Buscopan (hyoscine butylbromide) 30 minutes apart and then intravenous diazepam.

At this first presentation, he had a routine chest X-ray, which showed no abnormal findings. No electrocardiogram (ECG) was needed. The obstruction had passed through, and he was discharged with no follow-up, on the proton pump inhibitor (PPI) omeprazole 20 mg once daily for 2 weeks.

Followed standard local processes; however, a missed opportunity for diagnosis

During the next six months of summer and autumn, Nathan continued with daily life, enjoyed summer parties with the band and occasionally had a beer. His girlfriend had been cooking some new dishes after completing her chef training.

Between months six and eight Nathan had experienced a few episodes that he thought were bad indigestion or reflux. He stopped eating some foods, like bread, and was reluctant to try his girlfriend's new dishes. Nathan had in fact been experiencing minor FBOs but did not recognise them as such.

By month nine, Nathan had become reluctant to eat out, which had started to impact on his social life. He was also experiencing seasonal hay fever. Encouraged by his girlfriend, Nathan went to see his GP.

GP consultation (Month 9)

Based on a diagnosis of indigestion and reflux, Nathan's GP prescribed omeprazole 20 mg once a day for 1 month. He was told to report back if further supplies were needed. He also purchased antihistamines from his local pharmacy.

A missed opportunity for a detailed history

Nathan finished taking the omeprazole the following month, as he felt it wasn't helping, he did not request more supplies.

Three months later, Nathan was unable to swallow his own saliva after a band celebration.

A&E attendance and ENT admission (Month 13)

Nathan attended A&E with another FBO. Following local FBO guidelines, Nathan was admitted under the care of ENT, as he was pointing at his neck above the sternal notch to indicate where he felt the obstruction. The ENT team performed flexible nasoendoscopy in a treatment room, which revealed pooling of saliva in his hypopharynx. As the FBO did not resolve spontaneously, Nathan was taken to emergency theatre for removal of the food bolus under general anaesthetic. During the rigid oesophagoscopy, localised mucosal inflammation was detected in the middle section of his oesophagus, but the FBO had resolved on its own. He was discharged with no planned follow-up.

A missed opportunity for diagnosis by ENT team

Two months later, Nathan, concerned and anxious, saw his GP to find out if there was any communication following his admission.

GP consultation (Month 15)

Nathan's GP noted that an ENT investigation had already been conducted. The GP restarted him on omeprazole 20 mg once a day to be taken on an ongoing basis. He was given 1 month's supply and told to order repeat prescriptions. He was advised to chew food carefully, avoid fizzy drinks and spicy foods, and continue his lifestyle choice not to drink alcohol.

Lack of EoE awareness by GP

A month later Nathan was still not sure the omeprazole was making a difference, so he stopped taking it and did not request a repeat prescription when he ran out after one month. He started drinking milk, thinking he had acid reflux.

The following month, Nathan spent Christmas with his girlfriend's family. He had another episode of choking, left the table and was gone for most of Christmas lunch. His girlfriend was very worried and suggested taking him to A&E, but Nathan refused to go; it was Christmas, and he was embarrassed and conscious about what his potential in-laws would think.

However, concerned, and anxious about these episodes, he began to avoid eating in social situations, as he often found himself regurgitating. This made it difficult to travel and eat away from home, so he decided to leave his band. His girlfriend began to worry about cancer, remembering similar symptoms in her uncle, who had Barrett's-associated cancer.

After Christmas in early January, Nathan booked the earliest available appointment to see his GP. He described symptoms of regurgitation and food sticking in his throat. He also described intermittent chest pain, weight loss and issues with swallowing.

GP consultation (Month 18)

Nathan's GP referred him urgently to the gastroenterology team at the local hospital on a 2-week wait. He told him to restart omeprazole 20 mg twice daily for a month.

GP proactive to get a diagnosis and followed cancer diagnosis pathway

Nathan had an appointment with a gastroenterologist a month later.

Gastroenterology consultation (Month 19)

The gastroenterologist took a history and decided to book Nathan in for an endoscopy. He recommended that Nathan continue omeprazole long-term but to reduce to once-daily dosing after 4 weeks.

Aimed to obtain a diagnosis promptly

By Easter Nathan continued with his daily life. He was still taking omeprazole, and although his symptoms were present, they seemed to be under control. He had also been using a steroid nasal spray for hay fever. He attended hospital for his endoscopy.

Endoscopy (Month 21)

Nathan underwent flexible endoscopy as a day case without sedation. The consultant conducted the endoscopy and took two biopsies, which were sent off for analysis. Nathan was informed verbally that the scope looked normal.

The biopsy report showed no abnormality, so Nathan was discharged for GP follow-up.

Guidelines for EoE require 6 biopsies

A month later, Nathan's GP surgery contacted him to confirm that the results were clear and there was no evidence of cancer.

GP telephone consultation (Month 22)

Nathan's GP notified him that the results were all clear and there were no concerns, so no follow-up was needed. They made a joint decision for Nathan to stop taking omeprazole.

Cancer ruled out but no consideration of EoE based on patient's history

During the summer (three months later), Nathan presented to A&E with another FBO and provided a detailed history.

A&E attendance and ENT admission (Month 25)

The A&E team referred Nathan to ENT, and he was admitted again. An urgent inpatient rigid oesophagoscopy was carried out due to severe FBO still being present. No biopsies were taken. Nathan was started on omeprazole for 2 weeks and referred to his GP for follow-up.

ENT did not take the 6 biopsies needed for consideration of EoE

The following month, Nathan visited his GP to discuss his options, as he still had symptoms and continued to lose weight.

GP consultation (Month 26)

Nathan saw a locum GP, who took an in-depth history. The GP wrote back to the gastroenterology consultant regarding his concerns and Nathan's repeat A&E attendances.

An objective review with a detailed history due to increased awareness

Gastroenterology consultation (Month 28)

Nathan saw a gastroenterologist, who explained that he wanted to conduct specific biopsies. The gastroenterologist booked Nathan in for an endoscopy, where 6 biopsies would be taken.

**Correct
procedure**

Endoscopy and biopsies (Month 29)

Nathan underwent endoscopy as a day case. The endoscopist took 6 biopsies, which showed that he had EoE.

**Correct
diagnostic
pathway**

The following month, Nathan attended an outpatient clinic appointment. He was very anxious and concerned that he had a terminal condition. He continued to lose weight because of his concern and because he wasn't eating enough.

Gastroenterology follow-up (Month 30)

Nathan was seen in the outpatient clinic by a gastroenterologist, who gave him the diagnosis of EoE and spent time explaining this condition.

The consultant started Nathan on topical steroids – fluticasone 250 µg inhaler 2 puffs to be swallowed twice a day – and explained how to use this treatment. Nathan was given a 3-month prescription and, because swallowing the inhaled dose is unlicensed use, he was told to take the prescription to the hospital pharmacy.

The consultant explained to Nathan that a referral to a dietitian could be arranged if needed, but that the condition should resolve now there was a diagnosis and treatment had been started.

**Correct
diagnosis but
started on
complicated
treatment
plan**

Hospital pharmacy (Month 30)

Nathan went to the hospital pharmacy to collect his medicine. However, the pharmacy's instructions conflicted with the clinician's advice, telling him to inhale the medication as it would be used for asthma. The pharmacist discussed this with the clinician, who confirmed that Nathan should swallow the inhaled dose twice a day. The patient was given two inhalers and told to go to the GP for subsequent supplies.

**Confusing
treatment
plan for
patient**

A month after his follow-up appointment, Nathan was still concerned. He did not understand the condition and information about the illness and treatment confused him. He explored websites to try to learn more about EoE. He was especially confused regarding the treatment, as he understood it was not licensed for EoE and he struggled to take the treatment by swallowing it. Based on his research on the internet, Nathan decided to stop eating certain foods, such as eggs, dairy, gluten, fish, nuts and soya, which he had read cause the disease. He had started missing doses of his prescribed fluticasone.

Nathan was continuing to struggle with his medicine a month later, finding it cumbersome to administer, and he was no longer taking it regularly. He was still experiencing symptoms and thought that this was all that could be done and that no-one could help him. He was still losing weight because he was avoiding food. Travelling long distances was impossible unless he took his own food with him. He was always hungry and very anxious about eating in public. He went to see his GP to get further inhaler supplies.

GP consultation (Month 32)

The GP prescribed 3 inhalers with the instructions 'as directed', because he was not aware of the necessary unlicensed swallowing of doses from an inhaler. The GP was concerned about weight loss and contacted the gastroenterologist, who referred Nathan to the hospital dietetic service.

**Lack of
prescribing
and patient
support**

Three months later in early summer Nathan received a date for a remote dietitian appointment. He was sceptical before the consultation and did not want to discuss diet; however, his girlfriend reassured him that she would help.

Dietitian appointment (Month 35)

The dietitian advised that Nathan follow a two-food (milk and wheat) elimination diet due to his continuing symptoms. He would need an endoscopy if he followed the regimen.

**Dietitian
and clinician
recommendation**

Nathan was sceptical about the elimination diet suggested by the dietitian, but he was willing to try. His girlfriend supported him by cooking, but he only persisted with it for a few weeks.

One month later, Nathan attended his 6-month gastroenterologist review remotely.

Gastroenterology follow-up (Month 36)

Nathan explained that he was not happy. The elimination diet had not worked, his symptoms continued and he'd lost a lot of weight. He was struggling with the complexity of the medication and the fact that the GP and community pharmacist said that swallowing the dose was unlicensed, which made him uncomfortable, and he admitted that he did not always take it regularly. He mentioned that he had been using a steroid nasal spray for his hay fever.

The gastroenterologist explained that he would have conducted another endoscopy if Nathan had followed the diet, but he instead he offered to switch his treatment to a licensed oral dispersible tablet (ODT) formulation of budesonide, which is specifically designed and licensed for topical therapy of EoE. Nathan agreed to try the new treatment and was given a 3-month prescription of budesonide ODT at a dose of 1 mg twice a day. The consultant told Nathan to contact his secretary for a repeat prescription when he ran out. He would review Nathan in 6 months.

**Switched
to correct
licensed
treatment**

Nathan left his appointment with a better understanding of EoE. Reading the patient information leaflet for the new treatment, he was more confident that the medication would support his condition. His symptoms started to improve over the next few weeks, and he began to gain weight as he normalised his diet.

By autumn Nathan was responding to the new treatment and feeling much better. He was putting on weight and enjoying his food a bit more. However, he started to miss doses and forgot to get a repeat prescription from the consultant's secretary.

By Christmas, Nathan's symptoms started to reappear. It had been two months since his prescription ran out and he had not contacted the consultant's secretary for a refill. He contacted his GP to get a repeat prescription

GP consultation (Month 41)

The GP would not prescribe budesonide ODT and so instead prescribed a fluticasone inhaler labelled 'as directed'.

**Inappropriate
prescription**

In the new year, Nathan attended his 6-monthly review and requested more budesonide.

Gastroenterology 6-month review (Month 42)

At Nathan's 6-month review, the gastroenterologist reiterated that even though budesonide ODT is licensed, GPs would not prescribe this treatment because it was only for specialist initiation. He reminded Nathan that the hospital pharmacy would only provide a 3-month supply and that he would have to contact the hospital regularly to obtain prescriptions between clinic visits.

**Continued
licensed
therapy**

Six months passed, and Nathan was much happier. Although he missed occasional doses of his tablets, he had not been symptomatic. He proposed to his girlfriend, who accepted, and was considering re-joining the band.

Gastroenterology 6-month review – virtual (Month 48)

At Nathan's next 6-month review with the consultant, he was given a prescription for another 3 months of budesonide ODT at a dose of 0.5 mg twice daily, which he would have to collect from the hospital pharmacy. He was switched to annual review and told to contact the consultant's secretary for 3-monthly prescriptions.

A following six months later, Nathan was still putting on weight, enjoying being back with the band and planning the wedding. He contacted the hospital pharmacy for 3-monthly repeat prescriptions of budesonide oral dispersible tablet at the same dose.

Gastroenterology annual review (Month 60)

Nathan had an annual review with his consultant gastroenterologist, who continued to prescribe budesonide ODT at a dose of 0.5 mg twice daily.

Optimal management pathway

At his brother's graduation celebration BBQ, Nathan had an episode that felt like choking and couldn't swallow his own saliva. He ended up at A&E. Nathan was transferred to the admissions ward, but he was unsure why as his food obstruction had passed.

A&E attendance and gastroenterology admissions referral (Month 1)

Nathan presented to A&E with food stuck in his throat. He was referred straight to gastroenterology following a chest X-ray and received no treatment in A&E. Although the FBO had passed through, Nathan was transferred to the admissions unit to be seen by the gastroenterologist.

**Patient
admitted
for further
investigation**

Oesophago-gastro-duodenoscopy (OGD) (Month 1)

Nathan had OGD under sedation, with six biopsies taken at three levels (following the national guidelines¹). These showed clear evidence of EoE. His EoE endoscopic reference score (EREFS) was noted, and images were taken to be reviewed in 4–6 weeks. Nathan was started on a 3-month course of licensed treatment budesonide ODT 1 mg twice daily; he was given an initial 1-month supply, with the remainder to be provided at follow up in 1 month.

**Investigation
provided
early
diagnosis
and licensed
treatment
was initiated**

A month later, Nathan showed some signs of improvements, but he continued 'his normal' – fussy, slow eating and drinking lots of water with his food. He attended a hospital outpatient appointment to discuss the results of his biopsies.

Gastroenterology follow-up (Month 2)

The gastroenterologist who saw Nathan in clinic reviewed his histology results, which confirmed EoE, with >100 eosinophils/high power field (hpf; 0.345 mm²). The consultant decided to continue treatment with budesonide ODT 1 mg twice a day and Nathan received the remaining 2-months' supply of the initial 3-month course. Nathan was directed to the EOS Network (www.eosnetwork.org) for further support and information.

Patient support network put in place and continuation of treatment

Gastroenterology letter to GP (Month 2)

The consultant sent a letter to Nathan's GP regarding the endoscopic diagnosis of EoE. He explained that Nathan had been prescribed 3 months of budesonide ODT 1 mg twice daily and advised that no additional treatment such as a PPI would need to be prescribed.

Clear uncomplicated and licensed treatment plan communicated to GP

The rest of the summer and autumn Nathan continued with daily life, enjoyed summer parties with his band and occasionally had a beer. His girlfriend had been cooking some new dishes after completing her chef training.

A month after his gastroenterology follow-up appointment, Nathan contacted and joined the EOS Network. As a result, he felt well informed about his chronic disease and the ongoing management options and had also connected with other people living with EoE.

Nathan attended clinic for review two months later, although he was not sure that he needed to as he had been doing well without any symptoms.

Gastroenterology follow-up (Month 4)

Nathan's clinic follow-up went well, but the gastroenterologist wanted to rescope to ensure the treatment had worked. He booked Nathan in for a routine OGD.

Repeat OGD (Month 7)

Nathan underwent repeat OGD, with biopsies taken through a transnasal scope without sedation. Fewer oesophageal eosinophils were seen on histology than on his previous biopsies.

Over the next few months Nathan was getting some symptoms.

Gastroenterology follow-up (Month 9)

Nathan was seen in clinic and the gastroenterologist confirmed that the treatment had largely worked but recommended that he continue budesonide ODT at a dose of 0.5 mg twice daily long term, with review in 1 year. Nathan was given a prescription for 6 months of treatment to collect from the hospital pharmacy and told to contact the consultant's secretary to arrange a repeat prescription in 6 months.

The hospital pharmacy did not have a full 6 months' supply in stock, so Nathan was given a 3-month supply and advised to collect the remainder of the prescription in 3 months' time.

Treatment plan in place: but patient has to travel back to hospital regularly to collect prescriptions

A month later, Nathan began to develop seasonal hay fever and started to take an antihistamine from his local pharmacy. He was very happy, as he had proposed to his girlfriend, and she had accepted. He was eating well, so he stopped taking the regular budesonide ODT, as did not want to be taking too many medications.

Three months passed by, and Nathan's symptoms had restarted because he had not been taking his budesonide ODT. He contacted the consultant's secretary to obtain a repeat prescription. He also contacted the EOS Network for support and watched a webinar on long-term EoE, which helped him to understand the importance of maintaining his treatment regimen.

Gastroenterology secretary (Month 16)

Nathan contacted the consultant's secretary to obtain a repeat prescription. He was prescribed a 3-month supply of budesonide ODT 0.5 mg twice daily, which he collected from the hospital pharmacy.

Two months later and Nathan's condition was stable. He generally took his medicines daily and attended his next clinic appointment.

Gastroenterology follow-up review (Month 18)

At Nathan's clinic review, the gastroenterologist decided that he was doing well and could remain on long-term treatment with budesonide ODT 0.5 mg twice daily, with review in 1 year. He was prescribed a further 6 months' supply to be collected from the hospital pharmacy when needed and told to contact the consultant's secretary for the subsequent prescription.

**Effective
treatment**

Six months after his last appointment, Nathan decided to see whether changes to his diet could control his symptoms. He stopped taking budesonide ODT and began to exclude items from his diet. He was using a combined steroid and antihistamine spray and antihistamine tablets for his hay fever.

Nathan generally felt well after not taking his medicine for the last six months, but he had noticed that sometimes his food was beginning to stick in his throat again. This had been particularly bad over Christmas, when he had experienced bad dysphagia and chest pain.

GP consultation (Month 30)

Nathan went to see a GP and explained his history and admitted that he had not been taking his budesonide ODT regularly, as he was trying to control his symptoms with diet alone. The GP recommended that he attend his clinic appointment, which was the following week, to discuss with his consultant.

**GP
appropriately
directs
patient
back to EoE
specialist**

Gastroenterology follow-up review (Month 30)

Nathan explained to the consultant about stopping his budesonide ODT and changing his diet. The consultant emphasised that his condition is chronic and he needed to continue on long-term budesonide ODT to keep his symptoms under control and explained about potential complications of unmanaged EoE. He arranged for review in 6 months and reminded Nathan that he needed to contact his secretary every 6 months for his prescription and collect it from the hospital pharmacy, because it is not currently prescribed by GPs.

The consultant advised that a restricted two-food (milk and wheat) step-up or 6 food (milk, wheat, egg, soya, nuts and fish) step-down diet could be considered at a later stage. If Nathan wanted to pursue this as a treatment option, he would need to be referred to a specialist dietitian for help, as it can be difficult to effectively maintain and it would be important for him to have support and that he did not try it on his own.

Patient back on clear treatment pathway and engaged with plan

Nathan and his girlfriend got married a month later. He had decided to take the prescribed medicine as he wanted to enjoy his wedding and the start of his marriage without any worries.

For the next eighteen months, Nathan continued his treatment without any problems, collecting his prescription every six months from the hospital pharmacy. His annual review had been delayed due to COVID-19.

Nathan was happy, as he and his wife were expecting their first child at the end of the year. Nathan continued to take his budesonide ODT and his symptoms were under control.

Gastroenterology follow up review (Month 48)

The consultant was pleased with Nathan's progress and recommended continued long-term treatment with budesonide ODT 0.5 mg twice daily. He was given a 6-month prescription and moved back to annual review.

Nathan and his wife had a baby boy in December 2021. His symptoms were under control.

Gastroenterology secretary (Month 54)

Nathan obtained a 6-month prescription from the hospital pharmacy, which was organised by the consultant's secretary.

Five years after his initial diagnosis, Nathan's condition remained stable, and he and his wife discovered that they were expecting twins. He is now on the patient-initiated follow up (PIFU) model and can book in an appointment if his symptoms worsen. He comes in every six months for his maintenance prescription of budesonide ODT 0.5 mg twice daily.

Costs and workforce implications

For the financial evaluation, a detailed analysis was performed by mapping the activities involved in a suboptimal/typical versus optimal management pathway for the fictional patient, Nathan, highlighting the cost differences (see **Table 3**). This financial evaluation is intended to help commissioners and providers understand the implications of different treatment options for patients with EoE from quality-of-life and financial perspectives.

Through this process, it is possible to identify the cost drivers that would be incurred in primary and hospital care, using, where appropriate, the NHS National Tariff Payment System and Unit Costs of Health and Social Care which include:

- Unit costs of health and social care, including community-based social care and hospital-based health care staff
- Staff costs
- Drug costs.

The evaluation does not include the costs outside the health remit or the social, emotional, physical and financial costs to the patient and family members.

Note: The financial costs are indicative and calculated on a cost-per-patient basis. Local decisions to transform care pathways would need to take a population view of costs and improvement.

Table 3 shows that the costs for the suboptimal/typical pathway are £13,355 and for the optimal pathway are £14,725. More details can be found in **Table 5** and **Table 6** in the Appendix.

Although the optimal pathway is more expensive, the benefit to Nathan, his family and the healthcare system in the longer term is greater, with reduced risk of potential complications and effects on his mental wellbeing. The optimal pathway costs can easily be reduced due to the possibility of fewer clinic appointments if prescribing can be supported in the community, and with fewer outpatient follow-ups required if the patient is well managed and could be put onto the patient-initiated follow-up (PIFU) model.

In the optimal pathway, early awareness and investigations into Nathan's diagnosis and management lead to:

- earlier diagnosis and initiation of correct treatment
- avoidance of emergency surgery
- reduced anxiety and health concerns, with more awareness and support from patient networks
- continued growth in his personal life through social interactions and his ability to feel confident enough to get married, start a family and return to his hobby.

Table 3. Summary of NHS costs

Resource	Cost (£)	
	Suboptimal	Optimal
Community care	92	-
Dietitian	92	-
Primary care management	452	39
Omeprazole	69	-
GP	235	39
Fluticasone spray	148	-
Secondary care management	12,811	14,686
A&E	864	288
Chest X-ray	67	67
Omeprazole	16	-
FBO emergency surgery*	2,866	-
Gastroenterology referral	213	213
Endoscopy	1,338	892
Gastroenterology follow-up	510	595
Fluticasone inhaler	111	-
Budesonide ODT	5,160	10,965
Biopsies	1,666	1,666
Total	13,355	14,725

*Includes ENT non-elective admission. A&E, accident and emergency; ENT, non-elective admission; FBO, food bolus obstruction; GP, general practitioner; ODT, orodispersible tablet.

Financial calculation notes

- As noted above, the financial calculation presented here represents an indicative level of efficiency potential of the case only. Firstly, as the case is an example pathway, differential pathways for other patients may increase or reduce the potential benefit. Secondly, the potential releasing of resource associated with implementing the optimal pathway across a larger cohort of patients will be subject to over-arching contractual arrangement in place, previously between providers and commissioners and within the ICSs, which may differ across the country. For example, some of the financial benefits identified in the case may not be fully realisable where the elements of the pathway are subject to block contracts or risk/gain shares are in place. Equally, the release of resource may only be realised should there be a critical mass from within the targeted patient population.
- It should also be noted that the financial calculation is considered largely from a commissioner perspective. The impact on income and costs (including capacity management) for provider organisations will require consideration in the implementation of the optimal pathway.
- Each healthcare organisation and system will need to assess the potential for realising the financial benefits identified in the case.
- In the suboptimal/typical pathway, the cost is moderated by the following factors:
 - Although an endoscopy is required after an elimination diet, no endoscopy was undertaken in this scenario as the patient did not strictly adhere to the diet.
 - Costs do not consider any complications or severities of fibrosis or strictures, which may develop after a long diagnostic delay or when EoE is untreated or inappropriately treated once diagnosed.
- In the optimal pathway, the cost is moderated by the following factors:
 - The patient regularly stopped taking treatment, so costs for treatment are not included for some months.
 - The costs do not include the impact on the patient of the additional journeys by the patient to the hospital to collect prescriptions.
 - If maintenance treatment could be continued in the community, the patient would need fewer outpatient appointments, so cost savings could be made.
 - If the patient was moved to a PIFU model, the system would have made further cost savings and the patient could have accessed care only when needed.
- The financial impact on the quality of life for EoE is individual and will vary from person to person, needless to say that the benefits of an early diagnosis and intervention/treatment prevents unnecessary anxiety or stress for the patient. It allows the patient to learn to manage their condition and maintain an independent quality of life without complications or worsening of the disease.

The BSG/BSPGHAN guidelines for diagnosis and management of EoE published in 2022¹ provide clear guidance for A&E and other allied healthcare professionals on the diagnosis and management of patients with EoE. While the recommendations in these guidelines are being disseminated and implemented, there is greater need for awareness within the community and primary care of the importance of recognising the symptoms of EoE:

1. Detect



Raise clinician awareness of EoE and the importance of six endoscopic biopsies to identify those with undiagnosed EoE.

2. Protect



Prevent complications through early diagnosis, treatment and patient support.

3. Perfect



Facilitate healthcare professionals to offer optimal treatment and support within the community following diagnosis and initial treatment.

These measures enable patients to access specialist services when needed.

For clinicians

1. Improve awareness:



Across primary and secondary care on available guidance, understanding, diagnosis, investigation and management of EoE.

Among healthcare professionals and patients of the networks available to support those living with EoE.

2. Make every contact count:



Reduce repetitive appointments with a detailed history of symptoms.

Standardise endoscopic procedures to take the correct number of biopsies.

Standardise histological counting and reporting of eosinophils.

Simplify prescription regimens so that it is easier for patients to comply with and adhere to treatment.

3. Integrate records:



Assist with shared care management plans and monitoring.

4. Virtual clinics:



Enable clinicians to review urgent or high-risk cases.

Move to a PIFU model to avoid unnecessary clinic appointments.

For service providers

1. Make EoE awareness a system ambition:



Work with stakeholders across the system to improve awareness of EoE.

Ensure that A&E guidelines refer patients with symptoms of EoE, such as FBO, appropriately to gastroenterology for endoscopy rather than ENT.

4. Inequalities:



With health inequalities being a concern across the NHS health and social care system, work to understand local access issues.

2. Cross-sector working:



Set up a cross-sector process to manage these patients in the community to avoid unnecessary hospital contacts and visits to obtain repeat prescriptions.

Develop a formal transition process to ensure continued disease management from paediatric to adult care.

5. Shared learning and sharing best practice:



Encourage sharing of best practice and ideas to spread innovation and reduce variation.

Consider how the system can learn from events such as missed opportunities to intervene.

3. Support services:



Work with relevant stakeholders to ensure that patients with EoE have access to dietitians and network supports where needed.

For service transformation

1. Awareness:



Ensure greater understanding and awareness of guidelines, symptoms, diagnosis and management of EoE across the MDT (gastroenterology, allergy, ENT, A&E, pulmonology, dietetics and paediatrics).

Promote awareness and access to support networks like the EOS Network.

2. Engagement:



Engage the whole primary care team in long-term management of patients with EoE.

Organise remote specialist initiation and ensure continued treatment in the community once initiated by a specialist.

3. Access:



Ensure GPs have access to specialist clinicians for advice and urgent referrals.

Set up patient-initiated follow-up (PIFU) systems once patients have been stabilised and treatment initiated.

Arrange for specialist-initiated medicines to be reviewed in the community through structured medication reviews so that appropriate monitoring can occur.

This analysis demonstrates the marked differences in care that a patient with EoE can receive and the impact this can have on both patient outcomes and system costs.

The impact on the patient himself is perhaps the most notable difference, with delayed diagnosis resulting in repeated A&E attendance, major impacts on his personal and social life, and prolonged worry and confusion over his health. Nathan changed his lifestyle, avoided social situations and abandoned his hobby due to the continued symptoms and embarrassment around them. His emotional wellbeing was affected as he made these changes to his life and worried about the possibility of cancer.

Even when Nathan received the diagnosis of EoE, early treatment of this condition was inappropriate, complex and confusing. This led him to seek information online on other approaches, such as diet modification, and abandon prescribed treatments, which delayed achievement of remission, prolonged his symptoms and risked future development of further FBOs and complications. Once Nathan received appropriate and licensed treatment for EoE from his specialist, the prescribing mechanism – relying on him to call his consultant's secretary and collect his medication from the hospital pharmacy – was inconvenient for the patient, burdensome for the hospital administration team and offered no formal way to monitor adherence with treatment.

Comparison of costs between the pathways outlined shows a modest increase for the optimal pathway, largely due to the acquisition cost of the licensed treatment, but this increase resulted in a vastly improved patient experience. When all drug costs are disregarded, the costs and burden in terms of healthcare resource use, such as diagnostics, procedures, A&E attendance and clinic visits, is much greater in the suboptimal/typical pathway. Savings could be made through reductions in the number of hospital appointments required if patients are transitioned to PIFU (arranging an appointment when needed based on their symptoms and individual circumstances³²) and if the dose frequency of budesonide is further reduced to 0.5 mg once daily rather than twice daily once patients' symptoms have stabilised.²⁶

Increased awareness of EoE and the guideline-recommended diagnostic and treatment pathway for this condition¹ is needed to ensure that:

- EoE is considered in the differential diagnosis of all patients with a relevant history
- patients are directed to the appropriate specialist team to order investigations required to achieve early diagnosis
- licensed treatment is initiated early and monitored appropriately.

Looking to the future, follow-on prescribing of budesonide ODT in primary care through a shared-care pathway would simplify the treatment plan for patients, reduce the burden on secondary care and allow adherence to be monitored more robustly.

Abbreviations

A&E	accident and emergency
BMI	body mass index
BNF	British National Formulary
BSG	British Society of Gastroenterology
BSPGHAN	British Society of Paediatric Gastroenterology, Hepatology and Nutrition
COVID-19	coronavirus disease 2019
ECG	electrocardiogram
EREFS	EoE endoscopic reference score
ENT	ear, nose and throat
EoE	eosinophilic oesophagitis
FBO	food bolus obstruction
GORD	gastro-oesophageal reflux disease
GP	general practitioner
HES	Hospital Episode Statistics
hpf	high power field
ICS	integrated care system
IgE	immunoglobulin E
IT	information technology
IV	intravenous
MDT	multidisciplinary team
NICE	National Institute for Health and Care Excellence
ODT	orodispersible tablet
OGD	oesophago-gastro-duodenoscopy
PIFU	patient-initiated follow-up
PPI	proton pump inhibitor
SMC	Scottish Medicines Consortium

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Additional tables and figures

Table 4. Integrated Care System (ICS)-level data on estimated incidence of eosinophilic oesophagitis (EoE), 2020/21 based on estimated annual incidence of 10 per 100,000 population.

Sources: QOF 2020/2021,³³ Moawad (2018),³ Lucendo et al (2017).⁴

Organisation name	Total population	Estimated incidence of EoE
England	60,622,430	6,064
Bath & North East Somerset, Swindon & Wiltshire ICS	967,756	97
Bedfordshire, Luton and Milton Keynes ICS	1,050,027	105
Birmingham and Solihull ICS	1,338,829	134
Bristol, North Somerset & South Gloucestershire ICS	1,042,507	104
Buckinghamshire, Oxfordshire & Berkshire west ICS	1,910,451	191
Cambridge and Peterborough ICS	1,005,341	101
Cheshire and Merseyside health & care partnership	2,684,358	268
Cornwall and the Isles of Scilly ICS	585,711	59
Coventry and Warwickshire ICS	1,028,515	103
Devon ICS	1,256,751	126
Frimley Health and Care	796,927	80
Greater Manchester Health & Social Care Partnership	3,136,842	314
Hampshire and the isle of Wight ICS	1,888,507	189
Healthier Lancashire & South Cumbria	1,790,738	179
Hereford and Worcestershire ICS	807,412	81
Hertfordshire and West Essex ICS	1,590,213	159
Humber Coast & Vale Health & Care Partnership	1,762,440	176
Joined Up Care Derbyshire ICS	1,067,161	107
Kent and Medway ICS	1,930,418	193
Leicester & Rutland ICS	1,164,723	116
Lincolnshire ICS	802,353	80

Organisation name	Total population	Estimated incidence of EoE
Mid and South Essex ICS	1,242,029	124
Norfolk and Waveney ICS	1,073,983	107
North Central London Partners in Health & Care ICS	1,696,716	170
North East and North Cumbria ICS	3,126,274	313
North East London ICS	2,284,386	228
North West London ICS	2,649,584	265
Northamptonshire ICS	786,692	79
Nottingham and Nottinghamshire Health & Care ICS	1,104,075	110
One Gloucestershire	666,338	67
Our Dorset	791,100	79
Our Healthier South East London ICS	2,017,836	202
Shropshire, Telford & Wrekin ICS	506,227	51
Somerset ICS	583,192	58
South West London health & care partnership	1,710,135	171
South Yorkshire and Bassetlaw ICS	1,580,860	158
Staffordshire and Stoke on Trent ICS	1,162,073	116
Suffolk and North East Essex ICS	1,036,317	104
Surrey Heartlands Health & Care Partnership ICS	1,113,139	111
Sussex Health & Care Partnership ICS	1,798,146	180
The Black Country and West Birmingham ICS	1,490,126	149
West Yorkshire & Harrogate Health & Care Partnership	2,595,222	260

Figure 4. Integrated Care System-level data on estimated incidence of eosinophilic oesophagitis (EoE), 2020/21 based on estimated annual incidence of 10 per 100,000 population.

Sources: QOF 2020/2021,³³ Moawad (2018),³ Lucendo et al (2017)⁴

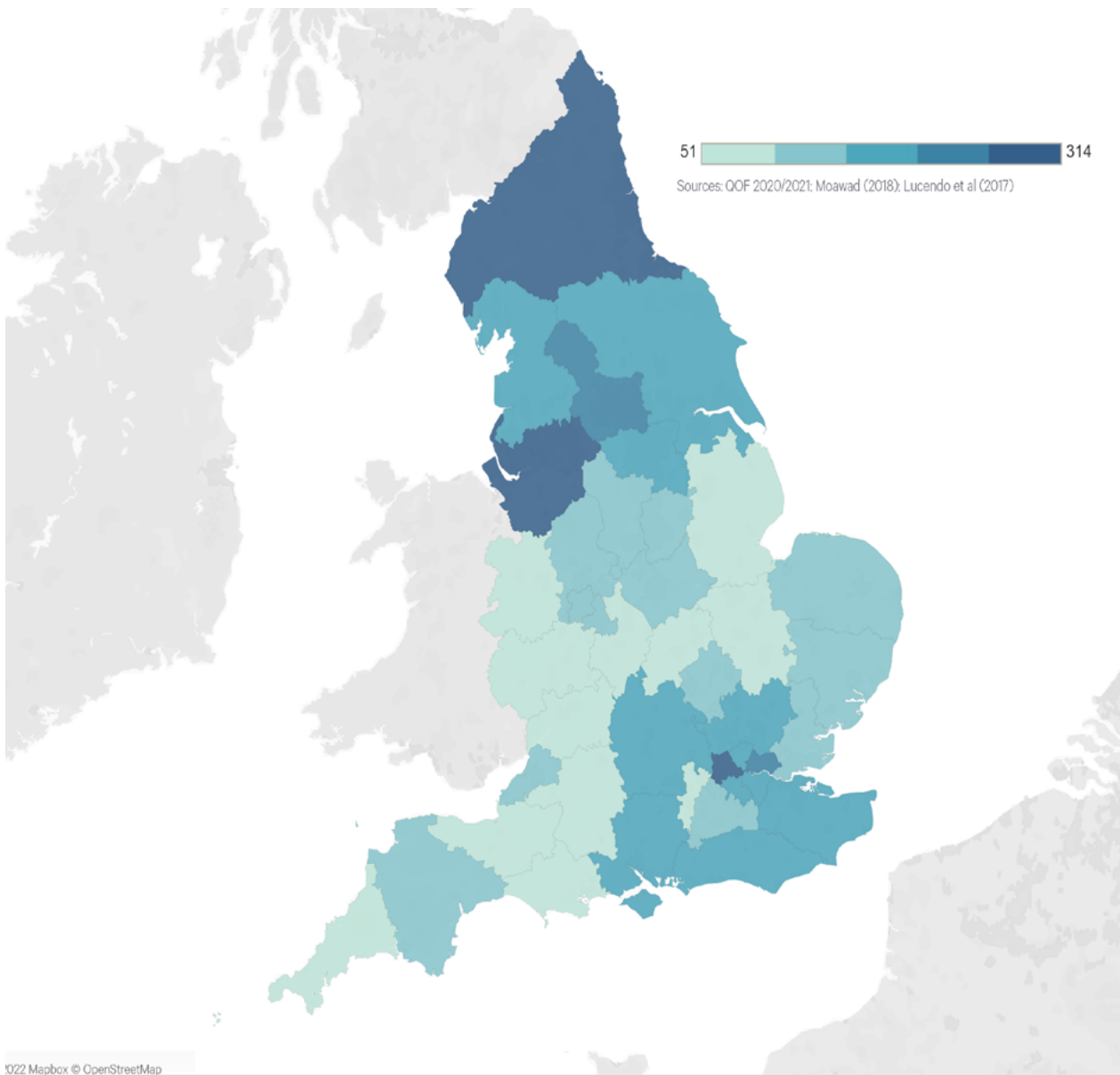


Table 5. Suboptimal/typical scenario costing breakdown

Resource	Quantity	Total costs (£)
Community care	1	92
Dietician	1	92
Primary care management	19	452
Omeprazole ³⁴	9	69
GP	6	235
Fluticasone 250 µg inhaler	4	148
Secondary care management	49	12,811
A&E	3	864
Chest X-ray	1	67
Omeprazole	2	16
ENT non-elective admission	2	-
Food bolus emergency surgery	2	2,866
Gastroenterology referral	1	213
Endoscopy	3	1,338
Gastroenterology follow-up	6	510
Fluticasone 250 µg inhaler	3	111
Budesonide ³⁴	24	5,160
Biopsy	2	1,666
Total	69	13,355

A&E, accident and emergency; ENT, ear, nose and throat; GP, general practitioner.

Table 6. Optimal scenario costing breakdown

Resource	Quantity	Total costs (£)
Primary care management	1	39
GP	1	39
Secondary care management	65	14,686
A&E	1	288
Chest X-ray	1	67
Gastroenterology referral	1	213
Endoscopy	2	892
Gastroenterology follow-up	7	595
Budesonide ³⁴	51	10,965
Biopsy	2	1,666
Total	67	14,725

A&E, accident and emergency; GP, general practitioner.



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