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2 **Systematic assessment of adult patients' satisfaction with various eosinophilic**
3 **oesophagitis therapies**

4 **Short title:** patients' satisfaction with EoE therapies

5 Ekaterina Safroneeva, PhD^{1*}, David Hafner, BMed^{1*}, Claudia E. Kuehni, MD, MPH¹, Marcel
6 Zwahlen, PhD¹, Sven Trelle, MD², Luc Biedermann, MD³, Thomas Greuter, MD³, Stephan
7 Vavricka, MD³, Alex Straumann, MD³, Alain M. Schoepfer, MD⁴

8 *equal contribution of first two authors

9 **Affiliations:**

- 10 1 Institute of Social and Preventive Medicine, University of Bern, Switzerland
- 11 2 Clinical Trials Unit Bern, Institute of Social and Preventive Medicine, University of
12 Bern, Switzerland
- 13 3 Division of Gastroenterology and Hepatology, University Hospital Zurich, Zurich,
14 Switzerland
- 15 4 Division of Gastroenterology and Hepatology, Centre Hospitalier Universitaire
16 Vaudois (CHUV), University of Lausanne, Lausanne, Switzerland

17 **Correspondence address:**

18 Ekaterina Safroneeva, PhD
19 Institute of Social and Preventive Medicine
20 University of Bern
21 Mittelstrasse 43
22 CH-3012, Bern, Switzerland
23 Tel: +41 (0) 31 631 59 71

24 Email: ekaterina.safroneeva@ispm.unibe.ch

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50 Ekaterina Safroneeva 1, 2, 3, 4, 5, 6, 8; David Hafner 2, 3, 5, 8; Claudia Kuehni 1, 2, 3, 5, 8;
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55

56 ABSTRACT

57 **Background and aims:** Treatment options for eosinophilic oesophagitis (EoE) patients
58 include drugs (proton-pump inhibitors [PPI], swallowed topical corticosteroids [STC]),
59 elimination diets, and dilation. Given the lack of data, we aimed to assess adult EoE patients'
60 satisfaction with different EoE-specific treatment modalities.

61 **Patients and methods:** We evaluated therapy satisfaction recalled over a 12-month period
62 using the validated "Treatment Satisfaction Questionnaire for Medication" (TSQM) that
63 assesses effectiveness, side effects, convenience, and overall satisfaction. The score for
64 each scale ranges from 0 (dissatisfied) to 100 (satisfied). To evaluate satisfaction with non-
65 pharmacologic therapies the questionnaire was modified and debriefed in three focus
66 groups. The final questionnaire was sent to 148 patients.

67 **Results:** Patient response rate was 74%. In the last 12 months, 24%, 75%, 19%, and 9%
68 were treated with PPI, STC, elimination diet, and dilation, respectively. Patients identified the
69 following considerations as important for therapy choice: effect on symptoms (89%), effect on
70 oesophageal inflammation (76%), side effects (69%), and ease of use (58%). Patients found
71 STC to be effective (83 points), convenient (83 points), and experienced no side-effects
72 when using this therapy. When using STC alone (43%), overall patient satisfaction was high
73 (86 points). Patients judged PPI to be most convenient (89 points), STC to be a bit less
74 convenient (83 points), and diet to be most inconvenient (46 points) of three therapies
75 examined.

76 **Conclusions:** Adult EoE patients consider both therapy effect on symptoms and
77 oesophageal inflammation as important criteria, when choosing EoE therapy, and appear to
78 be satisfied with use of STC.

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81 decision-making

82

83 INTRODUCTION

84 Three types of therapies, namely drugs, diets, and dilation, are used to manage adult
85 patients with eosinophilic oesophagitis (EoE).^{1,2} The drug-based therapy with most
86 randomized placebo-controlled trials-generated evidence of efficacy in EoE is swallowed
87 topical corticosteroids (STC) in a form of either syrup (budesonide diluted in sucralose
88 solution), powder (obtained from blisters of fluticasone propionate inhaler discus or
89 budesonide capsules), or spray (fluticasone propionate oral aerosol inhaler).¹ STC are
90 currently being used mostly off-label given that a formulation of budesonide developed
91 specifically for adult EoE patients has only recently been approved by the European
92 Medicines Agency (in 2017) and Swiss regulators (in 2018).³ Proton-pump inhibitors (PPI)
93 are used in a subset of EoE patients responsive to this medication or else in those suffering
94 from concomitant gastro-oesophageal reflux disease.¹ Six-food (or less) elimination diet is a
95 non-drug-based alternative for EoE management. Just like STC, the diet may lead to a
96 reduction of oesophageal inflammation and symptomatic relief.¹ Lastly, dilation of strictures
97 often results in symptom relief that may be long-lasting; however, this measure does not
98 affect the inflammatory activity of the disease.¹ These therapy options are associated with
99 either a risk of side effects, potential long-term sequelae associated with uncontrolled
100 inflammation (dilation), or else need for a long-term avoidance of staple foods, such as milk,
101 wheat and eggs (diet). As such, patients' perception of the efficacy and safety as well as life-
102 style preferences may profoundly influences the choice of EoE-specific therapy.

103 To date, adult patients' satisfaction with various EoE-specific therapies has not been
104 systematically assessed. The Treatment Satisfaction Questionnaire for Medication (TSQM) is
105 a validated, general measure of patients' satisfaction with medication.^{4,5} We used the
106 questions of the TSQM as well as those specifically developed for the purposes of this study
107 to perform a questionnaire-based survey. In this prospective survey study, we aimed to
108 evaluate the utilization of various EoE-specific therapies, assess adult patients' satisfaction
109 with the therapies they received in the last 12 months, and examine factors that are
110 important for patients' choice of therapy.

111 **METHODS AND PATIENTS**

112 An overview of the key steps described in the methods section is shown in **Figure 1**.

113 **Study population**

114 Between September 2016 and November 2016, adult EoE patients (≥ 17 years of age) were
115 recruited in 1 ambulatory care clinic in Switzerland as a part of the Swiss EoE Cohort Study
116 (SEECs). The study was approved by ethic committee of canton Vaud (CER-VD, protocol
117 number 148/15).⁶ Patients provided written informed consent for participation in the study.

118 Disease diagnosis was established by investigators according to standardized criteria.¹

119 Patients with concomitant gastro-oesophageal reflux disease were also included.

120 **Development of the preliminary version of the study questionnaire**

121 We first created the questionnaire querying various demographic and disease-specific
122 characteristics, utilization of various EoE-specific therapies and patients' satisfaction with the
123 therapies used in the last 12 months.

124 The initial questionnaire contained the following ten domains: socio-demographic
125 characteristics (eight items), EoE-specific patient history (three items), presence of gastro-
126 oesophageal reflux (one item), presence of atopic diseases (four items), five items on past
127 and present EoE-specific therapy (including PPI, STC, systemic corticosteroids, diets, and
128 dilation), and factors that are important for patients' choice of therapy (two items). In addition,
129 the questionnaire contained validated items (questions) from TSQM that assesses treatment
130 satisfaction with various therapies.^{4,5} Patients were asked to think of the satisfaction with
131 various therapies, when looking back at the 12-months period. The TSQM was previously
132 translated into German and underwent cultural adaption for Switzerland (TSQM version 1).
133 The validated TSQM covers the most relevant aspects of the patients' satisfaction with
134 medication. The TSQM consists of 14 items falling into four scales: effectiveness (three
135 items), side effects (five items), convenience (three items), and overall satisfaction (three
136 items) (**Supplementary Table 1**).^{4,5} Unlike many other similar measures, the TSQM may
137 also be used to compare various patient conditions and medication types. Treatment
138 Satisfaction Questionnaire for Medication scale was used five times in the initial

139 questionnaire (including PPI, STC, systemic corticosteroids, diet, and dilation). The TSQM
140 scale scores range from 0 (indicates lack of effectiveness) to 100 (indicates excellent
141 effectiveness).

142 **Focus groups and individual patient interviews**

143 The focus group and individual patient interviews were conducted in accordance with ISPOR
144 PRO Good Research Practices Task Force report.^{7,8} The purpose of the focus groups was to
145 aid in the item generation phase of questionnaire development and ensure that “respondents
146 understand how to complete the questionnaire, how to reference the correct recall period, the
147 meaning of the items, how to use the response scales, and any other questionnaire features
148 that may influence patient responses in the intended mode of administration.”^{7,8}

149 A board-certified psychologist (K.M., psychiatry clinic, University Hospital Basel)
150 conducted two rounds of the cognitive interviews based on semi-structured interview guides
151 that contained questions and probing strategies to assess patients' understanding of
152 questions/probing strategies were also used to assess appropriateness of recall period.
153 Lastly, content coverage, format, and length of the entire questionnaire were assessed. Each
154 focus group lasted approximately two hours. Two facilitators were also present during the
155 focus groups discussions (D.H., and either A.M.S. or A.S.). D.H. conducted 4 individual face-
156 to-face semistructured interviews to find out, if last changes to the questionnaire had to be
157 made. An individual patient interview lasted approximately 40 minutes. Focus groups/
158 individual patient interviews were recorded, translated from Swiss dialect of German (not a
159 written language) into German, and transcribed. The research team reviewed transcriptions of
160 the focus groups.

161 Forty-five and six EoE patients were approached during a routine clinical visit in the EoE
162 clinic (Olten, Switzerland) and invited to participate in the focus groups and the face-to-face
163 patient interviews, respectively. Thirty-three and two patients declined the invitation in the
164 focus groups and the face-to-face patient interviews, respectively. Twelve EoE patients were
165 interviewed during two focus groups (n = 6 for each focus group). Of the six patients with
166 mean age of 38.5 years (range 26-51) participating in focus group number one, two were

167 female. Of the six patients with mean age of 47.3 years (range 34-63) participating in focus
168 group number two, one was female. Four male patients with mean age of 59.5 years [range
169 44-86] were individually interviewed.

170 We created semi-structured interview guides, which contained questions and probing
171 strategies to assess patients' understanding of instructions, stem, response options and
172 format of individual items. Depending on the item, questions/probing strategies were also
173 used to assess appropriateness of recall period. Lastly, content coverage, format, and length
174 of the entire questionnaire were assessed.

175 **Final questionnaire**

176 We created a cognitive summary report and an item tracking matrix documenting all the
177 changes that were made, which included the following ones: 1) a single item assessing the
178 presence of atopic diseases was separated into 5 items; 2) the part about treatment
179 satisfaction with STC was expanded to include three different forms of application, namely
180 syrup, powder, and spray, as one participant of the focus group took the STC in two different
181 formulations and was satisfied with one form of application, but not with another; and 3)
182 several items querying the use of concomitant therapies was introduced.

183 The final questionnaire (**supplementary material**) consisted of the following 11 domains:
184 socio-demographic characteristics (7 items), EoE-specific patient history (3 items), presence
185 of reflux (1 item), presence of atopic diseases (4 items), concomitant therapies (including
186 antacids, H2-receptor antagonists, PPI, and corticosteroids - 7 items), 5 items on past and
187 present EoE-specific therapy (including PPI, STC, systemic corticosteroids, diets, and
188 dilation), and factors that are important for patients' choice of therapy (2 items). The final
189 questionnaire contains TSQM, which was used six times for assessment of satisfaction with
190 PPI, STC (once per different application form - syrup, powder and spray), and dilation.^{4,5} The
191 final questionnaire also included the items of Eosinophilic Esophagitis Activity Index patient-
192 reported outcomes (EEsAI PRO) questionnaire and adult EoE quality of life questionnaire
193 (EoE-QoL-A).^{9,10}

194 **Changes to Treatment Satisfaction Questionnaire for Medication**

195 TSQM was developed for pharmacologic treatments and used in its original form for PPI
196 and STC. Given the fact that some patients took PPI and/or STC for many years, “I don’t
197 remember” response option to item three of TSQM (“time until the drug started working”) was
198 introduced. TSQM was adapted for diet and dilation, for which not all TSQM items were
199 applicable (for diet, the item on ease of use related to formulation was removed; for dilation,
200 the entire convenience scale was removed). The word “medication” was replaced with either
201 “diet” or “dilation” and complementary verb. (For reviewers only: The summary of the
202 changes is shown in **Supplementary Table 2**).

203 **Data handling and statistical analysis**

204 We double entered the data into EpiData (version 3.1, Denmark) database, compared our
205 entries, and extracted the data into Stata (version 13, USA). Data were fairly complete, as
206 only two missing responses were found for the lead in items that inquired whether the patient
207 took STC in the last 12 months, and no missing values were found for PPI, diets, and
208 dilation. For all therapy types, no values for any of the TSQM items were missing. Descriptive
209 results are presented as frequencies and percentages of the group total or median,
210 interquartile range, and range. Multivariable logistic regression modelling was performed to
211 evaluate the potential factors that might be associated with the outcome “assigning most
212 importance to effects of therapy on symptoms and oesophageal inflammation as opposed to
213 symptoms alone”. The following variables were entered into the model as independent
214 variables: age, female gender, disease duration, history of oesophageal dilation, history of
215 endoscopic disimpaction, education level (presence of university education or equivalent¹¹),
216 and anti-inflammatory therapy at time of study participation (either individually or more than
217 one therapy). In a first step, the potential associated factors were tested separately. In a
218 second step, all factors with a P-value < 0.15 were entered together into the multivariable
219 logistic regression model. To assess the possibility of effect modification, we evaluated
220 pairwise interaction terms of predictor variables. A p-value < 0.05 was considered statistically
221 significant.

222 RESULTS

223 Patient characteristics

224 The final version of the questionnaire was sent by mail to 147 adults with EoE. The survey
225 response rate was 74% (108/147). Patient and disease characteristics are shown in **Table 1**.
226 Mean patient age was 46.9 (± 5.3) years, 85/108 patients (79%) were male, and mean
227 disease duration was 7.6 (± 5.1) years. At inclusion, 45%, 75%, and 19% were treated with
228 PPI, STC, and food elimination diet, respectively. In the past 12 months, 10 patients
229 underwent oesophageal dilation. Thirty-five patients (32%) were managed with more than
230 one therapy (28 patients [26%] with more than one anti-inflammatory therapy). Ten patients
231 (9.3%) did not receive any treatment.

232 Satisfaction with therapy

233 TSQM scales scores as well as average TSQM values for PPI, STC, and diet are shown in
234 **Table 2** (patients could be on more than one therapy in the past 12 months). When judging
235 the convenience of using these EoE-specific therapies, patients found use of PPI being most
236 convenient (score of 89). Although most patients needed to extract the steroid-powder
237 containing blister from the diskus of asthma-specific medication, they found STC to be
238 relatively convenient (score of 83). Patients on elimination diet found this therapy fairly
239 inconvenient (score of 46). Patients did not observe any side-effects associated with the use
240 of various EoE-specific therapies, which is consistent with their long-term use (especially PPI
241 and STC, which were used for the duration of 6 and 5 years, respectively).

242 We also examined the therapy satisfaction in the population that used STC only (in a form
243 of a powder), STC together with PPI, and STC together with elimination diets (**Table 3**).
244 Patients found STC to be effective (score of 83), relatively convenient (score of 78), and
245 experienced no side-effects when using this therapy. When using STC alone, overall
246 satisfaction was fairly high (score of 86).

247 Criteria important for the choice of therapy

248 The criteria that patients find important for the choice of therapy are shown in **Table 4**. The
249 effect of therapy on symptoms (89%) and oesophageal inflammation (76%), possible side

250 effects (69%), and ease of therapy use (58%) were identified by patients as important
251 considerations for the choice of therapy. When asked about the most important criterion for
252 the choice of therapy (**Figure 2**), 45%, 32%, and 11% of patients chose the effect of
253 treatment on symptoms and oesophageal inflammation, the effect of the treatment on the
254 symptoms alone, and the effect of treatment on oesophageal inflammation alone,
255 respectively, as deciding factor.

256 Step-wise logistic regression modelling was performed to identify factors associated with
257 assigning most importance to improvement in symptoms and inflammation compared to that
258 in symptoms alone as criteria for the choice of therapy (**Table 5**). In the univariable model,
259 female gender, STC and PPI use at the time of the study were positively associated with
260 putting greater emphasis on improvement in symptoms and oesophageal inflammation
261 compared to that in symptoms alone, whereas presence of at least university degree (or
262 equivalent) was negatively associated with this outcome. In the multivariable analysis, female
263 gender (OR 3.727, 95%-CI 0.996-13.944, P-value=0.050), STC use at the time of the study
264 (OR 3.760, 95%-CI 1.125-12.565, P-value=0.031), and PPI use at the time of the study (OR
265 2.911, 95%-CI 0.869-9.754, P-value=0.083) were positively associated with the outcome. In
266 the multivariable analysis, we observed a trend for negative association between presence of
267 at least university degree (or equivalent) and the outcome (OR 0.406, 95%-CI 0.148-1.117,
268 P-value=0.081). We also carried out the regression modelling, in which the use of more than
269 one anti-inflammatory therapy at the time of the study (as opposed to each therapy
270 individually) was examined. We found that use of more than one anti-inflammatory therapy is
271 positively associated with putting greater emphasis on improvement in symptoms and
272 oesophageal inflammation compared to that in symptoms alone in both univariable (OR
273 6.544, 95%-CI 1.753-24.427, P-value=0.005) and multivariable analyses (OR 9.294, 95%-CI
274 2.309-37.405, P-value=0.002 for more than one anti-inflammatory therapy; OR 3.874, 95%-
275 CI 1.061-14.152, P-value=0.040 for female gender; OR 0.385, 95%-CI 0.137-1.080, P-
276 value=0.070 for presence of at least university degree).

277

278 DISCUSSION

279 This is the first study that examines adult EoE patients' satisfaction with different
280 therapies. We developed a survey to assess treatment satisfaction with EoE-specific therapy
281 by consulting ISPOR guidelines and literature describing the use of TSQM as well as
282 obtaining input from EoE patients by the means of focus groups and individual interviews.
283 Patients with long-established EoE diagnosis appear to be satisfied with anti-inflammatory
284 therapies, especially STC. We also found that effect of therapy on symptoms and
285 oesophageal inflammation were important considerations for the choice of therapy in adults
286 with EoE, and that female patients and those using anti-inflammatory therapies at the time of
287 the study were more likely to assign greater importance to effect of therapy on both
288 inflammation and symptoms as opposed to symptoms alone.

289 With an average TSQM score of 80, 85, 77 for PPI, STC and diet respectively, EoE
290 patients appear to be satisfied with these EoE-specific therapies. Overall satisfaction scores
291 as well as various TSQM scales scores are consistent with our current knowledge about
292 these therapies. It is well known that whilst STC and diets appear to be efficacious/effective
293 in the entire EoE patient population, PPI are only effective in a subset of EoE.¹² Hence, the
294 effectiveness scores are higher for both STC and diet when compared to PPI. Although high
295 side-effects scales scores are indicative of lack of therapy-related side-effects, it is more
296 likely that these patients have been diagnosed with EoE for a relatively long time and would
297 have had time to switch the therapy in case of side-effects. It is also not surprising that, PPI
298 that are administered in a form of a tablet received the highest convenience score when
299 compared to STC blister that needs to be extracted from the fluticasone discus inhaler
300 developed for asthma patients and diets adhering to which require patients to cook their own
301 meals. Given that many of the patients take the pharmacologic therapies for an extended
302 period of time (median treatment duration of 5 years or longer), it is only fitting that overall
303 relatively high satisfaction scores are observed, as both PPI, STC, and diets have proven
304 efficacy/effectiveness in patients with oesophageal eosinophilia.¹²⁻¹⁴ The overall satisfaction
305 scores might have been different (and potentially lower), if therapy satisfaction would have

306 been evaluated in newly-diagnosed patients needing to decide on the type of therapy that
307 would work best for them and encountering side-effects of these therapies.

308 When asked about considerations that are important for the therapy choice, adult EoE
309 patients consider both effect of medication on symptoms and oesophageal inflammation as
310 important. The finding that from patients' perspective therapy should target both inflammation
311 and symptoms is consistent with the choice of endpoints for most recent trial testing short-
312 term efficacy of STC in adults with EoE for the purposes of regulatory approval.¹⁵ We found
313 that female patients, those using single anti-inflammatory therapy, or a combination of those
314 therapies at the time of the study were more likely to assign importance to effect of therapy
315 on both symptoms and oesophageal inflammation as opposed to symptoms alone. Given
316 that the majority of patients received a maintenance therapy of 0.25 mg of STC BID, a dose
317 that brings only 16% of all patients into a complete remission, it is likely that disease activity
318 in some of these patients on combination therapy was not adequately controlled.^{16,17}

319 According to Atkinson *et al.* therapy satisfaction is a subset of overall patient satisfaction.⁴
320 Besides therapy satisfaction, overall patient satisfaction covers all other "aspects of medical
321 treatments, interpersonal aspects of clinical care, and processes of treatment".⁴ Overall
322 patient satisfaction interacts with the behaviour of patients as well as with the decision
323 making. This relationship between overall patient satisfaction and patient's behaviour is not
324 considered to be strictly causal in nature, but rather an interaction between the domains that
325 can influence each other. For example, overall patient satisfaction (and therapy satisfaction)
326 can influence patient's behaviour. We hypothesize that when an EoE patient is satisfied with
327 the STC therapy (*e.g.* because of relative ease of use, effectiveness, or few side effects), it is
328 more likely that this patient will pursue the treatment in a long-term run, even though most
329 EoE symptoms would be gone following a short induction treatment. Given that EoE is a
330 chronic disease, it is important for patients to adhere to anti-inflammatory treatment, as
331 patients with an adequate disease control have fewer long-term complications, such as food
332 bolus impactions.¹⁸ It is also possible for patient's behaviour to influence therapy satisfaction.
333 We hypothesize that an EoE patient, who is well-informed about advantages (*e.g.* no need

334 for medication) and disadvantages (e.g. may lead to lifestyle alterations) of dietary therapy
335 for disease management is more likely to continue the therapy. As such, one could argue
336 that minimizing the rates of therapy discontinuation through, among other things, better
337 patient education might lead to a higher degree of satisfaction with EoE-specific therapy.

338 The results of this study should be interpreted with several considerations in mind.
339 Although this is the first study that attempts to assess patients' satisfaction with various EoE-
340 specific therapies, patients with long-established diagnosis from one gastroenterology
341 practice specializing in management of this condition were recruited. It is likely that the high
342 rates of therapy satisfaction might be a consequence of the following: 1) we ended up with a
343 population of patients that used the therapies for a long time; and 2) it is likely that at least a
344 proportion of patients, especially those participating in various clinical studies, were well
345 informed about various aspects of this disease. As such, our results may not be
346 generalizable to newly-diagnosed patients or those attending less-specialized
347 gastroenterology practices. Whilst the patients' satisfaction with PPI and STC could be
348 evaluated using the original form of the questionnaire, the questionnaire had to be adapted
349 for diet and dilation. Although minor word changes were performed, or else non-applicable
350 items were removed entirely, satisfaction with diet has been queried using a non-validated
351 form of this questionnaire, and the data obtained should be interpreted with caution. Although
352 we used a validated TSQM, it is important to point out that validity of the overall
353 questionnaire has not been rigorously assessed. This is especially true of the items querying
354 the importance of the effects of therapy on various aspects of the disease, as these were not
355 evaluated against another valid questionnaire or construct. The rate of dietary treatment
356 observed in this study is lower (19%) than that observed in centers specializing in elimination
357 diets (up to 57% in mixed adult and paediatric population).¹⁹ However, it is important to point
358 out that the removal of inflammation-causing foods, such as milk- and wheat-based products,
359 might pose challenges, as these foods represent important dietary staples of Swiss-German
360 patients. Therefore, it is likely that, among other things, Swiss German patients' dietary and

361 physician's personal preferences contributed to high rates of STC use in the current
362 population.

363 In conclusion, we found that patients with long-established EoE diagnosis appear to be
364 satisfied with anti-inflammatory therapies, especially STC, and consider both symptoms and
365 oesophageal inflammation as important targets for therapy.

366 TABLES

367 **Table 1:** Characteristics of the survey's respondents.

Characteristics (n=108)	Frequency	%
Age at EoE diagnosis (years), mean \pm SD	39.0 \pm 15.6	NA
Age at inclusion (years), mean \pm SD	46.9 \pm 15.3	NA
Diagnostic delay (years), median (IQR), range	2.3 (0.3 - 9.3), 0 - 38.3	NA
Disease duration (years), mean \pm SD	7.6 \pm 5.1	NA
Symptom severity as assessed by EEsAI PRO score [§] , median, (IQR), range	12 (0 - 27), 0 - 65	NA
EoE-specific quality of life as assessed by EoE-QoL-A ^{§§} , median, (IQR), range	0.5 (0.29 - 0.96), 0 - 1.83	NA
Male gender	85	78.7
Family history of EoE	23	6.5
Nationality		
- Swiss	98	90.7
- Non-Swiss	10	9.3
ISCED 2011 education levels		
- Level 3	50	46.3
- Level 6 or higher	58	53.7
Experienced food bolus impaction that required endoscopic disimpaction (ever)	39	36.1
Gastrooesophageal reflux disease		
- Ever diagnosed	28	25.9
- Heartburn in last 7 days	29	26.9
Concomitant allergies (ever in life)		
- Asthma	37	34.3
- Allergic rhinitis	64	59.3
- Neurodermitis	27	25.0
- Known food allergies	42	38.9
- More than 1 condition	54	50.0
EoE-specific therapy		
- Swallowed topical corticosteroids (budesonide or fluticasone), ever	106	98.1
- Swallowed topical corticosteroids at inclusion	81	75.0
- Elimination diets, ever	27	25.0
- Elimination diets at inclusion	20	18.5
- Oesophageal dilation, ever	38	35.2
- Oesophageal dilation within last 12 months	10	9.3
Proton-pump inhibitor therapy		
- ever	49	45.4
- at inclusion	26	24.1

368 **Abbreviations:** EoE, eosinophilic oesophagitis; EEsAI PRO, eosinophilic oesophagitis activity index patient-reported outcome questionnaire; EoE-QoL-A, eosinophilic oesophagitis quality of life questionnaire for adults; IQR, interquartile range; NA, not applicable; SD, standard deviation; ISCED, international standard classification of education.²¹

370 [§]The EEsAI PRO questionnaire assesses symptom severity in adults with EoE; score ranges from 0 (no symptoms) to 100 points (most severe symptoms) (7-day recall period).¹⁹

371

372

373 ^{§§}The EoE-QoL-A questionnaire measures EoE-specific quality of life; score ranges from 0 points (perfect QoL) to 4 points (very bad QoL) (7-day recall
374 period).²⁰

375 **Table 2:** Median TSQM scores and interquartile range.

TSQM scales	PPI (n = 27); median treatment duration 6 years [3 - 9]	STC (n = 83; median treatment duration 5 years [2 - 6])	Diet (n=21; median treatment duration 2 years [1 - 4.5])
Effectiveness	66.7 [38.9 - 77.8]	83.3 [66.7 – 100.0]	77.8 [50.0 – 88.9]
Side-effects [§]	100.0 [100.0 – 100.0]	100.0 [100.0 – 100.0]	100.0 [100 – 100.0]
Convenience	88.9 [77.8 – 100.0]	83.3 [66.7 – 100.0]	45.8 [33.3 – 66.7]
Overall satisfaction	71.4 [50.0 -85.7]	78.6 [64.3 – 92.9]	78.6 [50.0 – 92.9]
Average score	79.9 [70.3 – 85.5]	84.8 [73.0 – 93.1]	76.6 [59.8 – 81.9]

376 [§]For a side-effect scale, a score of 100 is given to patients, who do not experience side effects.

377 **Abbreviations:** PPI, proton-pump inhibitor; STC, swallowed topical corticosteroids; TSQM, treatment satisfaction questionnaire
378 for medication.

379

380 **Table 3:** Median TSQM scores and interquartile range for STC in a powdered form in
 381 patients with that therapy only as well as combined with either PPI or diets.

TSQM scales	STC only (n = 44)	STC+PPI (n = 19)	STC+Diet (n=9)
Effectiveness	83.3 [72.2 – 100.0]	77.8 [61.1 – 94.4]	83.3 [72.2 – 88.9]
Side-effects [§]	100 [100 – 100.0]	100.0 [87.5 – 100.0]	100 [100 – 100.0]
Convenience	77.8 [66.7 – 100.0]	83.3 [66.7 – 100.0]	94.4 [83.3 – 100.0]
Overall satisfaction	85.7 [64.3 – 92.9]	85.7 [57.1 – 96.4]	78.6 [71.4 – 85.7]

382 [§]For a side-effect scale, a score of 100 is given to patients, who do not experience side effects.

383 **Abbreviations:** PPI, proton-pump inhibitor; STC, swallowed topical corticosteroids; TSQM, treatment satisfaction questionnaire
 384 for medication.

385

386 **Table 4:** Criteria important for the choice of therapy (n=108)

	Frequency	%
Effect on symptoms	96	88.9
Effect on inflammation in the oesophagus	82	75.9
Potential side effects	75	69.4
Ease of use	63	58.3
Treating physician's recommendation	54	50.0
Compatibility with lifestyle	50	46.3
Price	21	19.4
Recommendation of other patients with this condition	12	11.1
One's own research (for example, on internet)	9	8.3
Needs of the family	5	4.6
Other Reasons	5	4.6

387

388 **Table 5:** Univariable and multivariable logistic regression evaluating factors associated with
 389 assigning most importance to control of inflammation and symptoms (n=49) over control of
 390 symptoms alone (n=34).

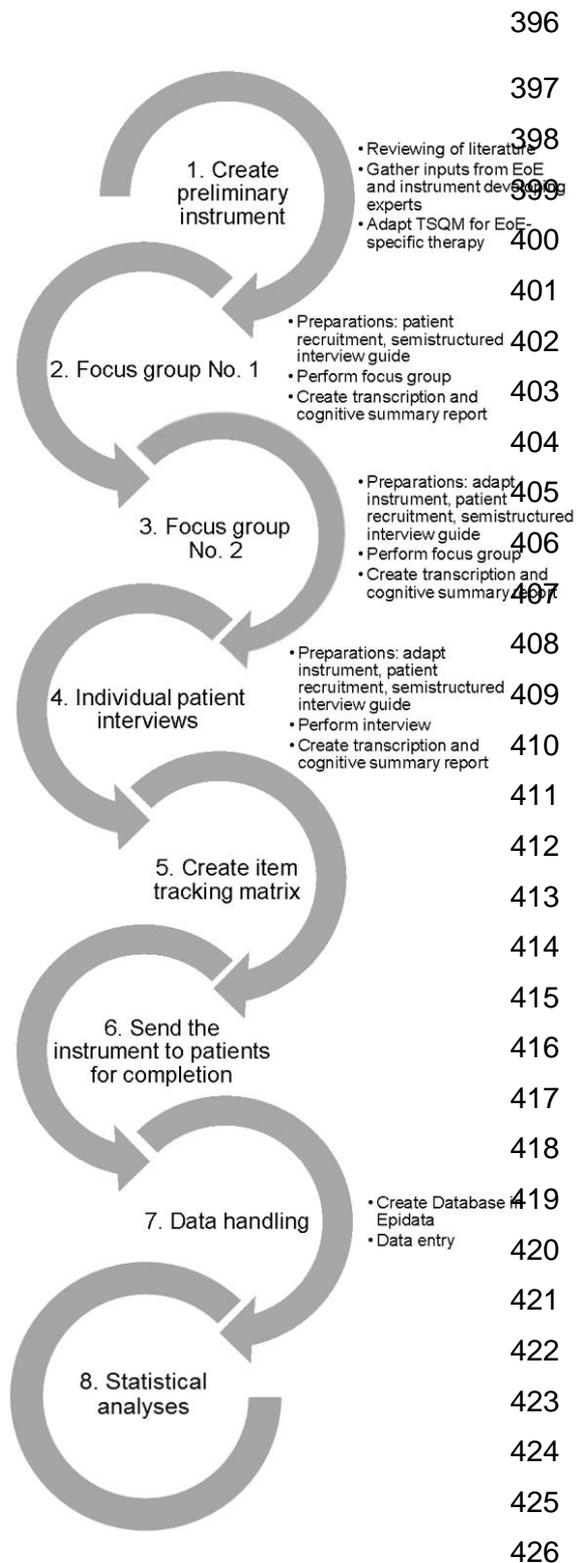
	Univariable			Multivariable		
	OR	95%-CI	P	OR	95%-CI	P
Age (years)	0.996	0.967-1.025	0.793			
Female	3.636	1.093-12.098	0.035	3.727	0.996-13.944	0.050
Disease duration (diagnosed) (years)	1.042	0.949-1.144	0.389			
Dilation (ever)	0.922	0.360-2.363	0.866			
Disimpaction (ever)	0.809	0.319-2.049	0.655			
Education level (ISCED level ≤3 vs. level ≥6)	0.390	0.156-0.971	0.043	0.406	0.148-1.117	0.081
STC use at the time of the study	2.451	0.863-6.963	0.092	3.760	1.125-12.565	0.031
PPI use at the time of the study	2.320	0.747-7.207	0.146	2.911	0.869-9.754	0.083
Elimination diet at the time of the study	0.989	0.335-2.922	0.984			

391 **Abbreviations:** ISCED, international standard classification of education; PPI, proton-pump inhibitors; STC,
 392 swallowed topical corticosteroids.

393

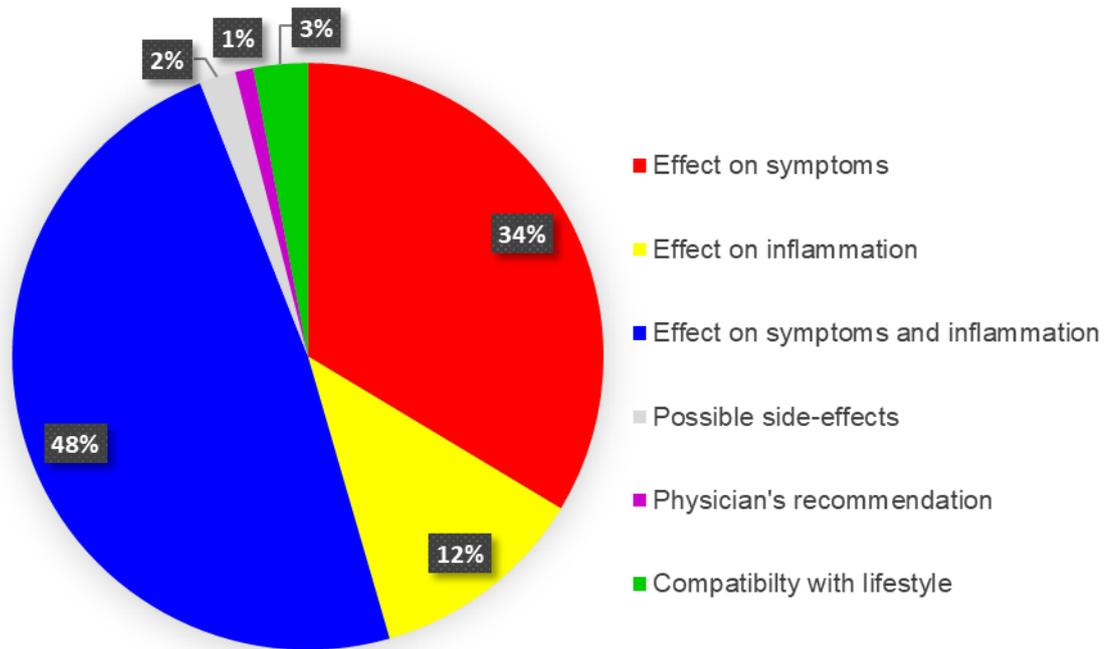
394 **FIGURES**

395 **Figure 1:** An overview of the key steps described in the methods section.



428 **Figure 2:** Most important criteria for the choice of therapy.

429



430

431

432 **SUPPLEMENTARY TABLES**433 **Supplementary Table 1:** Domains and items of the Treatment Satisfaction Questionnaire for

434 Medication.

Subscale	Items
Effectiveness	1. Prevents or treats 2. Relieves symptoms 3. Time to start working
Side effects	4. Presence of side effects 5. Bothersome side effects 6. Interference with physical function 7. Interference with mental function 8. Side effects impact on satisfaction
Convenience	9. Easy to use 10. Plan when to use 11. Convenient to take
Overall satisfaction	12. Confident in benefits 13. Good outweighs the bad 14. All things into account

435

436 **Supplementary Table 2:** Application of the TSQM for EoE-specific therapy.437 **CONFIDENTIAL (the questionnaire is proprietary, for reviewers only)**

	Original TSQM	Diet	Dilation
Effectiveness	Prevention or treatment		
	Wie zufrieden oder unzufrieden sind Sie damit, wie gut das Medikament zur Vorbeugung oder Behandlung Ihrer Erkrankung geeignet ist?	Wie zufrieden oder unzufrieden sind Sie damit, wie gut die Diät zur Vorbeugung oder Behandlung Ihrer Erkrankung geeignet ist?	Wie zufrieden oder unzufrieden sind Sie damit, wie gut die Dilatation zur Behandlung Ihrer Erkrankung geeignet ist?
	Symptom relief		
	Wie zufrieden oder unzufrieden sind Sie damit, wie das Medikament Ihre Beschwerden lindert?	Wie zufrieden oder unzufrieden sind Sie damit, wie die Diät Ihre Beschwerden lindert?	Wie zufrieden oder unzufrieden sind Sie damit, wie die Dilatation Ihre Beschwerden lindert?
	Time to effect		
	Wie zufrieden oder unzufrieden sind Sie damit, wie lange es dauert, bis das Medikament anfängt zu wirken?	Wie zufrieden oder unzufrieden sind Sie damit, wie lange es dauerte, bis die Diät angefangen hat zu wirken?	Wie zufrieden oder unzufrieden sind Sie damit, wie lange es dauerte, bis die Dilatation anfang zu wirken?
Side Effects	Presence of side effects		
	Verspüren Sie Nebenwirkungen, weil Sie dieses Medikament nehmen?	Verspüren Sie Nebenwirkungen, weil Sie diese Diät haben ?	Verspüren Sie Nebenwirkungen und/oder Beschwerden unmittelbar nach der Dilatation oder längerfristig ?
	Bothersomeness of side effects		
	Wie sehr machen Ihnen die Nebenwirkungen des Medikaments zu schaffen, das Sie zur Behandlung Ihrer Erkrankung nehmen?	Wie sehr machen Ihnen die Nebenwirkungen der Diät zu schaffen, die Sie zur Behandlung Ihrer Erkrankung haben ?	Wie sehr machen Ihnen die Nebenwirkungen der Dilatation zu schaffen, die Sie zur Behandlung Ihrer Erkrankung erhielten ?
	Interference with physical function		
	Wie sehr beeinträchtigen die Nebenwirkungen Ihren körperlichen Gesundheitszustand und wie Sie im Alltag zurechtkommen (d.h. Ihre Kraft, Energie, usw.)?		
	Interference with mental function		
	Wie sehr wirken sich die Nebenwirkungen auf Ihren geistigen Zustand aus (d.h. auf die Fähigkeit, klar zu denken, wach zu bleiben, usw.)?		
Side effect impact on satisfaction			
Wie sehr haben sich Nebenwirkungen des Medikaments auf Ihre allgemeine Zufriedenheit mit dem Medikament ausgewirkt?	Wie sehr haben sich Nebenwirkungen der Diät auf Ihre allgemeine Zufriedenheit ausgewirkt?	Wie sehr haben sich Nebenwirkungen der Dilatation auf Ihre allgemeine Zufriedenheit ausgewirkt?	

438 **Continued on the next page...**

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	Original TSQM	Diet	Dilation
Convenience	Ease of use		
	Wie einfach oder schwierig ist es, das Medikament in seiner derzeitigen Form zu nehmen?	not applicable	not applicable
	Planning for use of treatment		
	Wie einfach oder schwierig ist es, zu planen, wann Sie das Medikament jeweils nehmen?	Wie einfach oder schwierig ist es, die Menus zu planen?	not applicable
	Convenience of taking medication		
	Wie einfach und bequem ist es, das Medikament wie verschrieben einzunehmen?	Wie einfach und bequem ist es, die Diät wie verschrieben einzuhalten?	not applicable
Overall satisfaction	Confidence in benefits of treatment		
	Wie überzeugt sind Sie davon, dass es gut für Sie ist, dieses Medikament zu nehmen?	Wie überzeugt sind Sie davon, dass es gut für Sie ist, diese Diät zu nehmen?	Wie überzeugt sind Sie davon, dass es gut für Sie ist, eine Dilatation zu erhalten?
	Good outweighs the bad		
	Wie sicher sind Sie sich, dass die guten Seiten des Medikaments gegenüber den schlechten Seiten überwiegen?	Wie sicher sind Sie sich, dass die guten Seiten der Diät gegenüber den schlechten Seiten überwiegen?	Wie sicher sind Sie sich, dass die guten Seiten der Dilatation gegenüber den schlechten Seiten überwiegen?
	All things taken into account		
Wie zufrieden oder unzufrieden sind Sie insgesamt gesehen mit diesem Medikament?	Wie zufrieden oder unzufrieden sind Sie insgesamt gesehen mit der Diät?	Wie zufrieden oder unzufrieden sind Sie insgesamt gesehen mit dieser Therapie?	

441

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