



## What bothers severe asthma patients most? A paired patient-clinician study across seven European countries

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Complete List of Authors:	Ainsworth, Ben; University of Southampton; University of Bath Chatburn, Eleanor; University of Bath Bansal, Aruna; St John's Innovation Centre, Fulton, Olivia; European Lung Foundation, European Lung Foundation Hamerlijnck, Dominique ; patient experience expert, Coleman, Courtney; European Lung Foundation, Eger, Katrien; Amsterdam University Medical Centres, Hyland, Michael; University of Plymouth Holmes, Joshua; Queen's University Belfast, Wellcome-Wolfson Institute for Experimental Medicine Heaney, Liam; Queens University, Centre for Experimental Medicine; Belfast Health and Social Care Trust, Respiratory Medicine Sedlak, Vratislav; Charles University of Prague, Department of Respiratory Medicine Skr gat, Sabina; University Medical Centre Ljubljana Division of Internal Medicine, Department of Pulmonary Diseases; Medical Faculty, University of Ljubljana Edelba her, Natalija; University Medical Centre Maribor, Pulmonary department Ten Brinke, Anneke; Medical Centre Leeuwarden Porsbjerg, Celeste; Copenhagen University Hospital Bispebjerg, Respiratory Medicine; University of Copenhagen, Institute of Clinical Medicine Gaga, Mina; Athens Chest Hospital Sotiria, 7th Respiratory Medicine Department Chaves Loureiro, Claudia; University of Coimbra Djukanovic, Ratko; University of Southampton, Medicine; Berret, Emmanuelle; European Respiratory Society Kwon, Namhee; GlaxoSmithKline, Global Medical Franchise
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Abstract:	Introduction: Severe asthma is a complex, multi-dimensional disease. Optimal treatment adherence and outcomes require shared decision-making, rooted in mutual understanding between patient and clinician. This study used a novel, patient-centred approach to examine the most bothersome aspects of severe asthma to patients, as seen from both perspectives in asthma registries.

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	<p>Methods: Across seven countries, 126 patients with severe asthma completed an open-ended survey regarding most bothersome aspect(s) of their asthma. Patients' responses were linked with their treating clinician who also completed free-text survey about each patient's most bothersome aspect(s). Responses were coded using content analysis, and patient and clinician responses were compared. Finally, asthma registries that are part of the SHARP Clinical Research Collaboration were examined to see the extent to which they reflected the most bothersome aspects reported by patients.</p> <p>Results: Eighty-eight codes and 10 themes were identified. Clinicians were more focused on direct physical symptoms and were less focused on 'holistic' aspects such as the effort required to self-manage their disease. Clinicians accurately identified a most bothersome symptom for 29% of patients. Agreement was particularly low in younger patients and those infrequently using oral corticosteroids. In asthma registries, patient aspects were predominantly represented in questionnaires.</p> <p>Conclusions: Results demonstrated different perspectives and priorities between patients and clinicians, with clinicians more focused on physical aspects. These differences must be considered when treating individual patients, and within multi-disciplinary treatment teams. The use of questionnaires that include multi-faceted aspects of disease may result in improved asthma research.</p>



## What bothers severe asthma patients most? A paired patient-clinician study across seven European countries

Ben Ainsworth<sup>1,2,3</sup>, Eleanor Chatburn<sup>2\*,4</sup>, Aruna T Bansal<sup>5</sup>, Olivia Fulton<sup>6</sup>, Dominique Hamerlijnck<sup>6</sup>, Courtney Coleman<sup>6</sup>, Katrien Eger<sup>7</sup>, Michael Hyland<sup>8,9</sup>, Joshua Holmes<sup>10</sup>, Liam Heaney<sup>10</sup>, Vratislav Sedlák<sup>11</sup>, Sabina Škr gat<sup>12,13</sup>, Natalija Edelba her<sup>14</sup> Anneke ten Brinke<sup>15</sup>, Celeste Porsbjerg<sup>16</sup>, Mina Gaga<sup>17</sup>, Claudia Loureiro<sup>18,19</sup>, Ratko Djukanovic<sup>20</sup>, Emmanuelle Berret<sup>21</sup>, Namhee Kwon<sup>22\*</sup>

1. School of Psychology, Faculty of Environmental and Life Sciences, University of Southampton, Southampton, UK.
  2. Department of Psychology, University of Bath, Bath, UK
  3. NIHR Southampton Respiratory Biomedical Research Centre, Faculty of Medicine, University of Southampton, Southampton, UK
  4. Department of Clinical Psychology, University of East Anglia, Norwich, UK
  5. Acclarogen Ltd, Cambridge, UK
  6. European Lung Foundation, Sheffield, UK
  7. Department of Respiratory Medicine, Amsterdam University Medical Center, University of Amsterdam, Amsterdam, the Netherlands
  8. University of Plymouth, Plymouth, UK
  9. Plymouth Marjon University, Plymouth, UK
  10. Wellcome-Wolfson Institute for Experimental Medicine, Queen's University Belfast, Belfast, UK
  11. Department of Respiratory Medicine, University Hospital Hradec Králové, Charles University in Prague, Czech Republic
  12. Department of Pulmonary Diseases and Allergy, University Medical Centre Ljubljana, Slovenia
  13. Medical Faculty, University of Ljubljana, Slovenia
  14. Department of Pulmonary Diseases, University Medical Center Maribor, Slovenia
  15. Medical Centre Leeuwarden, Leeuwarden, Netherlands
  16. Department of Respiratory Medicine, Bispebjerg University Hospital, Copenhagen, Denmark
  17. Athens Chest Hospital Sotiria, Athens, Greece
  18. Pulmonology Unit, Hospitais da Universidade de Coimbra, Centro Hospitalar e Universitário de Coimbra, Portugal
  19. Centre of Pulmonology, Faculty of Medicine, University of Coimbra, Coimbra, Portugal
  20. Centre of Pulmonology, Faculty of Medicine, University of Coimbra, Coimbra, Portugal
  21. European Respiratory Society (ERS) Lausanne, Switzerland
  22. Respiratory Clinical Sciences, GSK, Brentford, Middlesex, UK
- (\*Affiliation at the time of manuscript writing)

**Keywords:** asthma symptoms, severe asthma, patient-reported outcomes, patient-clinician agreement

## Abstract

**Introduction:** Severe asthma is a complex, multi-dimensional disease. Optimal treatment adherence and outcomes require shared decision-making, rooted in mutual understanding between patient and clinician. This study used a novel, patient-centred approach to examine the most bothersome aspects of severe asthma to patients, as seen from both perspectives in asthma registries.

**Methods:** Across seven countries, 126 patients with severe asthma completed an open-ended survey regarding most bothersome aspect(s) of their asthma. Patients' responses were linked with their treating clinician who also completed free-text survey about each patient's most bothersome aspect(s). Responses were coded using content analysis, and patient and clinician responses were compared. Finally, asthma registries that are part of the SHARP Clinical Research Collaboration were examined to see the extent to which they reflected the most bothersome aspects reported by patients.

**Results:** Eighty-eight codes and 10 themes were identified. Clinicians were more focused on direct physical symptoms and were less focused on 'holistic' aspects such as the effort required to self-manage their disease. Clinicians accurately identified a most bothersome symptom for 29% of patients. Agreement was particularly low in younger patients and those infrequently using oral corticosteroids. In asthma registries, patient aspects were predominantly represented in questionnaires.

**Conclusions:** Results demonstrated different perspectives and priorities between patients and clinicians, with clinicians more focused on physical aspects. These differences must be considered when treating individual patients, and within multi-disciplinary treatment teams. The use of questionnaires that include multi-faceted aspects of disease may result in improved asthma research.

## Key Messages

### What is already known?

- The complex nature of severe asthma means that treatment adherence (including biologics) is suboptimal, leading to increased exacerbation and mortality
- Clinician and patient perspectives about their asthma may differ, causing poor adherence in patients through lack of motivation

### What did this study show?

- This patient-led study found that clinicians were not very accurate at identifying what bothered their patients most.
- Patients cared much more about the effort of self-management, and much less about the direct physical symptoms, than their clinicians thought.
- Aligning patient and clinician perspectives during consultations, and understanding the aspects of asthma that patients are bothered by, may improve severe asthma outcomes.

## Introduction

Severe asthma, defined as asthma that requires treatment with high-dose inhaled corticosteroids and additional controller medication to prevent it becoming uncontrolled or asthma that remains uncontrolled despite such treatment, is heterogeneous and is associated with substantial burden to patients and healthcare system [1 - 4]. People with severe asthma have increased morbidity and mortality rates and are five times more likely to experience asthma exacerbations, compared to mild/moderate asthma, leading to substantially lower quality of life [5 - 7]. The complex nature of the disease and accompanying comorbidities (including allergic rhinitis, chronic rhinosinusitis, obesity, gastro-oesophageal reflux disease, anxiety and depression), as well as the effects of treatment/treatment responses, impacts patients both physically and emotionally [8] affecting family and social relationships, employment and education [9]. Therefore, management of severe asthma should be equally multi-faceted, including appropriate medication and non-pharmacological therapies such as physiotherapy, supported self-management and psychological support [10].

Poorly controlled severe asthma remains common despite advances in treatment, especially the advent of biologics [11]. The combination of a high symptom burden and high treatment burden, including side effects of oral corticosteroids, leads many patients to have low expectations of levels of asthma control [12], which often results in poor quality of life. To improve asthma treatment outcomes, therefore, patients and clinicians must have similar understandings of the impact severe asthma has on people living with it, and the benefits of appropriate treatment [13]. The alignment of patient and clinician perspectives promotes trust and shared decision-making, in which both clinician and patient actively engage in treatment processes. This has been shown to improve adherence and quality of life in poorly-controlled asthma [14].

Current evidence indicates that patient and clinician perceptions of asthma are often not aligned. A large-scale survey with patients and physicians reported significant discordance in the subjective perception of asthma control [15,16], with evidence that patients perceive their own asthma as better controlled than their clinician does. Pertinently, clinicians tend to underestimate the effects on patients' daily lives, thus leading to worse asthma control [17,18]. Recent survey data highlighted the need for patients and physicians to work together in order to better understand the nature of their disease – whether it is well controlled, and how it can be improved using treatment guidelines[19]. A better understanding of the impact of the varied symptoms experienced by patients will aid clinicians to provide supportive, personalised treatment for severe asthma [20].

Several studies have used questionnaires and interviews to explore aspects of severe asthma that negatively impact patients including physical and emotional asthma symptoms, symptoms from comorbidities and medication side effects, to inform patient-reported outcomes that are used in severe asthma registries [21,22]. Registries that collect important data on patients' asthma encourage standardised reporting of well-established measures. However, registry variables may also be

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3 ‘medicalised’ and not reflect the multi-dimensional patient experience of severe asthma, hampering  
4 clinicians’ ability to provide supportive, personalised treatment.

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6 Therefore, this novel study used an inductive, patient-centred approach to compare the perceived  
7 impact of heterogenous, multi-dimensional aspects of severe asthma, from both patient and clinician  
8 perspectives. Furthermore, the study aimed to explore whether discrepancies between patient and  
9 clinician perspectives differed within patient subgroups, and examined how well the most important  
10 aspects were reported in dedicated registries collecting clinical information on people with severe asthma.  
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## 14 15 **Methods**

### 16 17 ***Design***

18 This observational qualitative study used online patient and clinician surveys developed through an  
19 iterative process of consultations with severe asthma patients, patient organisations, clinical asthma  
20 experts and psychology experts (see GRIPP report; Supplementary Material A).  
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### 24 25 ***Survey and Recruitment***

26 The cross-sectional survey was sent to clinicians from severe asthma clinics in seven European countries  
27 (Czech Republic, Denmark, Greece, Netherlands, Slovenia, Portugal, United Kingdom) recruited via the  
28 European Respiratory Society Severe Heterogeneous Asthma Research collaboration, Patient-centred  
29 (ERS SHARP) [23]. Clinicians completed the first part of the survey before eligible patients (over 18  
30 years, clinician-diagnosed severe asthma according to local guidelines) completed a linked patient  
31 component. Eligible patients were identified through opportunistic recruitment to the study by clinicians.  
32 To avoid biased recruitment, participating clinicians were asked to consecutively recruit eligible patients  
33 once they started the study. The responses given by patient and the clinician responsible for their care  
34 were anonymously linked via a unique web link to enable an assessment of agreement. Neither patients  
35 nor clinicians saw the others’ responses.  
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39 After providing informed consent, patients answered questions about their demographics and current  
40 treatment before completing an open-ended survey (see supplementary material B) about ‘what bothers  
41 you most about your asthma?’. Open-ended questions were used to collect new insights grounded in  
42 participant data. A follow-up question asked “Is there anything else that bothers you about your asthma  
43 and you would like to tell us?”, but this was rarely completed and not used in the analysis. Clinicians  
44 answered similar questions about “the most bothersome aspect of their patient’s asthma”. There was no  
45 limitation to the number of bothersome aspects that patients and clinician could report.  
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49 Patient eligibility criteria were physician-diagnosis of severe asthma, with at least 6 months follow-up in  
50 an asthma clinic, as well as having internet access and the ability to complete the study independently.  
51 Clinicians who were significantly experienced in severe asthma patient care were eligible. Patient  
52 eligibility was confirmed by the paired clinician who invited them to take part in the study. Surveys were  
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3 translated into each patient's native language by a professional translation agency, who translated  
4 responses back into English for analysis.  
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### 6 7 ***Qualitative Data Analysis***

8 Free-text survey responses were analysed using conventional content analysis, a widely used method of  
9 qualitative inquiry in healthcare research in which textual data is inductively analysed by the research  
10 team [24,25]. In this study, an experienced qualitative researcher (Chatburn) developed the initial  
11 codebook from an initial sample of 32 responses: After reading through and obtaining a sense of the data,  
12 'codes' were created that captured any bothersome aspects within the responses. These codes were  
13 clustered under higher-order headings, and then iteratively refined into 'themes'. For example, when  
14 participants reported feeling exhausted during their days, this was coded as 'tiredness or fatigue'. Similar  
15 codes such as 'tiredness or fatigue', 'sleep problems' or 'weight changes' were categorised under the  
16 theme of 'indirect physical consequences of asthma and asthma treatments'. For further details of how the  
17 themes were constructed please see Table 2.  
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19 The process of coding and categorisation was discussed with the research team throughout, and data  
20 credibility and trustworthiness were further strengthened by frequent dialogue with patients and  
21 clinicians.  
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23 The final categorisation of the patient data was reviewed and approved by additional patients. The  
24 researcher then applied the codebook from patient responses to clinician responses. Where any novel  
25 codes were present in the clinician responses, these were added to the codebook.  
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27 Once initial coding and categorisation was completed with sample responses, remaining patient responses  
28 were coded using the initial codebook. New codes were added during the coding of the remaining  
29 responses, and the initial 32 sample responses were recorded at the end, using the full codebook to ensure  
30 nothing was missed.  
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### 32 33 ***Analysis***

34 Patient and clinician answers were compared at the theme level, by examining the proportion of responses  
35 in which each theme was present. Significant differences between patient/clinician responses were  
36 identified using Fisher's exact test.  
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38 Responses were categorised by subgroup by patient age (55 years or older vs. younger than 55 years),  
39 patient gender (male vs. female), patient oral corticosteroid (OCS) use (every few months / few per year /  
40 annual vs. every few weeks / daily). Patient and clinician responses were compared within patient  
41 subgroups.  
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43 Clinician responses were viewed as 'in-agreement' with patients if a theme identified in a patient  
44 response was also present in the clinician response. Agreement was also examined within patient  
45 subgroups at a theme level (gender: male vs. female, age: under 55 vs 55 and over, OCS use: high (every  
46 few months or less) vs. low [every few weeks or more]).  
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### ***Registry Comparison***

All variables from ten accessible national and regional severe asthma registries from the SHARP network<sup>1</sup> were compiled and reviewed. Each variable was compared qualitatively against the codes and themes from the survey codebook to determine if a variable reflected any identified code or theme. For patient-reported outcome measures with multiple questions, each question was reviewed individually.

### ***Ethics***

The project received ethical approval from University of Bath Research Ethics Committee (ref 20:251) with specific approvals for each international site (Supplementary Material C). Anonymous datasets from the project are available in the online repository: [doi://10.6084/m9.figshare.20349138](https://doi.org/10.6084/m9.figshare.20349138). [Note: updated upon acceptance]

## **Results**

### ***Participants***

128 patients and 24 clinicians participated in the survey from 7 countries, with 126 patients having corresponding clinician data. Among the 126 patients included in the analysis, 70% were female (in line with previous sex differences observed in severe asthma prevalence [26]), and the majority (56%) were 45 – 64 years old. Forty-six patients reported using oral corticosteroids daily and 67% were current users of biological therapy for their asthma (Table 1).

### ***Codes and themes***

From 88 codes, ten themes were identified: direct physical symptoms of asthma, indirect physical consequences of asthma, limitations on daily life, sensitivity to triggers, effort required to self-manage asthma, burden of medication and side effects, fears worries and distress, stigma, interactions with health-care providers, and ‘nothing bothers me’ (Table 2). A full codebook, including all codes and example quotes for each, is available in Supplementary Material D.

### ***Patient and clinician perspectives of most bothersome aspects of severe asthma***

Overall, patients reported more bothersome aspects of severe asthma in their responses (total 436 codes, mean 3.5 per participant, range 1 – 19) than clinicians (total 213, mean 1.7, range 1 – 5).

When responses were allocated into different themes, patient responses included between one and six themes each (Figure 1). In total across patients, 278 themes were selected (Mean 2.21 per patient). For clinicians, there were 188 entries in total (mean 1.49 per physician, range 1-3). The proportion of total responses from patients and clinicians in which each theme was identified were compared (Figure 2).

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<sup>1</sup> Registries included were from severe asthma clinics in Belgium, Denmark, Germany, Spain, France, Greece, Italy, Portugal, UK and the SHARP Central Registry.



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3 Just 29% of themes (82 of 278) identified in patient responses were also present in the paired clinician  
4 response. In 46% of patients (58 of 126) no themes were agreed between patients and clinicians.  
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7 Both patients and clinicians reported 'direct physical symptoms of asthma' most frequently, followed by  
8 'indirect physical consequences' and 'limitations on daily life' (Table 3). Thereafter, patients reported  
9 'sensitivity to triggers', followed by 'effort required to self-manage'. In contrast, only three clinician  
10 responses concerned effort required to self-manage. For clinicians, fourth and fifth ranked themes were  
11 'burden of medication' followed by 'sensitivity to triggers'.  
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16 Compared with patients, clinicians reported 'Direct physical symptoms of asthma' more frequently  
17 (OR=1.71 [1.11-2.65]; p = 0.014), although both patients and clinicians were reported this most often.  
18 Notably, clinicians reported the effort required to self-manage asthma less frequently than patients  
19 (OR=0.15 [0.03-0.50]; p < .001). The frequency of other themes such as indirect physical consequences  
20 and limitations on daily life were broadly similar between patients and clinicians however, interestingly,  
21 stigma was mentioned only by patients and not at all by clinicians.  
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### 27 ***Patient and clinician perspectives in subgroups***

28 Differences between clinician and patient response proportions within subgroups of patients by age,  
29 gender, OCS use were evaluated (Figure 3). For complete comparisons (including patient vs. patient and  
30 clinician vs. clinician comparisons) see Supplementary Material E.  
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35 The accuracy of clinician responses only varied slightly across patient gender (female 29%, male 31%),  
36 but clinicians were more accurate for older patients (55 years old and under 26%, over 55 years old 35%)  
37 and those who used OCS more often (low use 26%, high use 34%).  
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### 41 ***Comparison with registry variables***

42 All themes, except 'effort required to self-manage asthma', were addressed by at least one registry  
43 variable. At a code level, 67% of codes were represented, although the breadth of coverage varied by  
44 theme: 100% of codes in the theme of direct physical symptoms were well covered in the registry  
45 variables, while 54% of indirect physical consequences were captured, and 0% of 'effort required to self-  
46 manage asthma'.  
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50 There were 13 questionnaires included across the registries (mean 4.3, range 1 – 8). When the  
51 questionnaires were excluded, the coverage for the most bothersome symptoms was significantly  
52 decreased (16% overall). None of indirect physical consequences, fear, worries, and distress, or stigma  
53 were addressed by the registry variables.  
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## 58 **Discussion**

### 59 ***Summary of findings***

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3 This study investigated patients' views on the most bothersome aspects of severe asthma by asking open-  
4 end questions with a free text response. This enabled patients to consider various aspects of discomfort or  
5 inconvenience due to their asthma, not limited to clinical symptoms. Consequently, many patients  
6 responded that much broader aspects of living with severe asthma were most bothersome.  
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9 This is the only study to evaluate the most bothersome aspect of severe asthma through a paired survey  
10 between patients and clinicians. This unique approach allowed comparison of views between individual  
11 patients and their clinicians'. Our study found that patients were less likely than clinicians to report the  
12 direct physical aspects of their disease as the most bothersome (22 % vs 33%), and more likely than  
13 clinicians to find the effort of self-managing their disease most bothersome (10% vs 2%). This was  
14 observed across almost all subgroups irrespective of patient's age, gender, and OCS use. The agreement  
15 between patient and clinician responses was poor (only 29% of aspects identified by patients were also  
16 identified by the clinician looking after them) although agreement was slightly higher for females, older  
17 patients and patients with high OCS use. This may reflect more agreement where clinicians have greater  
18 familiarity with particular groups of patients, such as female patients who are more common in severe  
19 asthma cohorts[27]. Previous research has observed more patient-centred interactions between patient and  
20 clinician when patients were older - which was associated with better patient satisfaction[28]. Finally,  
21 many aspects that patients considered important were only partially represented in clinical registry  
22 databases, mainly through standard PROs collected in the existing severe asthma registries.  
23 These findings are in line with previous evidence in other disease areas that clinician and patient  
24 experiences of disease do not always align [29], and that broader healthcare outcomes that encompass  
25 holistic aspects such as social and psychological elements, are often at, or near the top of, patient  
26 priorities[30].  
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### 38 ***Study implications***

39 Our study supports the reported substantial impacts of severe asthma on many aspects of a patient's life,  
40 highlighting the need for clinicians to understand and treat such complex diseases with multi-disciplinary  
41 approaches.  
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44 Clinicians may have a different perspective on the most bothersome aspects of disease because they have  
45 different priorities, such as reducing symptoms and exacerbations rather than impact of asthma on  
46 patient's daily life and emotion [31]. Although symptomatic improvement is an important treatment goal,  
47 patients frequently reported such non-clinical aspects as most bothersome. Therefore, the non-clinical  
48 bothersome aspects (such as the substantial effort required to appropriately self-manage severe asthma)  
49 may have more impact on patient well-being. These findings highlight the importance of integrative and  
50 inclusive multi-disciplinary care teams (MDTs) to support all aspects of care of people with severe  
51 asthma, requiring close and integrative collaboration from different healthcare professionals (including  
52 physicians, nurses, pharmacists, physiotherapists and psychologists) to provide multi-dimensional support  
53 [32,33].  
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3 Registries that collect data on patients are increasingly used to understand the impact of disease and  
4 treatment on patients. As demonstrated by our analysis, the multi-faceted nature of severe asthma is not  
5 well reflected in severe asthma registry variables across Europe. Data capture was inconsistent across  
6 registries. All registries had different combinations of questionnaires, with some using multiple  
7 questionnaires to address some aspects of disease whilst not capturing patient's most bothersome aspects,  
8 or capturing bothersome aspects with a single item within a questionnaire. Therefore, when interpreting a  
9 questionnaire, patient's responses to each question should be carefully reviewed. The findings highlight  
10 the need to use varied clinical tools, including questionnaires, to address the aspects of severe asthma that  
11 are most important for patients.  
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14 Improving the concordance between patient and clinician perceptions is crucial to improved asthma  
15 outcomes, particularly given the key importance of quality of life for people with severe asthma [34,35].

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17 Treatment adherence in people with severe asthma is frequently suboptimal and may be improved by  
18 shared decision-making centred around outcomes that are important to individual patients [36].

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20 Adherence may be improved through use of a common, agreed goal between patient and clinician,  
21 identified through explicitly confirming individual patient priorities ('what has been bothering you?')  
22 rather than focusing on symptom-focused discussions ('how have you been?') during consultations. Such  
23 approaches may be particularly important for particular patient subgroups [37,38] – such as males, those  
24 with lower OCS use, and younger patients. Future work should explore how these groups can be offered  
25 personalised, supportive treatment that maintains an appropriate therapeutic partnership [39].  
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### 33 34 ***Study strengths and limitations***

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36 A clear study strength is the extensive involvement of patient representatives at every stage of this  
37 international collaborative study – including conception, design, analysis, interpretation and reporting.  
38 This ensured the study findings are important for patients and, therefore, important for researchers and  
39 clinicians. Additionally, unlike previous studies, the 'bottom-up' reflexive content analysis meant the  
40 impact of existing clinical and research biases was reduced – although the inherent subjective nature of  
41 the qualitative methods should be acknowledged.  
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46 While a few studies have investigated patient and clinician treatment priorities [38], the novel design of  
47 pairing patient and clinician responses allowed the assessment of agreement for each individual patient.  
48 This showed not only differences between patient and clinician priorities, but also whether clinicians are  
49 able to understand what is important for their individual patients during treatment.  
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51  
52 The study has some limitations. Firstly, it must be recognised that the patient sample is from severe  
53 asthma centres in only seven countries. While large and seemingly broadly representative of severe  
54 asthma prevalence in European patient groups [26], our qualitative findings may not be representative of  
55 all patients, such as patients treated outside of severe asthma centres, and underserved groups who are  
56 less likely to respond to voluntary surveys. Secondly, the sample size within each separate site was too  
57 small to determine any patterns within each site. Thirdly, the study data is self-report and would be  
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3 strengthened by including objective, physiological measures (such as lung function) and clinical measures  
4 (such as comorbid conditions) in order to further understand patient perceptions across heterogenous  
5 characteristics. Future research should look to understand how contextual factors (such as the provision of  
6 psychological/behavioural support to develop adaptive coping strategies, or socioeconomic factors) can  
7 influence the patient-physician partnership, and understand their impact on relevant outcomes like asthma  
8 control.  
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### 13 **Conclusions**

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16 Patients and clinicians had different views on the most bothersome aspects of severe asthma in daily life.  
17 Whilst both reported physical symptoms, most patients shared a wide variety of aspects related to quality  
18 of life that frequently included the substantial effort required to self-manage their condition. During  
19 clinical consultation, physicians should respect the importance of their patients' most bothersome  
20 symptom and ensure that it is addressed, recognising that it may change from consultation to consultation,  
21 alongside other clinically relevant issues. Such an approach would enhance trust and strengthen the  
22 patient-physician partnership. Using questionnaires that include multi-faceted aspects of disease, within  
23 research, clinical practice and disease registries, may result in improved asthma treatments.  
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## Competing Interests

BA is a member of the UK Taskforce for Lung Health, has received honoraria for educational talks from AstraZeneca and sits on advisory boards for the Medito Foundation, earGym. MH has received grant income from Teva, GSK and Astra-Zeneca. Liam G. Heaney has received grant funding, participated in advisory boards and given lectures at meetings supported by Amgen, AstraZeneca, Boehringer Ingelheim, Chiesi, Circassia, Hoffmann la Roche, GlaxoSmithKline, Novartis, Theravance, Evelo Biosciences, Sanofi, and Teva; he has received grants from MedImmune, Novartis UK, Roche/ Genentech Inc, and Glaxo Smith Kline, Amgen, Genentech/Hoffman la Roche, Astra Zeneca, MedImmune, Glaxo Smith Kline, Aerocrine and Vitalograph; he has received sponsorship for attending international scientific meetings from AstraZeneca, Boehringer Ingelheim, Chiesi, GSK and Napp Pharmaceuticals; he has also taken part in asthma clinical trials sponsored by AstraZeneca, Boehringer Ingelheim, Hoffmann la Roche, and GlaxoSmithKline for which his institution received remuneration; he is the Academic Lead for the Medical Research Council Stratified Medicine UK Consortium in Severe Asthma which involves industrial partnerships with a number of pharmaceutical companies including Amgen, AstraZeneca, Boehringer Ingelheim, GlaxoSmithKline, Hoffmann la Roche, and Janssen. VS has received honoraria for educational talks and advisory board from Astra-Zeneca, GSK, Novartis, TEVA, Chiesi and Boehringer Ingelheim. AB has received honoraria for educational talks and advisory board from Astra-Zeneca, GSK, Novartis, Sanofi, TEVA, and grant income from Astra-Zeneca, GSK and TEVA. NE has received honoraria for educational talk and advisory board from Astra-Zeneca, Sanofi, Novartis, GSK, Amgen, Boehringer Ingelheim, Chiesi and Berlin Chemie. CL has received honoraria for educational talks and advisory board from Astra-Zeneca, GSK, Jaba-Recordati, Novartis, Sanofi, TEVA. RD has received honoraria for education talks and advisory board from AZ, GSK, Teva, Novartis and Sanofi. NK is a GSK employee and holds stocks of GSK at the time of manuscript writing. All other authors have no competing interests.

## Contribution of Authors.

Conceived the study: DH, NK, VS.

Study Design: BA, EC, CC, KE, DH, MH, NK, SS, VS.

Analysed the data: BA, ATB, EC, CC.

Interpreted the data: All authors.

Drafted the manuscript: BA, NK.

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Reviewed the manuscript and approved the content: All authors.

Met authorship criteria: All authors.

**Data-sharing statement**

Anonymous datasets from the project are available in the online repository: [doi://10.6084/m9.figshare.20349138](https://doi.org/10.6084/m9.figshare.20349138).

(Note: updated upon acceptance)

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**Figure Captions**

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2 **Figure 1.** Distribution of responses by the number of distinct themes reported by patients vs. clinicians.  
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5 **Figure 2.** A comparison of the percentage of responses for each theme, by responder group.  
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8 **Figure 3.** Percentage of responses for each theme, by patient subgroup.  
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## Tables

**Table 1. Participant demographics**

<b>Patients (N = 126)</b>		<b>n (%)</b>
Country	Czech Republic	21 (17)
	Denmark	19 (15)
	Greece	19 (15)
	Netherlands	17 (14)
	Slovenia	18 (15)
	Portugal	20 (16)
	United Kingdom	12 (10)
Gender	Female	88 (71)
	Male	36 (29)
Age (years)	< 34	13 (10)
	35-44	21 (17)
	45-54	34 (27)
	55-64	36 (29)
	≥ 65	20 (16)
Oral corticosteroid use	Annual	47 (38)
	Few per year	22 (18)
	Every few months	6 (5)
	Every few weeks	3 (2)
	Daily	46 (37)
Current use of biologics	Yes	84 (68)
	No	23 (19)
	Not sure	17 (14)
<b>Clinicians (N = 24)</b>		
Gender, n (%)	Female	13 (54)
	Male	11 (46)
Age, years, mean*		47.5
Experience in clinical practice, years, n (%)	0-9	4 (17)
	10-19	9 (38)
	over 20	11 (46)

Note: Two patients did not provide complete demographic data and have not been included in summary percentages. Standard deviation of clinicians SD could not be calculated as some sites only provided summary data.

For sub-group analysis, demographic data was divided into the following comparisons: young (< 34 / 35-44 / 45-54) vs. old (55-64 / ≥ 65), male vs. female, low OCS use (every few months/few per year/annual) vs. high OCS use (every few weeks / daily).

**Table 2. Identified themes and codes from patients and clinician responses.**

Theme*	Codes	Theme*	Codes
Direct physical symptoms of asthma (6)	• Breathing difficulties, shortness of breath • Coughing, • Chest tightness • Mucus and phlegm • Asthma attacks, flare ups, exacerbations • Noisy breathing	Burden of medication and their side effects (6)	• Dependence on medications taken • Corticosteroid side effects • Amount of medications taken • Need to always carry medications • Medications ineffective • Remembering to take meds, restock meds
Indirect physical consequences of asthma and asthma treatments (13)	• Tiredness or fatigue • Sleep problems • Susceptibility to respiratory infections • Nose, throat, or sinus problems • Pain • Weight changes • Poor physical fitness or stamina • Weakness • Palpitations • Headaches • Dizziness • Eczema • Allergic complaints	Fears, worries and distress (8)	• Specific fears about asthma • General distress about having asthma • Anxiety • Worries about asthma medications • Impact on mood • Impact on self-esteem, feeling useless, no freedom • Fears about asthma and COVID-19 • Having panic attacks
Limitations on daily life (missing out) (13)	• Unable to do activities you want to do • Walking and climbing stairs • Sports, exercise, active leisure • Family life, partner, caregiving • Work life • Social life • Normal daily life is not possible • Time outdoors • Hobbies • Poor quality of life in general • Personal care • Household tasks • Sex life	Stigma (4)	• Attracting attention, others think you are contagious • People do not understand • Asthma is stigmatising • Feeling different to others
Sensitivity to triggers (4)	• Physical exertion as trigger • Environmental triggers • Stress as trigger • Monitoring for and avoiding triggers	Interactions with healthcare providers (and hospital treatment) (5)	• Unanswered questions, not listened to • Not happy with care provision • Not understood by doctors • Need for surgeries • Need for hospital admission
Effort required to self-manage asthma (11)	• Managing activities, level, timing or setting of • Having to plan, anticipate, organise • Unpredictability of symptoms, uncertainty • Need to pause to rest, slow down, recover • Thing about asthma every day, managing it takes up time • Enhanced hygiene routines • Unable to make a plan or sudden need to change plans • Explaining things or training others • Symptoms never completely go away • Masking or hiding asthma symptoms • Doing breathing exercises	Nothing bothers me about asthma	

\* Numbers in brackets indicate the number of codes in each theme.

**Table 3. Frequency of themes on most bothersome aspect compared between patients and clinicians**

Theme	Patient (N=278) %*	Clinician (N=188) %*	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	22.3	33.0	1.71 (1.11,2.65)	0.014
Indirect physical consequences of having asthma and asthma treatment	16.5	19.7	1.24 (0.74,2.05)	0.391
Limitations on daily life missing out	14.0	12.8	0.90 (0.50,1.60)	0.783
Sensitivity to triggers	11.9	8.5	0.69 (0.34,1.34)	0.283
Effort required to self-manage asthma	9.7	1.6	0.15 (0.03,0.50)	<0.001
Burden of medication and their side effects	9.0	10.1	1.14 (0.57,2.23)	0.747
Fears, worries and distress	8.3	8.0	0.96 (0.45,1.99)	1.000
Nothing bothers me about asthma	3.2	4.8	1.50 (0.52,4.36)	0.465
Interactions with health providers and hospital treatment	2.9	1.6	0.55 (0.09,2.32)	0.537
Stigma	2.2	0.0	0.00 (0.00,1.25)	0.086

\*Percentage of total responses, allocated to each theme, by response group (N=278 for patients; N=188 for clinicians), compared using Fisher's Exact Test (FET)  
Odds ration represents clinicians (numerator) vs. patients (denominator)



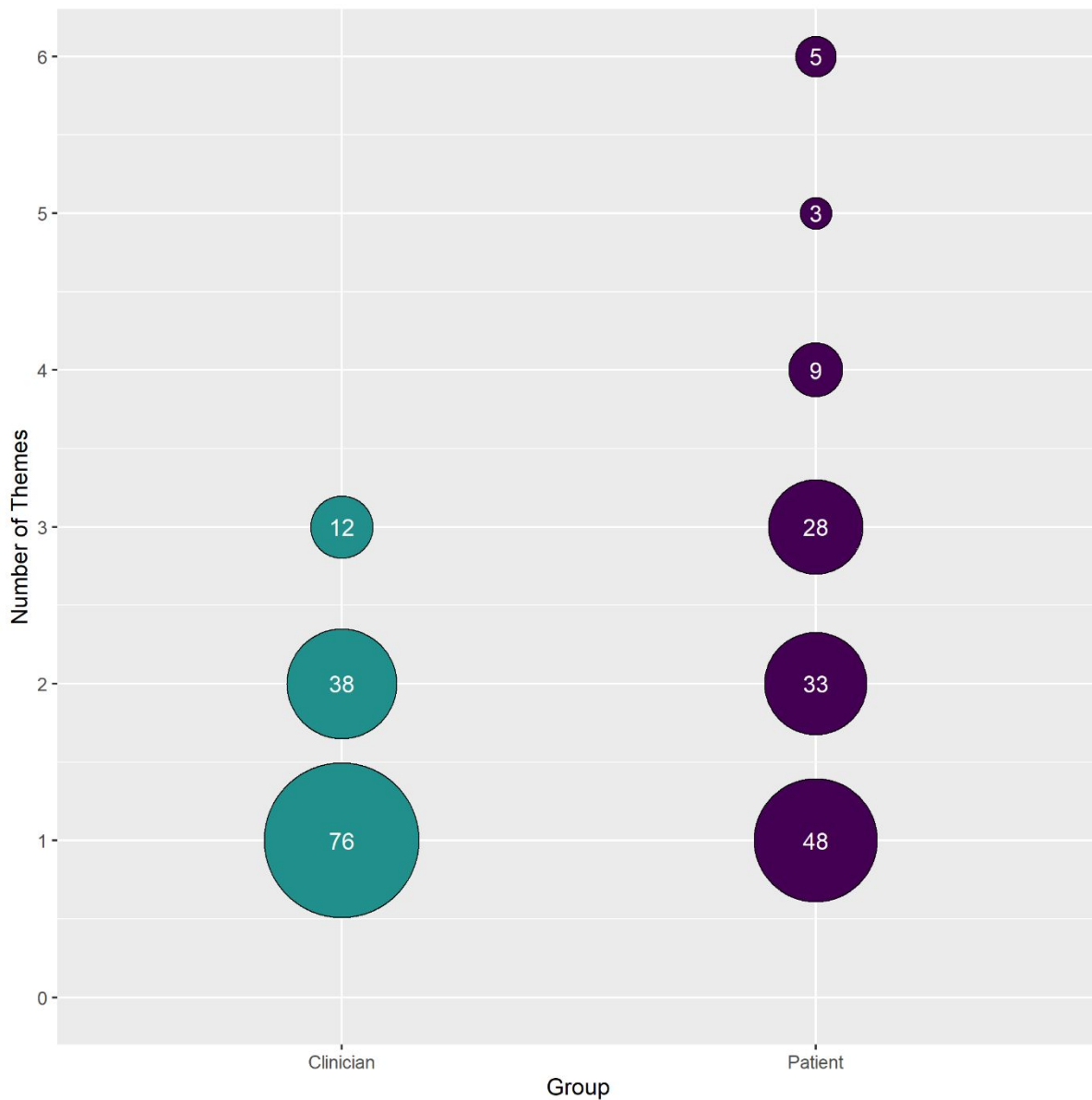
**Table 4. Themes and codes covered by registry variables in each theme including and excluding questionnaires.**

Theme	Number of Codes	N (%) of codes covered by registry variables	N (%) of codes covered by registry variables excluding questionnaires
Direct physical symptoms of asthma	6	6 (100)	6 (100)
Indirect physical consequences of asthma and asthma treatments	13	7 (54)	0 (0)
Limitations on daily life (missing out)	13	12 (92)	1 (8)
Sensitivity to triggers	4	3 (75)	2 (50)
Effort required to self-manage asthma	11	0 (0)	0 (0)
Burden of medication and their side effects	6	6 (100)	1 (17)
Fears, worries and distress	8	7 (87.5)	0 (0)
Stigma	4	2 (50)	0 (0)
Interactions with healthcare providers (and hospital treatment)	5	4 (80)	1 (20)
Nothing bothers me about asthma	NA	NA	NA
Overall Total	70	47 (67)	11 (16)

Identified PROs: ACT (Asthma Control Test), ACQ (Asthma Control Questionnaire), AQLQ (Asthma Quality of Life Questionnaire)/mini-AQLQ, CARAT (Control of AR and Asthma Test), ESS (Epworth Sleepiness Scale), EQ-5D, HAD (Hospital Anxiety and Depression scale), Nijmegen questionnaire, Pittsburgh vocal cord dysfunction index, SGRQ (St' George's Respiratory Questionnaire), SNOT-22 (Sino-Nasal Outcome Test), Dyspnoea VAS (Visual Analogue Scale), WPAI (Work Productivity and Activity Impairment).

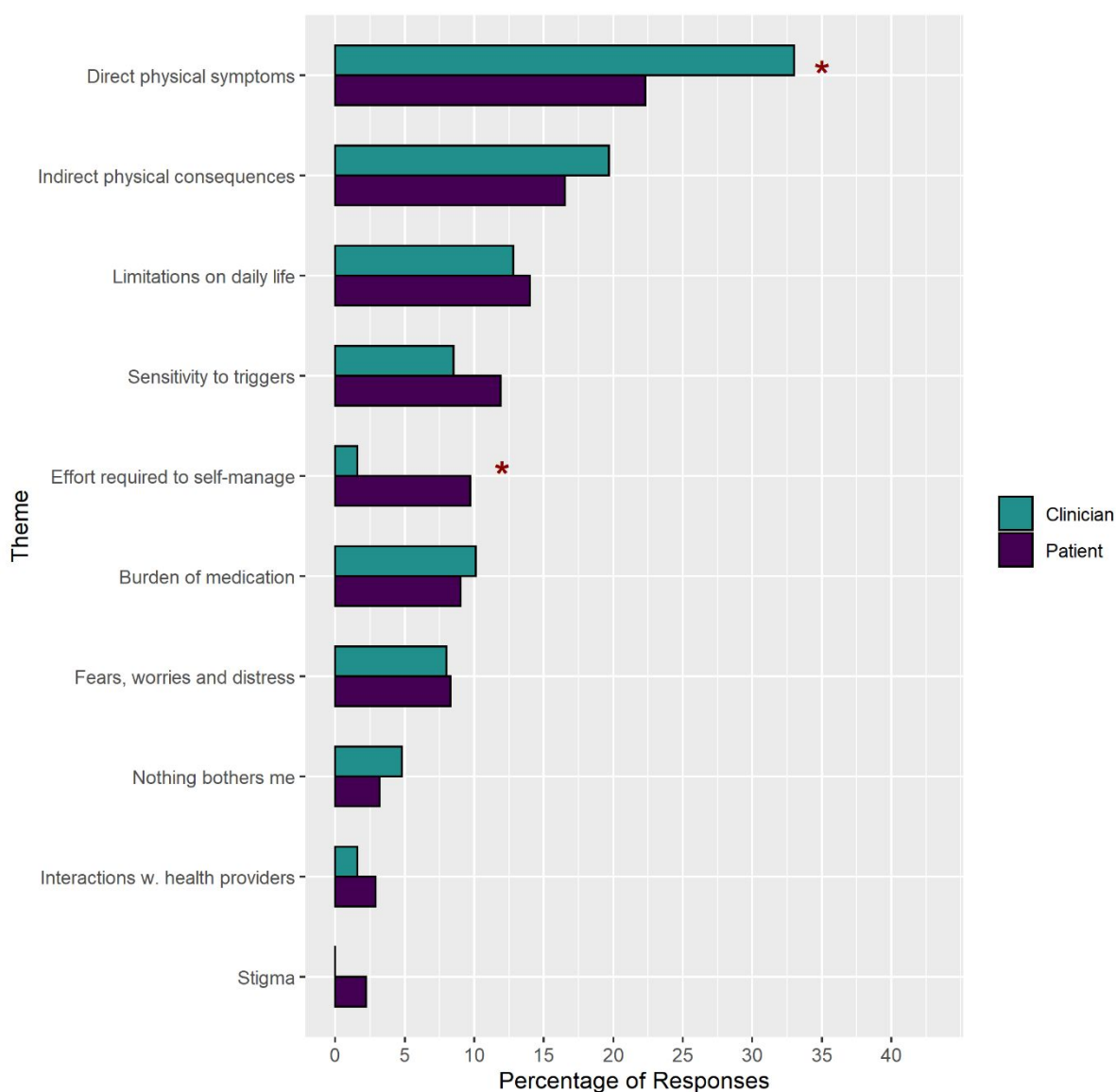
Figures

Figure 1. Distribution of responses by the number of distinct themes reported by patients vs. clinicians.



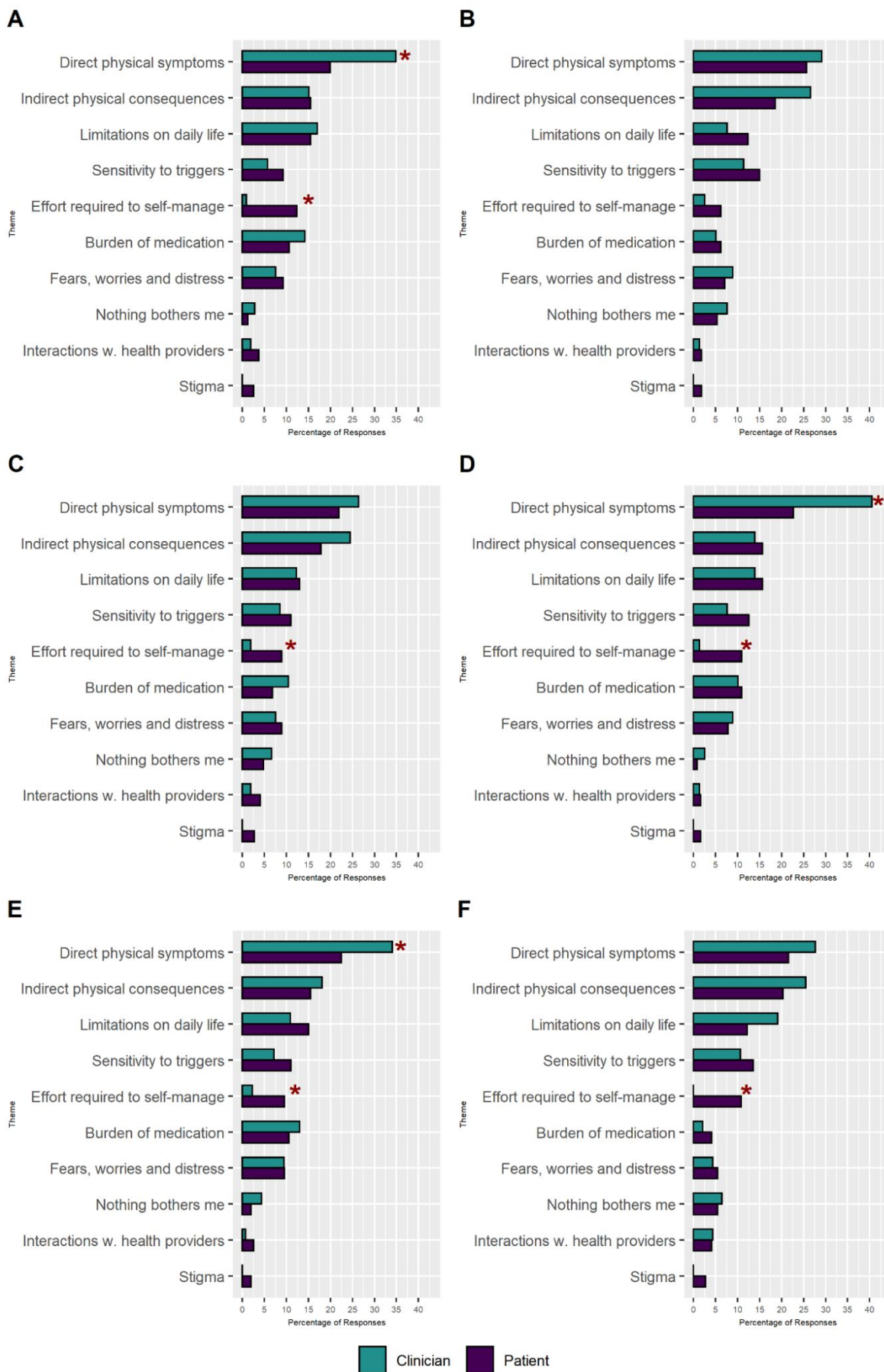
The size of bubble represents the number of responses and the numbers within bubble indicate the number of responses. For example, clinicians reported only one theme for 76 of the patients. By contrast, 48 patients reported only one theme.

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3 **Figure 2. A comparison of the percentage of responses for each theme, by responder group.**  
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42 \*An asterisk denotes a comparison with  $p < 0.05$ . For more detail on how the themes were defined, see  
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**Figure 3. Percentage of responses for each theme, by patient subgroup.** A) Younger than 55 years; B) 55 years or older; C) Female; D) Male; E) OCS low use; F) OCS high use.



Note: \*An asterisk denotes a comparison with  $p < 0.05$ . The number of participants and responses varied by subgroup: A) Younger than 55 years: 68 patients; 161 patient responses; 106 clinician response); B) 55 years or older: 56 patients; 113 patient responses; 79 clinician response); C) Female: 88 patients; 200 patient responses; 138 clinician responses; D) Male: 36 patients; 74 patient responses; 47 clinician responses; E) OCS low use: 75 patients; 146 patient responses; 106 clinician responses; F) OCS high use: 49 patients; 128 patient responses; 79 clinician responses.

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**Supplementary Material**

**A: GRIPP2 Reporting Checklist**

**B: Survey**

**C: Ethics**

**D: Codebook with quotes**

**E: Comparison of stratified patient groups**

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## Supplementary Material A: GRIPP2 reporting checklist

[Adapted from] GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ*2017; 358

<p><b>1: Aim</b> Report the aim of the study</p> <p>To explore the most bothersome aspects of severe asthma from both patient and clinician perspectives, identify areas of concordance and discordance, and examine the extent to which bothersome aspects are reported within national severe asthma registries.</p>
<p><b>2: Methods</b> Provide a clear description of the methods used for PPI in the study</p> <p>DH, the patient co-chair of SHARP (Severe Heterogenous Asthma Research collaboration, Patient-centred) co-developed the study concept with two professionals, VS and NK, and was a member of the study team. OF, the SHARP deputy patient-co chair, was a member of the project team throughout the study.</p> <p>In addition to DH and OF's role in the study team, members of European Lung Foundation's asthma Patient Advisory Group (PAG) were invited to input into the project at key points. PAG members are people living with severe asthma and come from across Europe. PAG members discussed the project during regular monthly videoconferences and were invited to ad-hoc meetings with the study team when specific input was required, for example to discuss the preliminary codebook.</p> <p>Patient representatives were involved in developing the study concept and protocol, project materials and survey design (e.g. informed consent materials, reviewing the language used in the survey for accessibility and understanding), piloting the survey (e.g. testing logic and user-friendliness in English before translation), developing recruitment materials (e.g. email invitations to patients), data analysis and interpretation (e.g. reviewing draft codebook), and discussions to develop the manuscript.</p> <p>DH worked with NK to review the registry variables and define the degree of coverage of the important aspects by existing registry variables.</p> <p>Two patient representatives (DH and OF) were involved in the study team during write-up. They reviewed study data, suggested additional interpretations of the results and identified areas for future research. The patient representatives reviewed drafts of the manuscript and are co-authors.</p>
<p><b>3: Results</b> Outcomes—Report the results of PPI in the study, including both positive and negative outcomes</p> <p>PPI contributed to the study in several ways, including:</p> <p><b>- Co-developing the study concept.</b> The concept for this study was developed through a conversation between VS and DH during the first SHARP consortium meeting. VS had not previously experienced PPI in research and was struck by the insights given by patient representatives during the consortium discussions. In conversation with DH, he began to wonder how in tune doctors are with severe asthma patients, and whether they would correctly identify the aspects of severe asthma most important to each individual. DH highlighted that existing severe asthma registries may be missing important outcomes, simply because patients have not been asked. The BIPAR study was developed as a result of these discussions.</p>

**- Influencing study design.** Patient representatives were involved in developing the study protocol and helping to define key aspects of the study. For example, early discussions suggested a quantitative survey approach, asking patients to rank pre-selected factors on a bothersome scale; however the patient member of the study team argued strongly that there was more value in an open-ended qualitative approach to cast a wide net and not allow the researchers' own pre-conceptions to limit the suggestions. Similarly, we considered unlinked surveys which would ask clinicians to generally list bothersome aspects of severe asthma. DH's contributions during discussions underlined the importance of having paired responses in order to assess how 'in tune' doctors are with the lived experience of patients. This is a highly novel approach.

**- Designing, refining and piloting the survey.** Patient representatives were involved in wording the survey questions – for example, should we ask for the most bothersome symptom or the most bothersome aspect? Should we use the word bothersome or important? How would this translate across languages and cultures? How much demographic information was needed and would patients be comfortable providing? How much time would it take to complete the survey? These discussions helped to make sure the survey wording was adapted to best meet the study aims and the consent and information for patients was accurate.

The PPI representatives indicated that patients would be able to answer the question “Have you taken / been prescribed a biological drug?” (with all generic biologic drugs listed). However, 13% of patients did not know whether they currently or previously took a biological drug. This was surprising and perhaps indicates that the patient representatives involved in the study design are not representative of the 'average' patient, having been involved in research PPI for many years.

**- Analysing the data and developing the codes.**

A group of patient representatives discussed the initial codebook and offered additional and alternative interpretations of some responses. For example, the PAG felt that the initial 'physical symptoms' theme captured both aspects directly linked to asthma, but also wider concepts around allergic comorbidities which can aggravate asthma and other symptoms like weight loss which may occur following an exacerbation. The PAG recommended having two categories to capture these different concepts and as a result the two themes were defined: “Direct physical symptoms of asthma” and “Indirect physical consequences of having asthma and asthma treatment”. The PAG also felt a separate theme was needed focused on side effects and treatment burden. During the PAG discussion the concept of 'missing out' on life came up, and this is reflected in the title of one theme – bringing patients' own words into the coding approach.

#### 4: Discussion

Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects

This study took a co-participatory approach, with patient partners as equal members of the study team involved throughout the project, supported by a wider Patient Advisory Group for consultation and input.

Patient and public involvement in this study was effective and influenced important aspects of the study design and outcomes, as noted in section 3. Several factors may have contributed to this success.

Firstly, the patient representatives are members of the European Lung Foundation's asthma patient advisory group and have been involved in the overall SHARP research consortium since the outset, some for nearly 6 years. Beyond this, many have been involved in asthma research and patient involvement through EU projects and national patient organisations for many years. They are experienced patient advocates.

Secondly, SHARP is a patient-centred research consortium, with two patient co-chairs sitting alongside two academic/clinical chairs. This has helped to embed a culture of patient involvement across the project and consortium members are used to welcoming patients to meetings and having their input during discussions. Patient representatives are invited to all consortium meetings.



From the project outset, it was clear that the study concept had come from a discussion around patient priorities and the patient co-chair was an equal member of the study team. This helped to embed a culture of checking in with the patient perspective during meetings, and to set time aside to discuss with the wider Patient Advisory Group when needed. Academic partners found the opportunity to work alongside patients in this way exciting and helped to motivate their participation in the project.

Nevertheless, there were challenges. The project has been running for X years and some individual patient representatives have faced significant challenges in that time, meaning they had to step away from the project.

While the research team were used to having patient representatives working alongside them on projects, they may not have received training to support them in facilitating patient involvement. Patient and public involvement practices vary across Europe and some professionals had little experience of working in this way.

The patient representatives involved came from the UK, Ireland, Hungary, Austria and the Netherlands. It may have been beneficial to have input from a more diverse group, to ensure the survey took account of different national approaches to severe asthma care.

#### **5: Reflections**

Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience

Patient involvement was well-embedded within the study from the outset, with patients as equal members of the study team from day 1. Their input materially changed the study concept, design, analysis and interpretation.

The key challenge was sustaining involvement throughout. Having more patient research partners, or utilising the Patient Advisory Group more consistently by having study team members attend periodic group meetings may have helped to address this barrier.

## Supplementary Material B

### Patient Survey Questions

1. What bothers you most about your asthma?
2. Is there anything else that bothers you about your asthma and you would like to tell us?
3. What is your age?
4. What is your gender?
5. How often do you take oral corticosteroids (such as prednisone and prednisolone) for your asthma?
6. Have you taken / been prescribed a biological drug (such as omalizumab, reslizumab, mepolizumab, benralizumab, or dupilumab)?

### Clinician Survey Questions

1. What do you think bothers this patient most about his/her asthma?
2. Please add anything else that bothers this patient about his/her asthma.

## Supplementary Material C

## Ethics Approvals

Approval Location	Institution	Reference
Overall	University of Bath, UK	20:251
Czech Republic	University Hospital Hradec Kralove	202012 P11
Denmark	VFD Center for Regional UDVIKling	VD-2018-31
Greece	Sotiria Thoracic Diseases Hospital of Athens	24938/23-9-20
Netherlands	Medisch Centrum Leeuwarden	RTPO 1106
Portugal	Comissao de Etical para a Saude	138/CES
Slovenia	National Medical Ethics Committee, Ministry of Health, Republic of Slovenia	0120-452/2020-3
United Kingdom	Health Research Authority, London Bridge Research Ethics Committee	20/PR/0873

## Supplementary Material D – Codebook

Code	Representative quotes (physicians)	Representative quotes (patients)
<b>Theme 1. Burden of medications and their side effects</b>		
Amount of medications taken or frequency	Patient needs to take a lot of asthma medication.	Needing lots of medication every day.
Dependence on medications	Dependence on drugs and cortisone./ Continuous administration of drugs.	I hate being dependent on inhalers and medication.
Corticosteroid side effects	Cortisone side effects.	The side effects of prednisone have had a huge impact on my body./ Oral steroids, it's very much a love hate relationship, I know I need them, but the list of side effects is endless.
Medications ineffective	Tried various nasal steroids with no effect.	Oral steroids no longer work for me.
Need to always carry medications		I cannot leave the house without my inhalers./ The need to always have medication at hand.
Remembering to take meds, restock meds	It can be difficult to remember to take her medicine.	I always have to go to the pharmacy for new inhalers.
<b>Theme 2. Direct physical symptoms of asthma</b>		
Asthma attacks, flare ups, exacerbations	Acute asthma attacks./ Disease exacerbations.	Acute asthma attacks./ Flares./ Exacerbations.
Breathing difficulties, shortness of breath	Shortness of breath./ Exertional dyspnoea.	Everyday shortness of breath./ I find it difficult to breathe./ A sensation of being suffocated.
Chest tightness	Chest pain./ Discomfort and pressure in the chest.	Chest pain./ Chest tightness./ A heavy feeling in my chest.
Coughing	Daily chronic cough./ Troublesome dry irritating cough.	Dry cough./ Coughing fits that are hard to calm down./ Coughing fits at night./
Mucus and phlegm	Phlegm that does not come out and disturbs breathing.	Bringing up phlegm all the time./ A lot of mucus.
Noisy breathing		Wheezing, a kitten-like sound./ When I breathe there is a noise like boiling.
<b>Theme 3. Fears, worries, and distress about asthma</b>		
Anxiety	Anxiety about her health.	I'm anxious about asthma./ Full of anxiety./ Nervous about asthma.
Specific fears about asthma	Fear of severe exacerbation and hospitalisation.	I'm constantly worried I'll have a severe asthma attack./ I'm afraid losing the inhaler, even the thought of it almost makes me panic./ Fear that asthma would recur in a severe form.
Impact on self-esteem, feeling useless, no freedom		I'm self-conscious about feeling like a patient./ I'm not free. Asthma makes me "weak", and I

		don't like that./ It makes me feel useless and like a burden.
Impact on mood	Symptoms vary with emotions.	My asthma is very closely linked to my mental state./ I find it really difficult at times as I am unable to do anything this is so depressing.
Having panic attacks		Sometimes I have a panic attack and I feel that I am out of breath.
Worries about asthma medications	Worry about increasing or decreasing the dosage of her medicine./ Worries about possibly getting pregnant, in terms of [...] medication.	Afraid of what's happening with my body because of the medicine I'm taking./ I'm afraid of either losing the inhaler or going anywhere without it, even the thought of it almost makes me panic.
Fears about asthma and COVID-19		My anxiety is through the roof at the moment, especially the last lockdown./ I am very worried about how my body might react if I fall ill with COVID-19.

#### Theme 4. Having to self-manage asthma

Doing breathing exercises	She regularly inhales and does breathing exercises to improve herself.	
Explaining things or training others		I have had my son trained since he was three to go call for help and bring me the inhaler when I have an attack./ I often have to explain that I have to be away for longer than for a normal toilet visit because I have to take medications.
Having to plan, anticipate, organise	Always need to take asthma into account for work, social occasions etc.	Having to plan every time I need to do something./ You have to be about how you spend your valuable hours each day, it's a task in itself and it isn't something that everyone thinks about.
Managing activities, level, timing or setting of	He is now slowly trying to increase his exercise level and getting out of the house.	I can manage an average of two hours of physical tasks like housework or gardening per day, then tired out.
Need to pause to rest, slow down, recover		I have to slow down and take a breather or even rest./ Even the simplest games are usually paused so I can get some rest and recover./ Sitting down for a break dozens of times, recovering.
Masking or hiding asthma symptoms		Masking your disabilities in front of colleagues and customers at work.
Symptoms never completely go away		What bothers me the most is that it does not go away.
Think about asthma every day, managing it takes up time	It is very time-consuming for her.	Before you do something, always think about whether you'll be able to do it.
Unable to make plans or sudden need to change plans		I don't plan anything as I may not be able to attend./ Not wanting to plan things in case I am

		exhausted, so I have to wait and see how I feel on the day.
Unpredictability of symptoms, uncertainty		The unpredictability of the attacks, I can't see them coming in advance./ Sometimes my asthma is quite erratic, no warning.
Enhanced hygiene routines		No dust in the home, air the home, keep bedroom warm, wash bedlinen once a week and the mattress every three months.

#### Theme 5. Indirect physical consequences of having asthma and asthma treatments

Allergic complaints	Allergic complaints	The unpredictability of allergic reactions.
Headaches		Lots of headaches.
Nose, throat, or sinus problems	ENT difficulties./ Chronic rhinosinusitis.	Runny nose./ Sinus problems./ Constant sensation of a lump in my throat.
Dizziness	Dizziness.	
Pain		The cough is painful when intensive./ Joint pain from Medrol, needing painkillers.
Palpitations	Palpitations.	Palpitations.
Poor physical fitness	Unable to get fit, poor stamina.	Unable to get fit.
Sleep problems	Ruined sleep at night.	Sleepless nights./ Frequent waking at night with a cough./ Severe insomnia.
Susceptibility to respiratory infections	Frequent respiratory infections./ Two hospitalisations in the last twelve months with pneumonia.	Frequent infections./ I'm more susceptible to respiratory diseases, an innocent "little cold" is enough to create a big problem.
Tiredness or fatigue	Tiredness./ Feelings of fatigue.	I get tired quickly./ I'm mega tired./ Chronic fatigue.
Weakness		Physical weakness./ Subjective feeling of weakness.
Weight changes	Increased body mass index.	Active movement is very limited, this leads to weight gain, I am conscious of every half kilo of weight in connection with shortness of breath.

#### Theme 6. Interactions with health providers, need for hospital treatment

Need for hospital admissions	Two hospitalisations in the last twelve months./ Unscheduled visits due to lack of control.	The constant hospital stays, of shorter or longer duration, are a nuisance./ Attacks of severe cases requiring hospital treatment.
Need for surgeries	Patient previously had nasal surgery three times.	I have unfortunately had three nasal operations with no major effect
Not understood by doctors		I feel most doctors don't understand how it makes you feel and sick you are and depressed you are as everything is done by figures from tests that day./ Even lung specialists don't always realise what the day-to-day life of a patient with serious asthma looks like or what kind of impact it has.

Not happy with care provision

I don't get examined enough or comprehensively enough./ My asthma plan is all about the steroids which now no longer work for me.

Unanswered questions, not listened to

Not knowing what the matter is with my lungs./ No one can explain why my lung capacity plunges for no apparent reason.

### Theme 7. Limitations on daily life, missing out

Normal daily life is not possible

Asthma makes normal life impossible./ Limitations in everyday life.

My asthma affects everything in my day-to-day life./ My asthma "slows down" my life. I am very tired of this.

Family life, partner, caregiving

Difficulties in daily activities with children

Asthma limits not only my life but the lives of those around me./ You can't be part of family life as a "normal" person would be, playing with children, being a good full-time parent./ Caring for the grandchildren./ I'm not being able to play tag with my daughter.

Hobbies

Restrictions on skating.

Limitations on hobbies, especially dancing./ Inability to sing, which is my main hobby.

Household tasks

I cannot even manage my own household tasks.

Sex life

I don't feel like having sex in the evening because it adversely affects my asthma, so I have to take more medication.

Personal care

When I am asthma has kicked off getting dressed tires me.

Poor quality of life in general

Exacerbations affect the patient's quality of life.

My quality of life has significantly worsened.

Social life

Limitations on social life.

A great effect on social life, if you have serious breathing problems you are less active in all respects./ More difficulty breathing if I talk for long periods.

Sports, exercise, active leisure

Very limited exercise capacity./ Problems prevent participation in normal sports activities.

I am unable to play sports./ I can't run with my dog./ Limitation of any form of greater activity.

Time outdoors

I can't go out into nature, into the hills.

Unable to do activities you want to do

Dyspnoea that limits activities./ He cannot do things as much as he would like at his age

I had hoped to do more in my retirement./ Not doing everything I want and having limitations./ Asthma prevents me from fully enjoying simple moments.

Walking and climbing stairs

He tolerates one flight of steps only.

Going upstairs causes me problems./ It's difficult for me to participate in walking

Work life

Had to give up job./ Lost job./ Difficulties in performance of her profession./ Working on the farm.

Some mornings, without any prior indication, I am unable to go to work.

**Nothing bothers me currently about asthma**

The patient has significantly improved with the new biological therapy and is almost symptom-free.

Currently my asthma is very well controlled so nothing bothers me./ Since the introduction of Xolair treatment, asthma does not affect my life.



**Theme 8. Sensitivity to triggers**

Environmental triggers	Sensitivity to stimuli./ Temperature fluctuations, perfumes, odours causing attacks.	Increased sensitivity to external influences./ My breathing and coughing is especially affected by weather, transitions from heat to cold./ Dust, cigarette smoke, petrol fumes, perfume, fragrances, these all make me cough.
Physical exertion as trigger	Difficulty breathing doing exercise.	I become short of breath when I move./ Asthma is worse during physical effort. Short of breath with a small amount of activity./ If I laugh too much, it easily triggers an attack.
Monitoring for and avoiding triggers	Limitations at his workplace, need to avoid pollen.	Places and environments need to be selected./ I can't go to somebody's home where there are animals.
Stress as trigger	Symptoms var[y] with emotions.	Very clearly increased sensitivity when stressed.

**Theme 9. Stigma of asthma**

Attracting attention, others think you are contagious		It can get uncomfortable in social situations./ Everyone immediately thinks that you have the flu./ Cough and COVID, in these strange times, everyone immediately turns away.
Asthma is stigmatising		You inadvertently attract attention in society, it is a sort of social handicap.
People do not understand		Other people think they understand but they don't./ No one understands.
Feeling different		I feel ill and different.
Social exclusion	Being outside of society, not being able to participate.	

**Theme 10. Nothing bothers me about asthma.**

### Supplementary Material E – Comparison of stratified patient groups.

#### **Age:** *Younger (<55 years, N=68) vs Older (≥55 years, N=56)*

There were no significant differences ( $p>0.05$ ) between older and younger patient responses. Similarly, there were no significant differences between the clinician responses for the two patient groups, although there was a trend towards clinicians reporting limitations on daily life (OR=0.40 [0.12-1.13];  $p = 0.08$ ) and burden of medications (OR=0.33 [0.08-1.08];  $p = 0.05$ ) more frequently for younger patients, while reporting indirect physical consequences (OR=2.03 [0.92-4.54];  $p = 0.06$ ) more frequently for older patients.

When patient responses were compared to clinician responses, by sub-group, greater disagreement was seen for the younger patient group. Specifically, clinicians reported direct physical symptoms more frequently than younger patients (OR=2.16 [1.19-3.92];  $p = 0.007$ ), and the effort required to self-manage, less frequently (OR=0.07 [0.00-0.44];  $p < 0.001$ ). For older patients there were no significant differences between clinician and patient responses. Both older and younger patients reported stigma as a bothersome aspect (older: 2.5%; younger 1.8%), but not a single clinician reported this for either patient subgroup (Figure 3A/3B, Table E1 – E4).

#### **Gender** *Female (N=88) vs male (N=36)*

There were no significant differences between male and female patient responses. Clinician responses however differed between groups. Clinicians reported burden of medication more frequently for females than for males (OR=0.15 [0.00-0.98];  $p = 0.048$ ).

When patient responses were compared to clinician responses, by sub-group, clinicians reported direct physical symptoms more frequently than their female patients (OR=1.78 [1.06-2.97];  $p = 0.03$ ), and effort required to self-manage, less frequently than their female patients (OR=0.21 [0.004-0.74];  $p = 0.007$ ). Similarly, clinicians reported effort required to self-manage less frequently than their male patients (OR<0.01 [0.00-0.87];  $p = 0.022$ ) but there were no other differences (Figure 3C/3D, Table E5 – E8).

#### **OCS Use:** *Lower use (every few months or less (N=75) vs higher use (every few weeks or more, N=49)*

There were no significant differences between patient responses in the low vs. high OCS use groups, although there was a trend that patients with high OCS use reported less frequently, that nothing bothered them (OR=0.16 [0.00-1.25];  $p = 0.07$ ). Similarly, there were no differences in clinician responses for patients who used low vs. high OCS, although there was a trend that clinicians reported direct physical symptoms more frequently in the high OCS group (OR=1.89 [0.97-3.71];  $p = 0.06$ ) and indirect physical consequences, less frequently in the high OCS group (OR=0.50 [0.21-1.14];  $p = 0.10$ ).

When patient responses were compared to clinician responses, clinicians reported the effort required to self-manage, less frequently than low-use patients (OR=0.20 [0.02-0.90];  $p = 0.03$ ), with no other significant differences. Clinicians reported direct physical symptoms of asthma more frequently than

their high-use patients (OR=2.31 [1.20-4.48]; p = 0.008), and effort required to self-manage, less frequently (OR=0.11 [(0.00-0.72); p = 0.01) (Figure 3E/3F, Table E9 – E12).

**Table E1: Percentage of total responses allocated to each theme, for patients in the younger vs. older age groups**

Theme	Younger	Older	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	19.9	25.7	1.39 (0.75,2.57)	0.302
Indirect physical consequences of having asthma and asthma treatment	15.5	18.6	1.24 (0.62,2.46)	0.516
Limitations on daily life missing out	15.5	12.4	0.77 (0.35,1.63)	0.489
Sensitivity to triggers	9.3	15.0	1.72 (0.77,3.89)	0.181
Effort required to self-manage asthma	12.4	6.2	0.47 (0.16,1.20)	0.102
Burden of medication and their side effects	10.6	6.2	0.56 (0.19,1.48)	0.278
Fears, worries and distress	9.3	7.1	0.74 (0.26,1.95)	0.659
Nothing bothers me about asthma	1.2	5.3	4.43 (0.77,45.72)	0.068
Interactions with health providers and hospital treatment	3.7	1.8	0.47 (0.05,2.67)	0.477
Stigma	2.5	1.8	0.71 (0.06,5.04)	1.000

**Table E2. Percentage of total responses allocated to each theme, for clinicians responsible for patients in the younger vs. older age groups**

Theme	Younger	Older	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	34.9	29.1	0.77 (0.39,1.50)	0.431
Indirect physical consequences of having asthma and asthma treatment	15.1	26.6	2.03 (0.92,4.54)	0.064
Limitations on daily life missing out	17.0	7.6	0.40 (0.12,1.13)	0.077
Sensitivity to triggers	5.7	11.4	2.13 (0.64,7.64)	0.181
Effort required to self-manage asthma	0.9	2.5	2.71 (0.14,162.24)	0.577
Burden of medication and their side effects	14.2	5.1	0.33 (0.08,1.08)	0.052
Fears, worries and distress	7.5	8.9	1.19 (0.35,3.95)	0.790
Nothing bothers me about asthma	2.8	7.6	2.81 (0.58,17.90)	0.174
Interactions with health providers and hospital treatment	1.9	1.3	0.67 (0.01,13.05)	1.000
Stigma	0.0	0.0	0.00 (0.00,Inf)	1.000

**Table E3: Percentage of total responses allocated to each theme, by response group for patients younger than 55 years** (68 patients; 161 patient responses; 106 clinician responses).

Theme	Patient	Clinician	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	19.9	34.9	2.16 (1.19,3.92)	0.007
Indirect physical consequences of having asthma and asthma treatment	15.5	15.1	0.97 (0.46,2.01)	1.000
Limitations on daily life missing out	15.5	17.0	1.11 (0.54,2.26)	0.865
Sensitivity to triggers	9.3	5.7	0.59 (0.18,1.66)	0.355
Effort required to self-manage asthma	12.4	0.9	0.07 (0.00,0.44)	<0.001
Burden of medication and their side effects	10.6	14.2	1.39 (0.62,3.13)	0.442
Fears, worries and distress	9.3	7.5	0.80 (0.28,2.09)	0.663
Nothing bothers me about asthma	1.2	2.8	2.31 (0.26,28.08)	0.389
Interactions with health providers and hospital treatment	3.7	1.9	0.50 (0.05,2.85)	0.484
Stigma	2.5	0.0	0.00 (0.00,2.29)	0.154

**Table E4: Percentage of total responses allocated to each theme, by response group for patients 55 years or older** (56 patients; 113 patient responses; 79 clinician responses).

Theme	Patient	Clinician	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	25.7	29.1	1.19 (0.59,2.37)	0.623
Indirect physical consequences of having asthma and asthma treatment	18.6	26.6	1.58 (0.75,3.34)	0.216
Limitations on daily life missing out	12.4	7.6	0.58 (0.17,1.71)	0.343
Sensitivity to triggers	15.0	11.4	0.73 (0.27,1.85)	0.526
Effort required to self-manage asthma	6.2	2.5	0.40 (0.04,2.15)	0.312
Burden of medication and their side effects	6.2	5.1	0.81 (0.17,3.31)	1.000
Fears, worries and distress	7.1	8.9	1.27 (0.38,4.22)	0.786
Nothing bothers me about asthma	5.3	7.6	1.46 (0.38,5.71)	0.556
Interactions with health providers and hospital treatment	1.8	1.3	0.71 (0.01,13.91)	1.000
Stigma	1.8	0.0	0.00 (0.00,7.62)	0.513

**Gender Strata****Table E5. Percentage of total responses allocated to each theme, for female patients vs. male patients**

Theme	Female	Male	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	22.5	21.6	0.95 (0.46,1.88)	1.000
Indirect physical consequences of having asthma and asthma treatment	15.5	20.3	1.38 (0.65,2.86)	0.365
Limitations on daily life missing out	15.0	12.2	0.79 (0.31,1.81)	0.697
Sensitivity to triggers	11.0	13.5	1.26 (0.51,2.96)	0.534
Effort required to self-manage asthma	9.5	10.8	1.15 (0.42,2.92)	0.820
Burden of medication and their side effects	10.5	4.1	0.36 (0.07,1.27)	0.146
Fears, worries and distress	9.5	5.4	0.55 (0.13,1.72)	0.335
Nothing bothers me about asthma	2.0	5.4	2.79 (0.50,15.39)	0.218
Interactions with health providers and hospital treatment	2.5	4.1	1.64 (0.25,8.70)	0.449
Stigma	2.0	2.7	1.36 (0.12,9.72)	0.663

**Table E6. Percentage of total responses allocated to each theme, for clinicians responsible for female patients vs. male patients**

Theme	Female	Male	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	34.1	27.7	0.74 (0.33,1.61)	0.474
Indirect physical consequences of having asthma and asthma treatment	18.1	25.5	1.55 (0.64,3.60)	0.294
Limitations on daily life missing out	10.9	19.1	1.93 (0.69,5.17)	0.206
Sensitivity to triggers	7.2	10.6	1.52 (0.39,5.22)	0.537
Effort required to self-manage asthma	2.2	0.0	0.00 (0.00,7.15)	0.572
Burden of medication and their side effects	13.0	2.1	0.15 (0.00,0.98)	0.048
Fears, worries and distress	9.4	4.3	0.43 (0.05,2.01)	0.362
Nothing bothers me about asthma	4.3	6.4	1.50 (0.23,7.36)	0.695
Interactions with health providers and hospital treatment	0.7	4.3	6.02 (0.31,360.89)	0.159
Stigma	0.0	0.0	0.00 (0.00,Inf)	1.000

**Table E7. Percentage of total responses allocated to each theme, by response group for female patients** (88 patients; 200 patient responses; 138 clinician responses)

Theme	Patient	Clinician	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	22.5	34.1	1.78 (1.06,2.97)	0.025
Indirect physical consequences of having asthma and asthma treatment	15.5	18.1	1.21 (0.65,2.23)	0.554
Limitations on daily life missing out	15.0	10.9	0.69 (0.33,1.39)	0.329
Sensitivity to triggers	11.0	7.2	0.63 (0.26,1.45)	0.264
Effort required to self-manage asthma	9.5	2.2	0.21 (0.04,0.74)	0.007
Burden of medication and their side effects	10.5	13.0	1.28 (0.61,2.64)	0.492
Fears, worries and distress	9.5	9.4	0.99 (0.43,2.20)	1.000
Nothing bothers me about asthma	2.0	4.3	2.22 (0.52,10.92)	0.327
Interactions with health providers and hospital treatment	2.5	0.7	0.29 (0.01,2.59)	0.407
Stigma	2.0	0.0	0.00 (0.00,2.19)	0.148

**Table E8. Percentage of total responses allocated to each theme, by response group for male patients** (36 patients; 74 patient responses; 47 clinician responses)

Theme	Patient	Clinician	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	21.6	27.7	1.38 (0.54,3.50)	0.514
Indirect physical consequences of having asthma and asthma treatment	20.3	25.5	1.35 (0.51,3.49)	0.510
Limitations on daily life missing out	12.2	19.1	1.70 (0.55,5.32)	0.307
Sensitivity to triggers	13.5	10.6	0.76 (0.19,2.66)	0.780
Effort required to self-manage asthma	10.8	0.0	0.00 (0.00,0.87)	0.022
Burden of medication and their side effects	4.1	2.1	0.52 (0.01,6.66)	1.000
Fears, worries and distress	5.4	4.3	0.78 (0.07,5.70)	1.000
Nothing bothers me about asthma	5.4	6.4	1.19 (0.17,7.41)	1.000
Interactions with health providers and hospital treatment	4.1	4.3	1.05 (0.08,9.55)	1.000
Stigma	2.7	0.0	0.00 (0.00,8.39)	0.521

*Steroid Strata***Table E9. Percentage of total responses allocated to each theme, for patients in the lower vs. higher steroid use groups**

Theme	Lower use	Higher use	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	21.9	22.7	1.04 (0.57,1.92)	0.885
Indirect physical consequences of having asthma and asthma treatment	17.8	15.6	0.86 (0.43,1.70)	0.746
Limitations on daily life missing out	13.0	15.6	1.24 (0.59,2.59)	0.604
Sensitivity to triggers	11.0	12.5	1.16 (0.52,2.60)	0.710
Effort required to self-manage asthma	8.9	10.9	1.26 (0.52,3.03)	0.685
Burden of medication and their side effects	6.8	10.9	1.67 (0.66,4.37)	0.286
Fears, worries and distress	8.9	7.8	0.87 (0.33,2.23)	0.829
Nothing bothers me about asthma	4.8	0.8	0.16 (0.00,1.25)	0.071
Interactions with health providers and hospital treatment	4.1	1.6	0.37 (0.04,2.13)	0.290
Stigma	2.7	1.6	0.56 (0.05,4.02)	0.688

**Table E10. Percentage of total responses allocated to each theme, for clinicians responsible for patients the lower vs. higher steroid use groups**

Theme	Lower use	Higher use	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	26.4	40.5	1.89 (0.97,3.71)	0.056
Indirect physical consequences of having asthma and asthma treatment	24.5	13.9	0.50 (0.21,1.14)	0.095
Limitations on daily life missing out	12.3	13.9	1.16 (0.44,2.99)	0.826
Sensitivity to triggers	8.5	7.6	0.89 (0.25,2.93)	1.000
Effort required to self-manage asthma	1.9	1.3	0.67 (0.01,13.05)	1.000
Burden of medication and their side effects	10.4	10.1	0.97 (0.32,2.82)	1.000
Fears, worries and distress	7.5	8.9	1.19 (0.35,3.95)	0.790
Nothing bothers me about asthma	6.6	2.5	0.37 (0.04,2.01)	0.305
Interactions with health providers and hospital treatment	1.9	1.3	0.67 (0.01,13.05)	1.000
Stigma	0.0	0.0	0.00 (0.00,Inf)	1.000

**Table E11. Percentage of total responses allocated to each theme, by response group for ‘lower use’ patients receiving OCS every few months or less (75 patients; 146 patient responses; 106 clinician responses)**

Theme	Patient	Clinician	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	21.9	26.4	1.28 (0.68,2.39)	0.455
Indirect physical consequences of having asthma and asthma treatment	17.8	24.5	1.50 (0.77,2.90)	0.210
Limitations on daily life missing out	13.0	12.3	0.93 (0.40,2.11)	1.000
Sensitivity to triggers	11.0	8.5	0.75 (0.28,1.90)	0.670
Effort required to self-manage asthma	8.9	1.9	0.20 (0.02,0.90)	0.028
Burden of medication and their side effects	6.8	10.4	1.57 (0.58,4.31)	0.360
Fears, worries and distress	8.9	7.5	0.84 (0.29,2.27)	0.819
Nothing bothers me about asthma	4.8	6.6	1.40 (0.41,4.85)	0.585
Interactions with health providers and hospital treatment	4.1	1.9	0.45 (0.04,2.58)	0.474
Stigma	2.7	0.0	0.00 (0.00,2.07)	0.141

**Table E12. Percentage of total responses allocated to each theme, by response group for patients receiving OCS every few weeks or more (49 patients; 128 patient responses; 79 clinician responses)**

Theme	Patient	Clinician	Odds Ratio (95% CI)	FET P-value
Direct physical symptoms of asthma	22.7	40.5	2.31 (1.20,4.48)	0.008
Indirect physical consequences of having asthma and asthma treatment	15.6	13.9	0.87 (0.35,2.05)	0.842
Limitations on daily life missing out	15.6	13.9	0.87 (0.35,2.05)	0.842
Sensitivity to triggers	12.5	7.6	0.58 (0.18,1.64)	0.355
Effort required to self-manage asthma	10.9	1.3	0.11 (0.00,0.72)	0.011
Burden of medication and their side effects	10.9	10.1	0.92 (0.32,2.49)	1.000
Fears, worries and distress	7.8	8.9	1.15 (0.35,3.51)	0.799
Nothing bothers me about asthma	0.8	2.5	3.28 (0.17,195.88)	0.559
Interactions with health providers and hospital treatment	1.6	1.3	0.81 (0.01,15.77)	1.000
Stigma	1.6	0.0	0.00 (0.00,8.63)	0.526



Supplementary Material F – Accuracy between clinician and patient responses

Accuracy: Percentage of Patient Themes Captured by Clinician

Group	Numerator	Denominator	Percentage Accuracy
All	82	278	29
Age < 55	42	161	26
Age >=55	39	113	35
OCS low	38	146	26
OCS high	43	128	34
Female	58	200	29
Male	23	74	31

Accuracy: Percentage of Clinician Themes Also Reported by the Patient

Group	Numerator	Denominator	Percentage Accuracy
All	82	188	44
Age < 55	42	106	40
Age >=55	39	79	49
OCS low	38	106	36
OCS high	43	79	54
Female	58	138	42
Male	23	47	49

Frequency of No Themes in Common; Denominator is the Number of Pairs

Group	Numerator	Denominator	Percentage Conflict
All	58	126	46
Age < 55	34	68	50
Age >=55	23	56	41
OCS low	43	75	57
OCS high	14	49	29
Female	42	88	48
Male	15	36	42