

Supplementary Material

A: GRIPP2 Reporting Checklist

B: Survey

C: Ethics

D: Codebook with quotes

E: Comparison of stratified patient groups

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

1: Aim

Report the aim of the study

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.

2: Methods

Provide a clear description of the methods used for PPI in the study

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.

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.

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.

DH worked with NK to review the registry variables and define the degree of coverage of the important aspects by existing registry variables.

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.

3: Results

Outcomes—Report the results of PPI in the study, including both positive and negative outcomes

PPI contributed to the study in several ways, including:

- **Co-developing the study concept.** 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.

- **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)
Theme 1. Burden of medications and their side effects		
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.
Theme 2. Direct physical symptoms of asthma		
Asthma attacks, flare ups, exacerbations Breathing difficulties, shortness of breath	Acute asthma attacks./ Disease exacerbations. Shortness of breath./ Exertional dyspnoea.	Acute asthma attacks./ Flares./ Exacerbations. 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.
Theme 3. Fears, worries, and distress about asthma		
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

Impact on mood	Symptoms vary with emotions.	don't like that./ It makes me feel useless and like a burden. 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

Unpredictability of symptoms, uncertainty

exhausted, so I have to wait and see how I feel on the day.

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
Social life

Exacerbations affect the patient's quality of life.
Limitations on social life.

My quality of life has significantly worsened.

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