

Online Supplementary Data

Content validity of the Severe Asthma Questionnaire from earlier studies

Findings of the initial patient interviews included (see [10] for more details):

- Identification of domains that included deficits caused by symptoms of severe asthma as well as side effects of medication.
- A failure of existing asthma specific quality of life scales to assess all the domains to severe asthma.

Findings of the four focus groups included (see [13] for more details):

- The recall period of two weeks was acceptable, but a two week window fails to reflect the patients' desire to express the variability of severe asthma. Patients welcomed the ability to rate their global quality of life during the worst and best months of the year.
- Patients suggested improvements to the wording of the draft questionnaire, including splitting some items in two (the items relating to family life), combining two items in one (relating to appearance and embarrassment).
- Patients suggested changes to some of the words in individual items and the response scale.
- Patients can help optimise the language of a questionnaire better if they are treated as partners in the process of questionnaire completion rather than only as a source of information.

Criteria for incomplete questionnaires

For the SAQ and MiniAQLQ, questionnaires were considered incomplete if more than one question was missed excluding the question on work. In the case of the SAQ patients are instructed not to answer this question if not in work. In the case of the MiniAQLQ patients often miss this question even though they are instructed to answer it in terms of other activities if not in work. For the ACT a questionnaire was considered incomplete if one or more questions were missed. An EQ-5D-5L was considered incomplete if two or more questions were missed.

If patients are not in work, then the SAQ score is the average of the 15 lifestyle questions that do not refer to work. If patients are in work, then an extra domain is added because patients then have an extra domain of quality of life. Using this procedure, the non-work domains are the same for in and out of work patients. In the case of the MiniAQLQ, if patients are not in work, then they are asked to answer the work question in terms of other activities. Although the average MiniAQLQ score is obtained from the same number of questions for in work and out of work patients, the non-work domains are no longer the same for in and out of work patients because the out of work patients are answering an additional non-work domain. An aim of content validity is to ensure that questions are interpreted in the same way by different patients. The procedure used by the SAQ achieves this aim and removes the inconsistency of some out of work patients completing the work item of the MiniAQLQ and some not doing so, which in the present study was 25 out of 160 participants.

Table E1.

SAQ response option frequencies

Item	1	2	3	4	5	6	7	Missing out of 160
1. My social life. For example: visiting friends, walking with friends, talking with friends, going to bars/restaurants, and parties.	14	26	26	28	21	15	29	1
2. My personal life. For example: washing, dressing, looking after myself, love life.	6	18	21	21	18	15	61	0
3. My leisure activities. For example: walking for pleasure, sports, exercise, travelling, taking vacations.	25	35	31	19	17	14	19	0
4. My jobs around the house. For example: housework, shopping, home maintenance, gardening.	17	26	28	26	19	21	21	2
5. My work or education. For example, missing days, can't do all I want to do.	18	18	14	18	13	13	34	32
6. My family life – how it affects me. For example: caring for children, family responsibilities	10	20	23	20	17	23	40	7
7. My family life – how it affects others. For example: others taking time off work, problems with childcare, family members becoming upset.	10	18	26	19	9	17	54	7
8. Depression. For example, feeling sad, fed up, blue.	16	29	23	20	23	19	25	5
9. Irritable. For example, snap at people, get angrier than I should.	17	27	23	27	16	22	26	2
10. Anxiety in general. For example, worry about things, always on edge.	23	24	27	15	16	26	27	2

11. Worry that asthma may get worse. For example, medicines no longer help, more frequent attacks.	21	41	23	14	21	14	24	2
12. Worry about long term side effects of medicines. For example, worry about cataracts, diabetes, bone fracture.	27	26	17	23	17	20	27	3
13. Getting tired. For example, feeling tired for no reason, waking in the morning feeling tired	38	32	32	15	15	15	11	2
14. Problems at night. For example, difficulty going to sleep, being woken very easily, waking often at night.	31	31	25	20	17	18	16	2
15. The way I look. For example, my weight, my skin bruises easily, using medicines in public, other people judging me	35	28	20	17	16	16	26	2
16. Problems with food. For example, I find I get very hungry, I just can't stop eating, stomach problems (e.g., pain, bloating, etc.)	21	21	13	28	18	25	31	3

Response options: 1 = very, very difficult (worst possible); 2 = very difficult; 3 = difficult; 4 = moderately difficult; 5 = slightly difficult; 6 = very slightly difficult (just noticeable); 7 = no problem

Table E2.

Intra-class correlation, confidence intervals and *n-values* for the 16 items of the SAQ

Item	Intra-class correlation
1. My social life. For example: visiting friends, walking with friends, talking with friends, going to bars/restaurants, and parties.	0.89 <u>0.80-0.94</u> 50
2. My personal life. For example: washing, dressing, looking after myself, love life.	0.86 <u>0.75-0.92</u> 50
3. My leisure activities. For example: walking for pleasure, sports, exercise, travelling, taking vacations.	0.93 <u>0.88-0.96</u> 51
4. My jobs around the house. For example: housework, shopping, home maintenance, gardening.	0.88 <u>0.79-0.93</u> 51
5. My work or education. For example, missing days, can't do all I want to do.	0.87 <u>0.72-0.94</u> 27
6. My family life – how it affects me. For example: caring for children, family responsibilities	0.89 <u>0.81-0.94</u> 46
7. My family life – how it affects others. For example: others taking time off work, problems with childcare, family members becoming upset.	0.87 <u>0.76-0.93</u> 46
8. Depression. For example, feeling sad, fed up, blue.	0.85 <u>0.73-0.91</u> 51
9. Irritable. For example, snap at people, get angrier than I should.	0.85 <u>0.74-0.91</u> 51
10. Anxiety in general. For example, worry about things, always on edge.	0.84 <u>0.71-0.91</u>

	51
11. Worry that asthma may get worse. For example, medicines no longer help, more frequent attacks.	0.84 <u>0.73-0.91</u>
	51
12. Worry about long term side effects of medicines. For example, worry about cataracts, diabetes, bone fracture.	0.66 <u>0.40-0.81</u>
	50
13. Getting tired. For example, feeling tired for no reason, waking in the morning feeling tired.	0.88 <u>0.78-0.93</u>
	51
14. Problems at night. For example, difficulty going to sleep, being woken very easily, waking often at night.	0.84 <u>0.71-0.91</u>
	51
15. The way I look. For example, my weight, my skin bruises easily, using medicines in public, other people judging me	0.86 <u>0.75-0.92</u>
	51
16. Problems with food. For example, I find I get very hungry, I just can't stop eating, stomach problems(e.g., pain, bloating, etc.)	0.77 <u>0.59-0.87</u>
	50

Table E3. Relationship between SAQ and SAQ-global scores

SAQ-global score and descriptors* of quality of life	Number of patients	Mean SAQ score** (SD)
0-9 Extremely bad	4	1.5 (0.6)
10-19 Very bad	6	3.0 (1.9)
20-29 Bad	10	2.0 (0.7)
30-39	12	2.7 (1.0)
40-49 Somewhat bad	26	3.3 (0.7)
50-59	21	3.8 (0.8)
60-69 Moderately good	19	4.3 (1.5)
70-79 Good	31	4.8 (1.1)
80-89 Very good	17	5.5 (1.6)
90-100 Nearly perfect/Perfect	8	6.4 (0.9)

*The position of descriptors is approximate in relation to numbers. The exact position is shown in the SAQ.

** Interpretation of mean: 1 = very, very difficult (worst possible); 2 = very difficult; 3 = difficult; 4 = moderately difficult; 5 = slightly difficult; 6 = very slightly difficult (just noticeable); 7 = no problem