### **Early View**

Original research article

# The effect of the COVID-19 pandemic on severe asthma care in Europe - will care change for good?

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The effect of the COVID-19 pandemic on severe asthma care in Europe - will care change for good?

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Take home message

Changes in severe asthma care caused by the COVID-19 pandemic included the transition to

video/phone consultations and home administration of biologics. Patients were satisfied with the

changes and showed no evidence of poor asthma control.

Keywords

asthma control, biologics, COVID-19, satisfaction with care, severe asthma care, telemedicine

#### Abstract

**Background** The COVID-19 pandemic has put pressure on health-care services forcing the reorganization of traditional care pathways. We investigated how physicians taking care of severe asthma patients in Europe reorganized care, and how these changes affected patient satisfaction, asthma control and future care.

**Methods** In this European-wide cross-sectional study, patient surveys were sent to patients with a physician-diagnosis of severe asthma, and physician surveys to severe asthma specialists between November 2020 and May 2021.

Results 1101 patients and 268 physicians from 16 European countries contributed to the study. Common physician-reported changes in severe asthma care included use of video/phone consultations (46%), reduced availability of physicians (43%) and change to home-administered biologics (38%). Change to phone/video consultations was reported in 45% of patients, of whom 79% were satisfied or very satisfied with this change. Of 709 patients on biologics, 24% experienced changes in biologic care, of whom 92% were changed to home-administered biologics and of these 62% were satisfied or very satisfied with this change. Only 2% reported worsening asthma symptoms associated with changes in biologic care. Many physicians expect continued implementation of video/phone consultations (41%) and home administration of biologics (52%).

**Conclusions** Change to video/phone consultations and home administration of biologics was common in severe asthma care during the COVID-19 pandemic, and was associated with high satisfaction levels in most but not all cases. Many physicians expect these changes to continue in future severe asthma care, though satisfaction levels may change after the pandemic.

#### Introduction

Severe asthma, affecting around 3.7% of adults with asthma in Europe, is a heterogeneous chronic respiratory disease characterized by persistent symptoms, impaired lung function and frequent exacerbations most commonly triggered by viral infections, resulting in disease worsening and increased vulnerability [1, 2]. Treatment depends on complex regimes of high-dose maintenance medications, including biologics [3]. Traditional models of care for patients with severe asthma require frequent attendance to specialist centers and review by a multidisciplinary team to assess asthma control, monitor lung function and inflammation parameters, evaluate response and adherence to medication, check for adverse effects, and dispense or administer medication such as oral corticosteroids (OCS) and biologics [4, 5].

The coronavirus disease 2019 (COVID-19) pandemic has placed major challenges on healthcare services, forcing reorganization of traditional care pathways and reducing the capacity for face-to-face consultations globally [6]. The crisis created considerable challenges to maintain access to and delivery of effective severe asthma care for many vulnerable patients. Several expert-opinion papers have provided recommendations for reorganization of severe asthma care during the pandemic, though, large-scale real-world data on how physicians managed in practice and the resultant impact on severe asthma patients are lacking [7–11].

The 'Severe Heterogeneous Asthma Research collaboration, Patient-centered' (SHARP), is a Clinical Research Collaboration of the European Respiratory Society (ERS) that forms a network of severe asthma experts and patients from different European centers to promote patient-centered severe asthma research on a pan-European scale [12]. The aims of this European-wide survey-based study by SHARP are to investigate the effect of the pandemic on the organization of severe asthma care (1) from the physician-perspective; (2) from the patient-perspective, including the impact of changes in

care and treatments on satisfaction with care and asthma control; and (3) to evaluate which aspects of reorganized care physicians expect to be continued in future care.

#### Methods

#### Design

This was a cross-sectional study in which a patient survey was sent to patients with severe asthma, and a physician survey was sent to severe asthma specialists. The survey was launched on 30 November 2020 and closed on 9 May 2021. Members of the European Lung Foundation's asthma Patient Advisory Group (PAG) and representatives of national respiratory patient organizations were actively involved in the conception and design of the study (details in supplementary file 1) [13].

#### Survey development and setting

The surveys were developed in an iterative manner by the authors, involving physicians (severe asthma experts), psychologists and patients. The patient surveys were translated by professional translators into the native languages of the 16 countries. The translations were reviewed by the SHARP National Leads. Physicians were asked to recruit severe asthma patients from their outpatient clinics for the patient survey, and to complete the physician survey. Both online and paper versions of the patient survey were available, while only an online version was used for the physician survey. SurveyMonkey (SurveyMonkey, Momentive Inc, USA) was used for the online survey. Paper versions of the patient survey were used if online versions were not available, and results from these paper version surveys were transferred into the SurveyMonkey system by the local research team. Data collection was anonymous.

#### Patient and physician selection

Patients were eligible for inclusion if they had physician-diagnosed severe asthma and had been followed up in a severe asthma clinic for at least 6 months from the beginning of the COVID-19 pandemic. Participating physicians included national leads from SHARP member countries and physicians in their Respiratory Societies, who were identified by the national leads to have significant

experience treating severe asthma patients. All participating physicians were instructed not to exclude any severe asthma patient on their consultation hour when recruiting patients for the study.

#### Survey content

The patient survey consisted of multiple-choice questions including demographics, medication use, changes in care and (biologic) treatments, patient satisfaction with any changes in care or treatments, and patient perceptions of any change in asthma control induced by changes in care or treatments. Full patient and physician surveys are included in the supplementary material (supplementary file 2 and 3, respectively). A scale ranging from 1 to 5 was used for answering questions about satisfaction, with a higher score meaning a higher level of satisfaction. 'Satisfaction with care' was then calculated as a mean of the scores of 7 questions (question 16A-G, in which 16C-G were reverse coded), 'satisfaction with changes in care' as a mean of the scores of 2 questions (16H-I), and 'satisfaction with changes to biologic treatments' consisted of the score of a single question (16J). A scale ranging from 1 to 5 was used for answering questions about patients' perceived change in asthma control, with a higher score meaning a worsening in asthma. Change in asthma control due to 'changes in care' was then calculated as a mean of the scores of 3 questions (question 17A-C) and change in asthma control due to 'changes in biologic treatment' consisted of the score of a single question (17D). Questions 17A-D comprised statements indicating that asthma symptoms had got worse, with responses 1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree. The physician survey contained multiple-choice questions about the reorganization of severe asthma care and treatments, the challenges they faced in reorganization of care, and physicians' perspectives on which of these changes may be implemented in future care. The physician survey was conducted in English.

#### **Ethics**

Approval for the study was obtained from the medical ethical board of the Amsterdam University Medical Center (W20\_463 # 20.512) and the ethical boards of every individual country where there was a requirement for ethics approval for survey-based studies. All patients and physicians provided digital or written informed consent for participation in this study.

#### Statistical analysis

Descriptive statistics and t-tests were used for comparisons between groups. P values ≤0.05 were regarded as a statistically significant difference. Statistical analyses were performed using IBM SPSS v.25 software (IBM Corp., Armonk, NY, USA).

#### **Results**

Patient and physician participation

The physician survey was completed by 268 severe asthma specialists from 16 countries in Europe. Of 1119 returned patient surveys, 1101 were complete and included for analysis. Numbers of participating physicians and patients per country; and baseline patient characteristics of included patients are shown in Table 1.

Physician-reported changes in care during the COVID-19 pandemic

Ninety percent (242 of 268) of participating physicians reported at least one change in severe asthma care in their center during the COVID-19 pandemic, and the nature of the changes are shown in Table 2. Changes were either the result of "voluntary" physician-induced changes in reorganizations of severe asthma care, or due to "involuntary" pandemic-induced changes, mainly concerning reduced staff or resource capacity.

Patient-reported changes in care during the COVID-19 pandemic and impact on satisfaction with care and asthma control

Of 1101 included patients, 494 (45%) experienced a change in severe asthma care. Table 3 shows the nature of these changes in care and the associated levels of satisfaction with care as well as changes in care. Patients for whom care had changed were significantly less likely to be satisfied with care compared to patients who experienced no changes in care (p <0.001). In a further analysis of only those patients who were changed to video/phone consultations from face-to face the majority was satisfied, see Figure 1.

Table 3 also shows change in perceived asthma control. For those patients who reported a change, the mean score was 1.9 indicating that, on average, they disagreed with the three statements

indicating poorer control. Reports of different types of change also showed mean levels indicating disagreement with the assertion that asthma symptoms had got worse.

Patient-reported changes in biologic care during the COVID-19 pandemic and impact on satisfaction with care and asthma control

Of 709 patients using asthma biologics at the start of the pandemic, 167 (24%) reported a change in their biologic treatment. The different types of changes in biologic care, and associated satisfaction ratings and impact on asthma control are presented in Table 4. Patients on biologics reporting a change in provision of biologic care were significantly less satisfied with care, than those who reported no change in provision of biologic care (p <0.001). In a further analysis of patients who experienced a change in biologic care during the pandemic, the large majority of patients reported a switch to home-administered biologics. Figure 2 shows that a small percentage of patients were not satisfied with this change. Only 3 of 153 patients (2%) of patients who switched to home-administration of their biologic, agreed or agreed strongly that their symptoms had worsened because of this change.

Table 4 also shows the mean score of responses to a single statement indicating that change in biologic care produced a worsening of asthma control. On a scale ranging from 1 to 5 (in which 1 = strongly disagree and 5 = strongly agree), a mean score of 1.9 shows that on average patients who were on biologics disagreed with this statement. Ninety-two percent of those patients reporting a change in biologic treatment reported that the change was due to home administration, and for these patients the mean was 1.76 indicating a slightly greater trend towards strong disagreement with the statement that asthma symptoms had worsened.

Physicians' expected changes to future severe asthma care

The majority of participating physicians (78%) expect that certain aspects of reorganized care will be continued in the future. Figure 3 presents physicians' beliefs about how severe asthma care will change as a result of the COVID-19 pandemic.

#### Discussion

The results of this European-wide survey showed that both physicians and patients reported changes in severe asthma care during the COVID-19 pandemic. Physicians expected these changes to outlast the pandemic, and the majority of patients were satisfied by the changes that were made, the most common changes being the use of video/telephone consultations and home administration of biologics. There was no evidence that changes led to poorer perceived asthma control.

Although this study is the first that has investigated the effect of the pandemic on severe asthma care, our results can be compared to other disease areas. A global survey from the World Health Organization showed that more than 50% of 163 participating countries reported disrupted outpatient services for non-communicable diseases with limited access, reduced staff capacity, alternate locations or different modes of care [6]. Consistent with the results of our study, replacement of face-to-face consultations into telemedicine deployments were reported in approximately 60% of countries. Several other studies investigated patient satisfaction with video/phone consultations during the COVID-19 pandemic, both in allergy/immunology and other services (e.g. rheumatology, inflammatory bowel disease, oral/maxillofacial surgery, urology), and all confirmed high satisfaction levels in the majority of patients [14–20]. In addition, some other studies, mainly involving allergy/immunology clinics, reported increased prescriptions of home-administered biologics [21–23]. Apparently, even patients requiring complex care, including those with severe asthma, are willing to switch to a different type of care if circumstances demand it.

In our study changes in asthma care resulted from decisions made either by the hospital, the doctor or by the patients themselves, and changes took various forms. Some of the changes were due to

reduced staffing, and low staffing will impact care irrespective of whether there is a pandemic. There was evidence of reduced satisfaction in care in those patients experiencing a change compared to those not experiencing a change, but it does not follow that change caused reduced satisfaction as other unknown factors also contribute to satisfaction levels. We found no evidence that any one type of change was associated with lower satisfaction than any other.

Slightly more than half of physicians in our study reported that the change to home administration of biologics would be more frequent in future care. In our study we found no evidence that home administration was associated with better or worse asthma control for the group as a whole. Although the majority were satisfied with that change, a small minority were not satisfied indicating the need to personalize this aspect of patient care post-pandemic.

Telemedicine in the field of asthma is not new, and several studies including meta-analyses suggested positive effects of telemedicine on asthma control and quality of life in asthma patients, though numerous human-related, technical and reimbursement barriers hampered widespread implementation [24–27]. The emergence of the COVID-19 pandemic seems to have accelerated the transition towards telemedicine modalities, although its precise role in future severe asthma care needs further exploration. In our study, satisfaction levels with video/phone consultations were high. Seventy-nine percent of patients were satisfied or very satisfied with this change, while only 7% of patients were not satisfied. Preferences in the mode of consultations may vary between patients, or may vary over time in individual patients. In addition, previous reports suggested benefits to telemedicine modalities in asthma patients living in rural/remote areas, while other studies suggested decreased benefits in vulnerable patient populations, including those with lower socioeconomic status, with language barriers or poor internet access [28–30]. Better understanding of patient characteristics associated with dissatisfaction or poorer clinical outcome, would allow for accurate patient selection and a personalized approach to telemedicine deployments in severe

asthma patients. It is conceivable that a hybrid form of care delivery will emerge in future severe asthma care, in which virtual and face-to-face consultations are alternated, tailored to individual patient preferences and needs.

Limitations of this study include a possible underestimation of the proportion of patients with changes in care and the inability to calculate survey response rates, since numbers of provided surveys were incomplete. Further, we made no distinction between phone or video consultations, which are quite different modalities regarding logistics and patient-physician interaction, but a recent study in an allergy/immunology service evaluating patient satisfaction with in-person, video or phone consultations during the pandemic did not find a significant difference in satisfaction levels between these encounter modalities [19]. Lastly, we did not make comparisons between countries, because multiple factors could influence the results.

#### Conclusions and implications for clinical practice

Although severe asthma specialists across Europe reported numerous challenges in reorganization of severe asthma care, this reorganization was achieved with high levels of patient satisfaction and just limited effects on asthma control. Video/phone consultations and home-administered biologics were shown to work well for both physicians and most patients. For the small minority of patients who were dissatisfied, either face-to-face consultations are needed or assistance to improve their satisfaction with this mode of communication, consistent with previous research [29–31]. It remains to be seen whether the level of satisfaction with video/phone consultations will remain high after the pandemic. A personalized approach may be the way forward for a sustainable implementation of telemedicine modalities and home administration of injectable biologics in severe asthma care.

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#### **Tables**

Title Table 1. Country breakdown of physician and patient respondents to questionnaires

Country	Physicians	Patients				
	n	n	Female	Use of biologics	Daily OCS	
			n (%)	n (%)	n (%)	
Belgium	13	102	57 (56)	86 (84)	9 (9)	
Estonia	8	14	13 (93)	6 (43)	5 (36)	
France	28	15	10 (67)	13 (87)	5 (33)	
Greece	18	122	82 (67)	74 (60)	35 (29)	
Hungary	40	110	71 (65)	71 (65)	22 (20)	
Italy	31	52	38 (73)	28 (54)	13 (25)	
Latvia	4	54	33 (61)	24 (44)	19 (35)	
Lithuania	15	53	35 (66)	41 (77)	8 (15)	
Netherlands	2	114	69 (61)	79 (69)	27 (24)	
Romania	31	12	5 (42)	9 (75)	3 (25)	
Russian Federation	13	55	34 (62)	11 (20)	9 (16)	
Serbia	15	74	50 (68)	45 (60)	30 (41)	
Slovenia	2	70	51 (73)	64 (91)	12 (17)	
Sweden	9	122	60 (49)	67 (55)	34 (28)	
Switzerland	19	57	25 (44)	46 (81)	19 (33)	
United Kingdom	20	75	43 (57)	45 (60)	31 (41)	
Total	268	1101	676 (61)	709 (64)	281 (26)	

**Footnote Table 1.** Number of returned physician surveys per country, and number and characteristics of participating patients per country. Data are presented as n (%). OCS: oral corticosteroids.

Title Table 2. Physician-reported changes in delivery of care

Change in care	n (%)				
Re-organization in care by physicians (i.e. voluntary)					
Change to video/phone consultations	122 (46)				
Outpatient clinic continued with social distancing	142 (53)				
Urgent consultations only	44 (16)				
New patients postponed	32 (12)				
Switch to home-administered biologics	102 (38)				
Changes induced by the pandemic (i.e. involuntary)					

Reduced capacity outpatient clinic	109 (41)
Reduced capacity lung function lab	159 (59)
Fewer physicians available	115 (43)
Fewer nurses available	76 (28)

**Footnote Table 2.** Changes in severe asthma care during the COVID-19 pandemic as reported by the participating severe asthma specialists (n=268). Data are presented as n (%).

**Title Table 3** Satisfaction scores with types of change in care and asthma control

		Satisfaction with care	Satisfaction with changes in care	Effect on asthma control attributed to changes in care
	n (%)	mean (SD)	mean (SD)	mean (SD)
		All patients (n	=1101)	
No change	607 (55)	4.42 (.61)*	-	-
Change	494 (45)	3.85 (.72)*	3.68 (.93)	1.90 (.84)
	Patients wh	o reported type of	change in care (n=467	·)
Phone/video consultations	212 (45)	3.96 (.67)	3.81 (.87)	1.80 (.78)
Monitored my asthma at home	24 (5)	3.55 (.76)	3.65 (.86)	2.24 (.70)
The location of my appointments was changed	43 (9)	3.90 (.68)	3.78 (.91)	1.86 (.87)
Attended alternative unit (e.g. ED)	10 (2)	3.66 (.92)	3.55 (1.28)	2.50 (1.25)
I chose to cancel appointments	61 (13)	3.60 (.74)	3.30 (1.00)	2.07 (.96)

Cancelled or	117 (25)	3.79 (.74)	3.55 (.97)	1.91 (.85)
postponed by clinic				

**Footnote Table 3.** Patient-reported changes in severe asthma care during the COVID-19 pandemic and associated levels of satisfaction with care and changes in care, and patient-perceived effect on asthma control. Higher satisfaction scores indicate better satisfaction (range 1-5, 1 = very low satisfaction and 5 = very high satisfaction); higher asthma control scores indicate greater agreement with statements that changes in care induced worsening of asthma control (range 1-5, 1 = strongly disagree and 5 = strongly agree). Data are expressed as n and percentages (%), or mean and standard deviation (SD). E.D: Emergency Department. \*t (1068) = 15.82, p < 0.001, d = 0.96.

**Title Table 4.** Satisfaction scores with types of change in biologic care and asthma control

		Satisfaction with care	Satisfaction with changes in care	Effect on asthma control attributed to changes in biologic treatment
	n (%)	mean (SD)	mean (SD)	mean (SD)
	Al	l patients on biolo	gics (n=709)	
No change	542 (76)	4.40 (.59)*	-	-
Change	167 (24)	3.93 (.68)*	3.72 (1.08)	1.90 (.88)
Patients	on biologics w	ho reported type o	of change in biologic c	are (n=167)
Switch to home administration	153 (92)	3.96 (.67)	3.90 (.87)	1.76 (.74)
Treatment less frequent	4 (2)	4.05 (.46)	3.83 (.53)	2.22 (1.57)
Treatment postponed	7 (4)	3.63 (.84)	3.92 (1.02)	2.05 (.83)
Treatment stopped	3 (2)	3.04 (.33)	3.17 (.29)	3.22 (.69)

**Footnote Table 4.** Patient-reported changes in biologic care during the COVID-19 pandemic and associated levels of satisfaction with care and changes in care, and patient-perceived effect on asthma control. Higher satisfaction scores indicate better satisfaction (range 1-5, 1 = very low satisfaction and 5 = very high satisfaction); higher asthma control scores indicate greater agreement with a statement that changes in biologic care induced worsening of asthma control (range 1-5, 1 = strongly disagree and 5 = strongly agree). Data Of 709 patients on biologics, 26 did not complete the questions concerning satisfaction with care. Data are expressed as n and percentages (%), or mean and standard deviation (SD). \* t(674) = 8.47, p < 0.001, d = 0.72.

#### Figures titles and footnotes

**Title Figure 1.** Satisfaction with change to video/phone consultations.

**Footnote Figure 1.** A change to video/phone consultations was reported by 212 patients, of whom 207 indicated their satisfaction level with this change. Data are expressed as percentages (%).

**Title Figure 2.** Satisfaction with change to home-administered biologics.

**Footnote Figure 2.** Satisfaction with change to home-administered biologics in patients reporting this change in their biologic care (n=153). Data are expressed as percentages (%).

**Title Figure 3.** Physicians' expected changes to future severe asthma care.

**Footnote Figure 3.** Physicians' beliefs about how asthma care will change following the pandemic (n=268). Data are shown as %.

## Supplementary material File 1: Guidance for Reporting Involvement of Patients and the Public (GRIPP)-2 form

(BMJ 2017; 358 doi: https://doi.org/10.1136/bmj.j3453; [13])

Section and topic	Item
1: Aim Report the aim of the study	To investigate the effect of the coronavirus pandemic on severe asthma care in Europe from physician and patient perspectives. To evaluate which changes in care are expected to continue in future.
2: Methods Provide a clear description of the methods used for PPI in the study	Members of European Lung Foundation's asthma Patient Advisory Group (PAG) and representatives of national respiratory patient organizations were invited to join the research team. A patient member of the PAG developed the initial concept of the study, which was then led by a scientific member of SHARP. Members of the PAG and patient organisation representatives were involved in refining the scope of the survey, suggesting answer fields and domains, reviewing the language used in the survey for accessibility and understanding, and reviewing patient recruitment, information and consent materials. They piloted the electronic survey in English, before translation.  Two patient representatives were involved in the study team during analysis and write-up. They reviewed survey data, suggested additional interpretations of the results and identified areas for future research. The patient representatives reviewed drafts of 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:  - Suggesting the concept of the study by identifying the need to understand the pandemic's impact on severe asthma care in Europe and working with the study team to refine and further develop the study aims.  - Refining and improving the patient survey by suggesting answer options and additional themes to explore, for example when asking how a patient's treatment with biologic medications changed, patient representatives suggested additional answer options including 'I was afraid to travel to the hospital'. They also suggested additional questions: 'I was reluctant to access asthma care because I did not want to bother my clinician' and 'I was reluctant to access asthma care because of fear I would get exposed to coronavirus'.  - During study analysis and write-up, patient representatives challenged assumptions and highlighted additional important considerations for future research, for example of initial patient satisfaction with virtual appointments may not be sustained as the pandemic restrictions become a 'new normal' and the sense of everyone adapting to an emergency wanes.
<b>4: Discussion</b> Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	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 5 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. Other patient representatives were staff or volunteers of national patient organisations who are familiar with international collaboration and inputting into research from a patient perspective.  Secondly, SHARP is a patient-centred research consortium, with two patient co-

Section and topic

Item

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.

In this way, the consortium was well set-up in terms of patient involvement in order to respond quickly to the emerging pandemic. Following a patient representatives' suggestion to initiate a project to understand the impact of the pandemic on severe asthma care and the approval of the project, patients were then involved from the outset in all meetings and project activities.

Nevertheless, there were challenges. Many of the individual and patient organisation representatives dropped out after the first few meetings, once the project concept had been agreed and the survey design was approaching finalisation. Reasons for this included an explosion of work for patient groups caused by the pandemic, virtual meeting fatigue and prioritising personal mental and physical health needs. One representative also felt frustration that their feedback was not being taken on board or given the same weight as the professional team members, and decided to step down from the project.

The patient involvement lead from European Lung Foundation was not able to attend all project calls and therefore was not able to provide the level of facilitation and oversight as may have been needed to ensure patient views were included.

The patient representatives involved came from the UK, Ireland and Netherlands, supported by patient organisations from France, Ireland, UK and Spain. It may have been beneficial to have input from a more diverse group, with experience of different healthcare systems in order to ensure the survey took account of different national responses to the pandemic, and to address health and socioeconomic inequalities.

#### 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 design, analysis and interpretation.

The key challenge was sustaining involvement throughout, however it was more critical to have a broad number of patient contributors at the survey design phase which we achieved. There was inconsistency in ensuring patient suggestions were considered and incorporated, or a satisfactory explanation was given as to why this could not be done – perhaps due to a lack of patient input oversight from the study team.

#### **Supplementary material File 2: Patient survey**

Dear Sir or Madam,

☐ Female

☐ Prefer not to say

The purpose of this survey is to understand whether and how the coronavirus outbreak (COVID-19) has changed severe asthma care and how it has affected the well-being of patients with severe asthma. This data will help us improve the care of asthma patients in the future. The questionnaire is anonymous, and answers will be kept confidential. The survey contains 17 questions and takes approximately 5 minutes to complete.

When responding to the questions, please report about your situation during the first wave of the

COVID-19 pandemic. In case you have further questions on this survey, please contact [National Lead Contact]. Thank you very much for helping improve severe asthma care, The SHARP team. G G G G G 1. Do you agree to answer the following questions anonymously for scientific research? □No, I don't agree, and will therefore not complete this survey □Yes, I agree 2. Which country do you live in? 3. What is your age? ☐ 18-40 years ☐ 40-65 years  $\square$  >65y years 4. What is your gender? ☐ Male

5.	Do you think you had COVID-19?  □No □Yes but I was not diagnosed by a doctor and was not tested □Yes and I was diagnosed by a doctor, but was not tested □Yes and I had a positive test result □Yes and I was admitted to hospital with a diagnosis of COVID-19 □Yes and I was admitted to hospital intensive care unit with a diagnosis of COVID-19 □I don't know
6.	At the beginning of the coronavirus outbreak in Europe (February 2020) did you use asthma inhalers (relievers + preventers) every day?  □No □Yes
7.	At the beginning of the coronavirus outbreak in Europe (February 2020) did you use prednisolone (or similar) steroids tablets every day?  □No □Yes
8.	Did your appointments at the asthma clinic change during the coronavirus outbreak?  □No □Yes
9.	If you answered yes to the previous question (tick all that apply):  □Not applicable, my appointments stayed the same □ My appointments were cancelled or postponed □ I chose myself to cancel my appointments □The location of my appointments was changed □ My lung function test was cancelled □ I monitored my asthma at home with a peak-flow meter or other device □ My appointments were changed into telephone or video consultations □My asthma problems were resolved in other units (e.g. emergency ward) □ Other (please specify):

10. If you had appoin	ntments by tele	phone or video,	were you sati	sfied?	
very		neither		Very	not
dissatisfied	dissatisfied	satisfied nor dissatisfied	satisfied	satisfied	applicable
11. Did the frequenc corona outbreak?	y of contact wit	h your asthma	doctor or nurse	e change dur	ing the
□No, contact	remained the	same			
□Yes, I comp	oletely lost cont	act			
□Yes, I had I	ess contact				
□Yes, I had ı	nore contact				
12. At the beginning	of the coronav	virus outbreak d	id you use bio	logic medica	tions*
(injections) for your a	asthma and did	the treatment of	change?		
□Not applica	ble, I did not us	se biologic medi	cations		
□Yes, I used	biologic medic	ations			
☐ was suppo	osed to start a b	oiologic treatme	nt, but this wa	s postponed	
* Biologic medication	ns for severe as	sthma includa:			
Xolair (omalizumab		suma morado.			
Nucala (mepolizuma					
Cingaero (reslizuma					
Fasenra (benralizur	,				
Dupixent (dupiluma	b)				
13. If you used biolo outbreak, how did th	~		-	-	
☐My treatme	nt was unchang	ged			
	nt was postpon	-			
□My treatme	nt stopped				
☐ received le	ess frequent tre	eatments			
☐ switched t	o administerinç	my injections r	nyself at home	Э	
☐ Other (plea	ise specify):				

14. If your treatment with biologic medications changed, what was the reason?								
(tick all that apply)								
□Not applicable, my treatment was unchanged □It was decided by the clinic □ had to stay home because of COVID-19 symptoms □ was not able to get transport to the hospital □ was afraid to travel to the hospital □My biologic medications were not available at the pharmacy □The pharmacy was unable to deliver medication to my home □I was not able to collect my biologic medication at the pharmacy □I was afraid to pick up my biologic medication at the pharmacy □Other								
15. Apart from biologic medications (injections), asthma medications?	, did you have trouble getting your other							
□No								
□Yes								
16. To what extent do you agree with the following outbreak  A. My care was good	ing statements during the coronavirus							
strongly disagree disagree neither aç disag	30166 300000 30166							
B. It was easy to get in contact with my asth	hma doctor or nurse at the asthma clinic							
strongly disagree disagree neither aç disag								
C. I received less care for my asthma than I	C. I received less care for my asthma than I needed							
strongly disagree disagree neither agree or agree Strongly agree								
D. It was difficult to access asthma care	D. It was difficult to access asthma care							
strongly disagree disagree neither ag	strongly disagree disagree neither agree or							

E. I was reluctant to coronavirus	access asthr	na care because of	fear I would	I get exposed to
strongly disagree	disagree	neither agree or disagree □	agree	Strongly agree
F. I was reluctant to	access asthr	<u>na care because I c</u>	lid not want	to bother my clinician
strongly disagree	disagree	neither agree or disagree	agree	Strongly agree
G. It was difficult to g	jet my asthm	a medication		
strongly disagree	disagree	neither agree or disagree □	agree	Strongly agree
H. I was satisfied w	ith changes i	n my asthma care		
strongly disagree	disagree	neither agree or disagree □	agree	Strongly agree
I. I was satisfied w	<u>ith changes i</u>	n getting my asthma	a inhalers	
strongly disagree	disagree	neither agree or disagree	agree	Strongly agree
J. I was satisfied w	<u>ith changes i</u>	n my biologic treatm	<u>nent</u>	
strongly disagree	disagree	neither agree or disagree	agree	Strongly agree

17. How did changes during the coronavirus outbreak affect your asthma?								
A. Changes in type of contact with my asthma doctor or nurse made my asthma worse								
strongly disagree	disagree	neither agree or disagree	agree 	strongly agree	not applicable			
	Ш	Ц	Ш	Ц	Ц			
B. <u>Changes</u>	in frequency of	of appointment with	n my doctor o	r nurse my ast	hma worse			
strongly disagree □	disagree	neither agree or disagree □	agree	strongly agree	not applicable □			
C. <u>Changes</u>	in access to n	ny asthma inhalers	s made my as	thma worse				
strongly disagree	disagree	neither agree or disagree	agree	strongly agree	not applicable □			
D. <u>Changes</u>	in my biologic	treatment made r	ny asthma wo	<u>orse</u>				
strongly disagree	disagree	neither agree or disagree	agree	strongly agree	not applicable			
<u> </u>		To To	1-33 <sup>-2</sup>					
		nymously and treate						
		nce with the privacy						
collected and	collected and in compliance with data protection rules.							
By submitting	By submitting my answers, I agree that my data will be used anonymously for research purposes.							
Thank you for	Thank you for your time and engagement.							
Thank you for	Thank you for taking the time to complete this survey.							

#### **Supplementary material File 3: Physician survey**

Dear colleague,

The purpose of this SHARP survey is to better understand how the coronavirus outbreak has changed severe asthma care and how it has affected the well-being of patients with severe asthma. This data will help improve the care of severe asthma patients in the event of a 2nd wave. All answers are collected anonymously and treated in strict confidence. Results from the survey will be kept in accordance with the privacy laws of the country in which the data will be collected and in compliance with GDPR data protection rules. The survey contains 15 questions and takes approximately 5-10 minutes to complete.

Thank you very much for your time and help!

The SHARP team.

	you agree to answer the following questions anonymously for scientific search?
	□No, I don't agree, and will therefore not complete this survey
	□Yes, I agree
1.	In which country is your hospital/clinic located?
2	Was severe asthma care reorganised in your clinic during the COVID-19
۷.	, ,
	outbreak
	□No
	□Yes, the organisation of consultations changed
	(tick all that apply)
	□Consultations continued but with social distancing measures
	□Consultations continued but at a reduced capacity
	□Consultations continued at another location
	□Only urgent consultations were held
	□Consultations for new patients were postponed
	□Consultations switched to telephone, video or e-mail
Other:	:

☐Yes, the organisation of other disciplines/departments changed
(tick all that apply)
□Respiratory nurses assisted more than before in severe asthma
care
□Pulmonary function tests were cancelled
□Pulmonary function tests were performed at reduced capacity
□Other: :
☐Yes, the delivery / administration of biologic medications changed
(tick all that apply)
□Not applicable (biologics are not available in our clinic)
□Administration of biologics was cancelled or postponed
□Clinical administration of biologics was switched to self-
administration at home
□In-hospital administration of IV biologics was switched to
subcutaneous administration
□Initiation of biologics was postponed
□Other: :
☐Yes, new IT technologies were introduced to improve communication
between hospitals, clinic, GP practices or other care givers. If yes,
please provide some
explanation:
3. Did the frequency of contact with your severe asthma patients change
during the COVID-19 outbreak?
□Yes, I had less contact

	□Yes, I had more contact
	□Other: :
4.	Were doctors or nurses from your department assigned to special COVID-
	19 units, and did this affect severe asthma care?
	□No
	□Yes, fewer physicians were available for severe asthma care
	□Yes, fewer nurses were available for severe asthma care
	□Yes, fewer nurses were available for administration of biologics
	□Other: :
5.	Did you receive guidance/instructions on whether and how to change
	severe asthma care in your department?
	· · · · · · · · · · · · · · · · · · ·
	□No, we could decide ourselves
	□Yes, we received instructions from our hospital / centre
	□Yes, we received guidelines from our government
	Other: :
6.	Did you observe that asthma control in your severe asthma patients
	worsened due to changes in severe asthma care?
	□No
	□Yes, certainly in many patients
	□Yes, certainly in some patients
	□Yes, possibly in some patients
	□Other:

7.	Did you observe that asthma control in your severe asthma patients
	improved due to changes in self-isolation?
	□No
	☐Yes, certainly in many patients
	☐Yes, certainly in some patients
	□Yes, possibly in some patients
□Othe	er:
8.	Do you expect some changes in organization of asthma care will
	continue after the corona crisis? (tick all that apply)
	□No
	□Yes, consultations will more often take place on-line
	□Yes, biologics will more often be self-administered at home
	□Other: :
9.	Do you have any specific advice for your colleagues on how best to
	organize asthma care during a possible 2nd wave? If yes, please provide
	your advice in the open field.
	□No, not really
	□Yes, open field for text: