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

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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.
4: Discussion 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-

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	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 socio-economic 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.