Supplementary File

Supplementary Table 1: Guiding questions for discussion

Part A

The following questions were used to guide patients to think about their progression through different stages of illness and care:

1. **Pre-diagnosis** – Before being told you have asthma/COPD
    - Prior awareness or knowledge of the disease
    - Experiences at any time in your life (e.g., living or working conditions) or risk factors that could have contributed to development of your asthma/COPD
    - Encounters with the health system that may have been missed opportunities for diagnosis or prevention
2. **Diagnosis** – When you were told you have asthma/COPD
    - How you entered the health care system for exploration or treatment related to asthma/COPD
    - How and when you were told by a HCP that you had asthma/COPD
    - Follow-up after your diagnosis
3. **Maintenance** – Preventing flare-ups, worsening symptoms, or disease progression
    - Experiences with the health system related to obtaining care
    - Resources or supports to manage symptoms and prevent flare-ups (e.g. care plan)
    - Experiences with the health system related to maintain stable asthma/COPD
4. **Exacerbation** – Attacks or flare-ups that required additional medication or medical attention to stabilise
    - Strategies to deal with exacerbations
    - Experiences seeking or receiving care during exacerbations
    - Resources or supports to recover from exacerbations and prevent future ones
5. **Severe illness** – Worsening symptoms over time or disease progression
    - Determining whether your condition is stable or progressing
    - Health system experiences related to severe persistent asthma or severe/end-stage COPD
    - What you would like when or if your asthma/COPD condition gets worse or progresses
6. **COVID-19 pandemic** – Impacts of the pandemic on experiences with health care and illness
    - Any experience interacting with (or avoiding) the health system relating to your asthma/COPD at anytime during the COVID-19 pandemic
    - Resources or supports needed to manage illness and prevent exacerbations during the pandemic

Part B. The following questions were used to guide the discussion of patients' experiences through each stage of care:

- **Process**
    - What were your **experiences** (good/bad/neutral) with care during this stage? What happened, when, where, who was involved during this stage?
    - **How do you decide** how good the care was for asthma or COPD (i.e., what criteria or factors would you consider in determining whether you received quality care)?
- **Feelings**
    - What were you **feeling** during this time?
    - What were your **key thoughts** during this stage?
- **Praise points**
    - What **worked well** for you at this stage?
- **Pain points**
    - What **didn't work** for you at this stage?

- **Opportunities**
  - Where do you see **opportunities to improve the care** experience for you and others like you?
  - **What do you wish you had known** that may have made things better or helped you to avoid this journey (i.e., not gotten COPD or asthma)?

GRIPP2 short form checklist for Opportunities to Improve Health Services for the Prevention and Care of Airways Disease- Insights from the patient journey

Section and topic	**Item**	**Reported on page No.**
1: Aim	Report the aim of PPI in the study	Pg. 3
2: Methods	Provide a clear description of the methods used for PPI in the study	Pgs. 3-5
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	Not reported
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	Pg. 11-12
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	12

Staniszewska, S., Brett, J., Simera, I. *et al.* GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Res Involv Engagem* **3**, 13 (2017). https://doi.org/10.1186/s40900-017-0062-2

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Reported on Page:
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	1-2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	2-3
Purpose or research question - Purpose of the study and specific objectives or questions	3

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	3
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Not reported
Context - Setting/site and salient contextual factors; rationale**	4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	6

Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4-5
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	4-5
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	5
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	5
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	5

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 6-10, Table 2, Figures 1A & 1B
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-10

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	11-12
Limitations - Trustworthiness and limitations of findings	12

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	6
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	6

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research. **The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388