

## **Supplementary Materials**

### **Results**

#### **Participant Responses – Symptoms**

Across the individual interviews, a range of symptoms was reported (see Figure S1; illustrative participant quotes are also provided in Table 2 in the main manuscript). Shortness of breath was most commonly reported as a main symptom (n = 29 [n = 28 spontaneously reported]), followed by cough (n = 27 [n = 12 spontaneously reported]), and mucus (n = 22 [n = 11 spontaneously reported]) (Figure S1). Shortness of breath was the most concerning and most frequent symptom reported in all three countries (concerning: n = 16 [UK, n = 5; USA, n = 8; Germany, n = 3]; frequent: n = 14 [UK, n = 4; USA, n = 5; Germany, n = 5; data not shown]).

When describing exacerbations and reported symptoms, the terminology for “frequency” and “duration” varied across the individual interviews and focus groups. Five out of the 10 participants who spontaneously reported an “exacerbation” referred to a worsening of their symptoms, which required hospitalization, antibiotics, and/or steroids, that lasted more than 1 day and occurred between once every few weeks to once or twice per year. The remaining 5 participants referred to episodes of shorter duration (up to half an hour or until a rescue medication was used), which occurred between 3 times per month to once or twice per year.

#### **Participant Responses – Health-Related Quality of Life (HRQoL)**

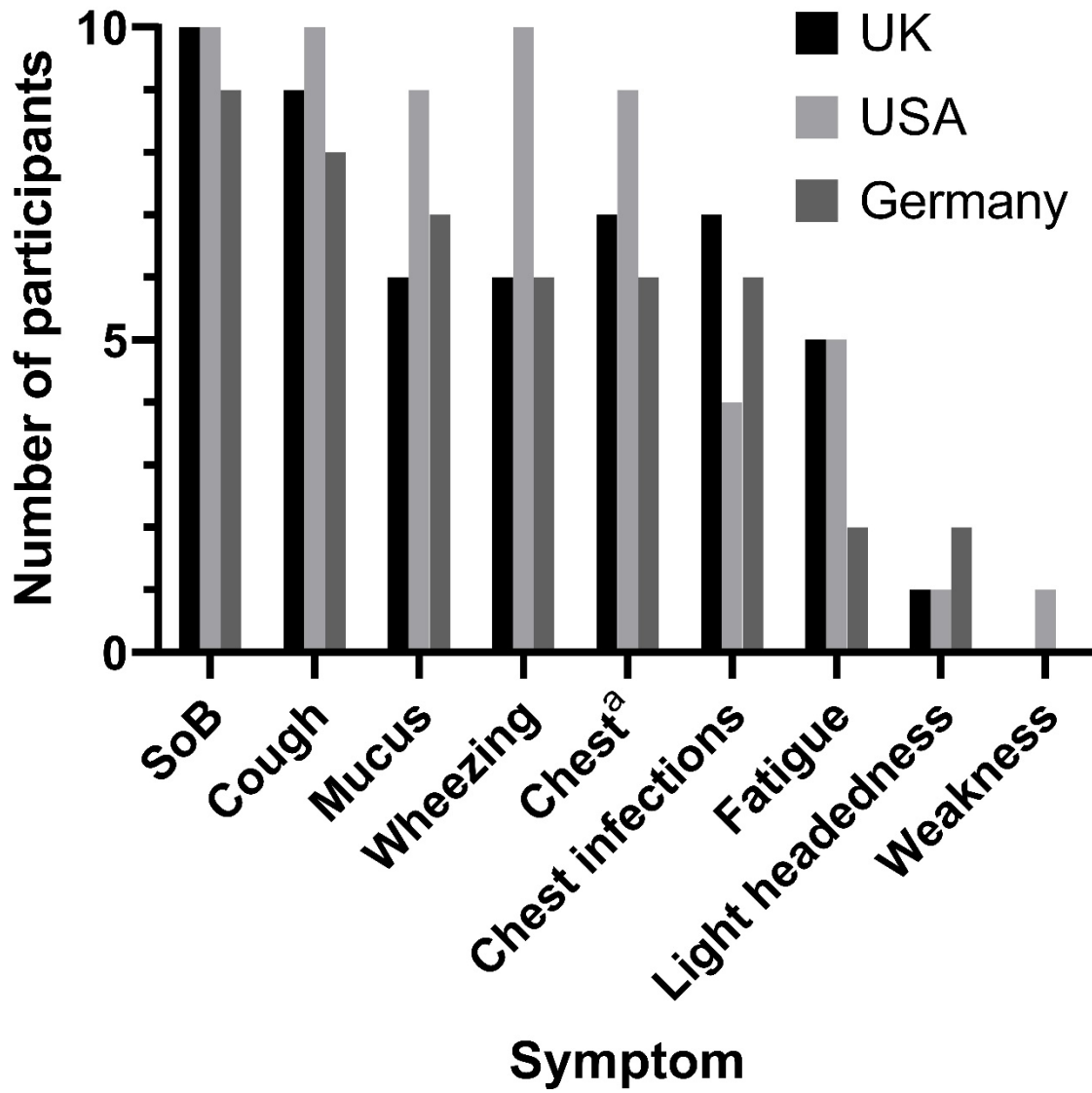
A range of different impacts of chronic obstructive pulmonary disease (COPD) on everyday life were described by participants in the individual interviews. Most common was the impact on the ability to carry out physical activities, followed by social life and sleep (Table 2 in the main manuscript and Figure S2). Physical activities impacted by COPD included walking (n

= 14), climbing stairs/steps (n = 12), running (n = 10), walking uphill (n = 7), playing football (n = 3), playing golf (n = 2), and a range of other sports/activities (n = 1 each). Participants reported that coughing (n = 10), breathing difficulties (n = 8), wheezing (n = 5), and chest tightness (n = 1) were the symptoms that impacted their sleep. COPD was reported to impair sleep in two main ways: waking up (n = 17 [UK, n = 6; USA, n = 8; Germany, n = 3]) and difficulty getting to sleep (n = 3 [n = 1 in each country]). In addition to coughing, wheezing, and difficulty breathing, one participant from the UK stated that the “fear of losing your breath” also kept them awake.

### **Participant Responses – Other Outcomes**

Notable results from the UK focus group were that participants would like a dose counter on inhalers and increased monitoring between visits to the doctor. While they stated that pharmacies were useful to discuss their condition, they believed that pharmacists lacked “COPD training”. In the USA, participants highlighted the benefit of a “pulmonary physical therapy program/pulmonary respiratory program”, the desire for an inhaler where the user does not have to rinse their mouth after use, and a desire for alternatives to an inhaler (e.g., a pill or an injection). Comparatively, participants in Germany discussed the benefit of “lung sport” (a special sport for pulmonary diseased people), a similar desire for an alternative to an inhaler (e.g., a pill) and the categorization of medications by insurance companies into a “completely unsuitable category of agents”, which impacted on whether medications were available to patients living with COPD.

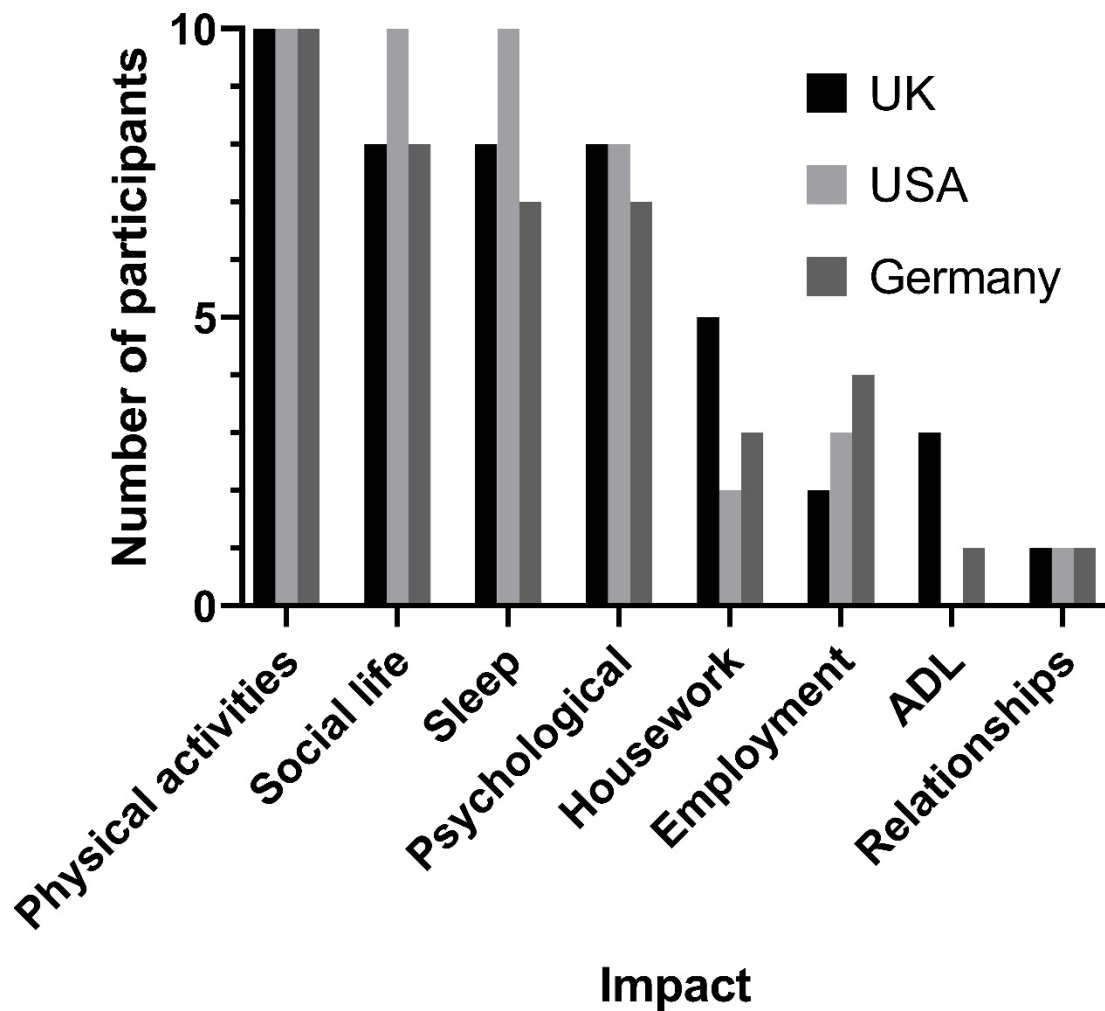
Figure S1. Most Frequently Reported Main Symptoms in Individual Interviews (N = 30; n = 10 per country)



<sup>a</sup>chest tightness, pain, or pressure

SoB=shortness of breath; UK=United Kingdom; USA=United States of America

Figure S2. Impacts of COPD on Daily Life Reported in Individual Interviews (N = 30; n = 10 per country)



ADL=activities of daily living; COPD=chronic obstructive pulmonary disease; UK=United Kingdom; USA=United States of America

**Table S1. Qualitative Individual Interview Guide**

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**Symptoms**

1. When were you formally diagnosed with COPD?
2. How is your condition at the moment?
3. What are the main symptoms that you experience with COPD? [*Probe into any of the symptoms below which have not already been mentioned by participant.*]
  - Shortness of breath
  - Coughing
  - Coughing up mucus (can change color/thickness during exacerbation)
  - Wheezing
  - Chest tightness, pain, or pressure
  - Trouble sleeping
  - Frequent chest infections
4. Which symptom concerns you the most?
  - a) Why?
5. Which symptoms do you experience the most frequently?
6. Which symptoms are the least frequent?

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**HRQoL**

7. How does COPD affect your everyday life? [*Probe into any impacts below which have not already been mentioned by participant.*]
    - Physical activities – ability to exercise, climbing stairs, walkable distance
    - Social life – ability to visit family and socialize with friends, join social clubs
    - Hobbies – ability to do all desired activities
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- Sleep – effect of COPD on sleep, ability to sleep through the night
  - Psychological – depression, fear of exacerbations

8. What are the reasons why you cannot do *[insert activity]*? *[Probe: physical restrictions of COPD or psychological (e.g., fear of exacerbation, worried or embarrassed about taking medication).]*
9. How have these impacts changed over time since you were diagnosed?
- a) When did you first notice *[insert activity]* was becoming more difficult to do?
  - b) How did the change start?
  - c) How does this make you feel?

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### **Current Treatment**

We are now going to talk about the treatments that you currently take for your COPD.

These can either be long-term treatments which are taken primarily to prevent a recurrence of your symptoms, or short-term rescue/relief treatments which you take when your symptoms may have become particularly bad, this is often referred to as a flare-up or an exacerbation of symptoms. First, I would like to find out about your long-term/preventer medication.

10. How do you feel about using your current long-term/preventer medication?
- a) How do you feel about the way it controls your COPD symptoms?
  - b) What do you like about your current medication?
  - c) What do you dislike about your current medication?
  - d) Have you ever been on a different type of treatment than your current one?  
*[Probe for oral tablet, inhaler, other.]*
    - i. How does it compare? *[Probe: dosage frequency, symptom-free period, side*
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*effects, taste, ease of use.]*

11. Do you feel that your current medication works well to manage your COPD symptoms?
- a) Do you ever worry about your medication not working?
    - i. Why?
12. How often has your doctor told you that you should take the treatment? *[If the participant takes more than one treatment, ask for all.]*
13. At times, some people miss taking their medication as often as their doctors has told them to take it, for a range of different reasons. Have you ever missed taking your preventer medication?
- a) *[If Yes:]* How often do you miss taking your medication? What are the reasons you have missed taking your medication?
  - b) Does taking your medication affect your daily routine? *[Probe for: differences between weekdays and weekends, during holidays.]*
  - c) Are there any times that you are more or less likely to miss a dose?
14. Are there any features of your medication that affect how you take your medication? *[Probe for taste, side effects.]*
15. How often do you or your doctor discuss your treatment and how it is going for you?
- a) How do you feel about how often you have these discussions?
  - b) Considering your current situation, how willing to switch to a new therapy would you be?
    - i. What would influence your willingness to switch?
16. Next I want to discuss your reliever/rescue medication. Do you ever need to use a
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reliever/rescue medication?

- a) How often do you need it? [*Probe: frequency, e.g., daily, weekly, monthly, every 3 months.*]
- b) Can you describe the kinds of situations when you typically need rescue medication?
- c) How well does the reliever/rescue medication work to manage your symptoms?
- d) How quickly does your treatment take effect, i.e., you have relief of symptoms?

17. Overall, do you have any other concerns about your medication(s)? [*Probe for potential side effects, becoming tolerant, how often they need to take the medication, picking up infections.*]

*[If not already done so, ask participant if they would like to take a break. Pause recorders if necessary – inform participant if/when recorders have been stopped and restarted.]*

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### **Treatment Preferences**

Now I would like to ask you about how important different aspects of COPD treatment are to you if you had a range of treatments to choose between.

18. How important is it that your inhaler is easy to use?

- a) Is your current inhaler(s) easy to use?
- b) How long does it take to use each time you take your treatment?
  - i. How do you feel about this?

19. How important is treatment effectiveness to you?

- a) What does ‘effective treatment’ mean to you?
  - b) How long do you have relief from your symptoms (i.e., no shortness of breath or difficulty in breathing) when you use your current treatment? [*Probe: hours, days.*]
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c) Do you always have relief from your symptoms for the same periods of time?

i. If not, please describe.

d) Are there times during the day/week that your COPD symptoms seem better controlled? [*Probe: mornings versus evenings, weekdays versus weekends.*]

20. How important is how often that you are supposed to take your maintenance/preventer medication?

a) Would you prefer to take medication more or less often? Why?

b) Are there specific times of the day when you prefer to take your medication?

c) How do you feel about taking your medication in public or in front of friends/family?

21. How important is the number of inhalers that you have to use?

a) How many inhalers do you currently need to use as part of your COPD treatment?

b) What would be your ideal number of inhalers?

22. How important is the speed with which you can feel the medication working?

a) How quickly can you feel your treatment take effect, i.e., you have relief of symptoms? [*Probe: specific length of time, e.g., 15 min, 30 min, 1 hour.*]

b) How is this different for rescue and maintenance medication?

23. How important is it that COPD does not disturb or wake you during the night?

a) Is your sleep impacted by your COPD? If so, how?

b) Do you ever wake up in the night needing your medication? If yes, please describe.

i. Does your medication give you relief?

24. How important are side effects to you?

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a) Do you experience any side effects due to treatment? [*Probe: dry mouth, hoarseness, sore throat/tongue, thrush, nausea, headache, skin effects, pneumonia, tremor, other.*]

i. If yes, please describe [*Probe: frequency, severity.*]

b) How do these side effects impact your daily life? [*Ask for each side effect.*]

c) Are you anxious of side effects potentially occurring?

25. How important is avoiding exacerbations of your COPD to you?

a) Do you ever experience flares/severe attacks/exacerbations due to COPD? An exacerbation is when your symptoms may have become particularly bad, this often referred to as a flare or an exacerbation of symptoms.

b) Which symptoms do you experience?

c) How long do you experience them for?

d) How often do you experience an exacerbation?

e) What is the outcome of a typical attack? [*Probe: calling for a doctor, need to go to hospital, other.*]

f) Has an exacerbation or hospitalization ever led to a change in treatment?

g) How does an exacerbation impact you? [*Probe: emotional impact, activities they are unable to do.*]

h) Are you anxious of exacerbations potentially occurring?

26. How important is cost of medication/prescription to you?

a) How do you currently pay for your medication? [*Probe on insurance, co-payments.*]

b) Does this impact on how often you take your medication?

c) [*If participant does not pay:*] Would you be willing to pay for your medication?

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If so, for what reasons? [*Probe for ease of use, symptom control, frequency, speed of relief, sleep, side effects etc.*]

d) [*If participant does pay:*] Would you be willing to pay more for your medication? If so, for what reasons? [*Probe for ease of use, symptom control, frequency, speed of relief, sleep, side effects etc.*]

27. So far we have discussed how easy it is to use your inhaler, treatment effectiveness, how often you take your medication, speed of feeling relief, sleep disturbance, side effects, exacerbations of your COPD, and cost. Out of those, which three aspects do you consider to be the most important in terms of your COPD treatment?

28. In addition to those we have discussed [*list aspects again if necessary*], do you think there are any aspects that may be important and we haven't discussed today? [*Probe: why are they important?*]

29. That's all of my questions. Is there something else you would like to talk about in relation to your COPD treatment and lifestyle or do you have any other questions or concluding remarks?

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[*Text*] are cues for the interviewer

COPD=chronic obstructive pulmonary disease; HRQoL=health-related quality of life

**Table S2. Focus Group Discussion Guide**

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**Instructions**

1. First, I would like to start by going around the group; please could you tell me your first name and complete this sentence “My COPD is…” using one or a few words. *[Proceed with introductions.]*

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**Symptoms**

2. Can you describe the main symptoms that you experience with COPD?

Symptoms to probe for:

- Shortness of breath
- Coughing
- Coughing up mucus (can change colour/thickness during exacerbation)
- Wheezing
- Chest tightness, pain or pressure
- Trouble sleeping
- Frequent chest infections

3. Which of these symptoms are the most severe to you or affects your life the most?

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**HRQoL**

4. How does COPD or the treatments you have to take for it affect your everyday life?

*[Probe into any impacts below which have not already been mentioned. Also, probe for reasons they can/cannot do things; due to physical restrictions of COPD or psychological (e.g., worried or embarrassed about having taking medication, their moods/emotions).]*

- Physical activities – ability to exercise, climbing stairs, walkable distance
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- Social life – ability to visit family and socialize with friends, join social clubs
  - Hobbies – ability to do all desired activities
  - Sleep – effect of COPD on sleep, ability to sleep through the night
  - Psychological – depression, fear of exacerbations

5. What is the worst aspect of having COPD? *[Can include anything including the symptoms, HRQoL impacts, tasks or activities they find difficult or are unable to do or aspects of treatment they do not like about their treatment.]*

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### **Current Treatment**

We are now going to talk about the treatments that you currently take for your COPD.

These can either be long-term treatments which are taken primarily to prevent a recurrence of your symptoms, or short-term rescue/relief treatments which you take when your symptoms may have become particularly bad; this is often referred to as a flare or an exacerbation of symptoms.

6. How do you feel about using your current treatment? When answering please let us know which kind of treatment you use (for example oral versus inhaler, more than one treatment).
- a) What are the main factors that you like about your current treatment?
  - b) What are the main factors that you dislike about your current treatment?
  - c) What would be the main thing(s) you would like to change about your current treatment?
  - d) How often do you have to use additional medication to control your symptoms during a flare up/exacerbation?
    - i. How does this affect you?
  - e) Considering your current situation, how willing to switch to a new therapy
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would you be?

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### **Treatment Preferences**

Now, thinking about your current medication, I would like to discuss how important different aspects of COPD treatment are to you. *[Use the following list to allow discussion and probe for why they are important/not important.]*

- Inhaler ease of use
- Treatment effectiveness *[Probe: what does treatment effectiveness mean to you?]*
- Frequency that you are supposed to take your medication
- The number of inhalers you have to use as part of your COPD treatment
- How quickly you can feel your medication working
- Being disturbed or woken up during the night due to your COPD
- Treatment side effects
- Avoiding exacerbations
- Cost of medication/prescription

7. Do you think there are any aspects that may be important about COPD and the treatment of COPD that we haven't discussed here today?
8. To close the focus group, we will go around the group again. I would like you to imagine an ideal treatment which would have all the best aspects in it for you and tell the group one or two of those best aspects. This can be anything that we have discussed, or any other aspects that come to mind.

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*[Text]* are cues for the interviewer

COPD=chronic obstructive pulmonary disease; HRQoL=health-related quality of life