

COPD Exacerbations: a Priority-Setting Partnership (PSP) Survey

Why we need your help?

Chronic obstructive pulmonary disease (COPD) is a very common lung condition. You may know it as emphysema or chronic bronchitis. COPD is NOT the same as asthma or bronchiectasis. In addition to daily symptoms such as breathlessness and cough, people living with COPD are prone to developing periods when their symptoms get worse. There are many terms for these including ‘chest infections’, ‘flare-ups’, ‘lung attacks’ or ‘exacerbations’. In this survey we will call them ‘exacerbations’. We are conducting a survey to identify the most important unanswered questions that relate to exacerbations of COPD from the point of view of patients, carers and clinicians. These questions will then be ordered in priority which will help clinicians and researchers address new research into COPD exacerbations and make a real difference to people living with COPD.

Who can get involved in this survey? Please complete this survey if you are:

- a person with COPD
- a family member of someone with or who had COPD
- a carer of someone with or who had COPD
- a healthcare professional or support worker working with people with COPD

What do we mean by unanswered questions?

An unanswered question is a question which has not been previously examined in medical research, or one where existing research has not given a clear enough answer.

Do I have to write a research question and check that it is unanswered?

No. The most important thing is to draw on your personal experience of COPD exacerbations. It is enough to write a short sentence about something that is important to you, and for which you haven’t been able to find an answer. The team collecting your responses will turn these into questions and check against existing research to find out whether they have indeed been answered or not.

What will happen to my questions?

- We will collect your survey responses and use them to make a list of priority research ideas
- These questions will then go through a process of prioritisation that patients, their relatives and healthcare professionals will be a part of
- The questions for which answers are not already available will be published on the JLA and BLF websites anonymously
- This will result in a ‘Top 10’ list of research topics, which we will use to influence the people and organisations who fund future research decisions.

Who is leading this research?

This survey is part of a research study being led by Professor John Hurst, Professor of Respiratory Medicine at University College London. The study co-ordinator is Mr Jaber Alqahtani. This research is funded by the British Lung Foundation, and being run in partnership with the James Lind Alliance, part of the NHS research arm called the NIHR. If you have any questions or concerns, please do not hesitate to contact us.

Email: jaber.alqahtani.18@ucl.ac.uk

Follow us on Twitter: @COPdPsp

When you have completed the questionnaire, please give it back to the person who gave it to you. They will then transfer your answers on to our on line form. This form cannot be sent back to the PSP team.

Section 1: Background Questions (please put a tick in one box for each question):

1. Please select the gender you identify with*

- Male
- Female
- Prefer not to answer
- Other

2. How old are you (in years)?

- 18-29
- 30-49
- 50-69
- 70-79
- ≥80
- Prefer not to say

3. Please select your ethnicity (UK Office for National Statistics categories and order) :

- White —English/ Welsh/ Scottish/ Northern Irish/ British
- White—Irish
- White—Gypsy or Irish Traveller
- Any other White background
- Mixed ethnic groups—White and Black Caribbean
- Mixed ethnic groups—White and Black African
- Mixed ethnic groups—White and Asian
- Any other Mixed/Multiple ethnic background
- Asian/Asian British—Indian
- Asian/Asian British—Pakistani
- Asian/Asian British— Bangladeshi
- Asian/Asian British— Chinese
- Asian/Asian British— Any other Asian background
- Black—African
- Black— Caribbean
- Black—British
- Any other Black/ African/ Caribbean background
- Arab
- Any other ethnic group
- Prefer not to say

4. Which of the following best describes you?

- Person with COPD
- Carer/Partner/Relative of someone with COPD
- Carer/Partner/Relative of someone who died with COPD
- Member of the Public
- Nurse
- Respiratory physiologist
- Counsellor
- Physiotherapist
- Doctor
- Community Worker
- Pharmacist
- Dietitian
- Occupational Therapist
- Psychologist
- Social Worker
- Other, please specify:_____

5. If you are a Health-care Professional, in which setting do you mostly work?

- Primary Care
- Community Care
- Secondary Care

6. We would like to check we have received responses from across the UK. Please tell us in which region you live. We are only looking for responses from people in the UK!

- East Midlands
- East of England
- London
- North East
- North West
- Northern Ireland
- Scotland
- South East
- South West
- Wales
- West Midlands
- Yorkshire and The Humber

Section 2: Questions or areas important to you.

1. What questions, if any, do you have about the PREVENTION of COPD exacerbations ('flare-ups')? Please list your questions here.

FOR EXAMPLE: in a similar survey asking about cystic fibrosis, people wanted to know how best to prevent the stomach problems that they can affect them.

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2. What questions, if any, do you have about the DIAGNOSIS of COPD exacerbations ('flare-ups')? Please list your questions here.

FOR EXAMPLE: in a similar survey asking about autism, people wanted to know which medical test should be used to diagnose autism and at what age.

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3. What questions, if any, do you have about the TREATMENT of COPD exacerbations ('flare-ups')? This includes all aspects of treatment including medicines (usual or 'rescue packs'), physiotherapy, Pulmonary Rehab/exercise—anything! Please list your questions here.

FOR EXAMPLE: in a similar survey asking about diabetes, people wanted to know which type of insulin was safest and had the fewest side-effects?

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4. Do you have any other questions relating to COPD exacerbations? Please list your questions here.

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How will the COPD Priority Setting Partnership (PSP) use my information?

There is no need for you to tell us any contact details unless you would like to take part in the next phase of the process or you want to know about the survey results. Your responses will be kept separate from any personal details that you provide, so that we will not know who you are in any of the survey results. We will keep the information that you give us safe. All data collected in this survey will be held anonymously and securely. No personal data will be requested as part of the survey responses. The data in this survey will be owned by University College London and will not be passed to a third party but the information will be discussed at the Steering Committee. We will store this information in line with the Data Protection Act 2018 and your responses and email address (if you include it) will be permanently deleted 3 months after the results of the PSP are published.

Next steps

If you would like to take part in the next stage of the project, which is to vote for the questions you think are most important, we need your contact details. You will be able to vote even if you didn't submit any questions.

Contact details

Your details will be kept on a confidential and secure database in connection with the conduct, analysis, and follow-up of this survey, but will be used for no other purpose. We will not pass your details on to any third parties.

Name

Email address

If you wish to have a copy of the final result of the PSP, please put your email address in the contact details and tick 'yes' below:

Yes

No

These are our contact details if you wish to contact us:

PSP Coordinator: Jaber Alqahtani

E-mail: jaber.alqahtani.18@ucl.ac.uk

Phone # 07846713703

Thank you for completing this survey.