

## Life with a Lung Condition Survey

1. Who are you completing this survey for?
  - a. Myself
  - b. My child(ren)
  - c. Someone I care for
  - d. Other

### About you

2. Which of the following best describes you?
  - a. Male
  - b. Female
  - c. Non-binary
  - d. Prefer not to say
  - e. Other
3. What is your age? *Please type in a number*
4. Which nation do you live in?
  - a. England
  - b. Northern Ireland
  - c. Scotland
  - d. Wales
  - e. Other

5. What region do you live in?
- a. (If England) East Midlands
  - b. (If England) East of England
  - c. (If England) London
  - d. (If England) North East
  - e. (If England) North West
  - f. (If England) South East
  - g. (If England) South West
  - h. (If England) West Midlands
  - i. (If England) Yorkshire and Humber
  - j. (If Northern Ireland) Belfast
  - k. (If Northern Ireland) Northern
  - l. (If Northern Ireland) Southern
  - m. (If Northern Ireland) South Eastern
  - n. (If Northern Ireland) Western
  - o. (If Scotland) Central Scotland
  - p. (If Scotland) Glasgow
  - q. (If Scotland) Highlands and Islands
  - r. (If Scotland) Lothian
  - s. (If Scotland) Mid Scotland and Fife
  - t. (If Scotland) North East Scotland
  - u. (If Scotland) South Scotland
  - v. (If Scotland) West Scotland
  - w. (If Wales) Aneurin Bevan
  - x. (If Wales) Betsi Cadwaladr
  - y. (If Wales) Cardiff and Vale
  - z. (If Wales) Cwn Taf Morgannwg
  - aa. (If Wales) Hywel Dda
  - bb. (If Wales) Powys
  - cc. (If Wales) Swansea Bay

6. Which part do you live in (England only)?
- a. (If East Midlands) Derbyshire and Nottinghamshire
  - b. (If East Midlands) Leicestershire, Rutland, and Northamptonshire
  - c. (If East Midlands) Lincolnshire
  - d. (If East of England) Bedfordshire and Hertfordshire
  - e. (If East of England) East Anglia
  - f. (If East of England) Essex
  - g. (If North East) Northumberland and Tyne & Wear
  - h. (If North East) Tees Valley and Durham
  - i. (If North West) Cheshire
  - j. (If North West) Cumbria
  - k. (If North West) Greater Manchester
  - l. (If North West) Lancashire
  - m. (If North West) Merseyside
  - n. (If South East) Berkshire, Buckinghamshire, and Oxfordshire
  - o. (If South East) Surrey, East Sussex, and West Sussex
  - p. (If South East) Hampshire and Isle of Wight
  - q. (If South East) Kent
  - r. (If South West) Cornwall and the Isles of Scilly
  - s. (If South West) Devon
  - t. (If South West) Dorset and Somerset
  - u. (If South West) Gloucestershire, Wiltshire, and the Bristol/Bath area
  - v. (If West Midlands) Herefordshire, Worcestershire, and Warwickshire
  - w. (If West Midlands) Shropshire and Staffordshire
  - x. (If West Midlands) West Midlands
  - y. (If Yorkshire and Humber) East Riding and North Lincolnshire
  - z. (If Yorkshire and Humber) North Yorkshire
  - aa. (If Yorkshire and Humber) South Yorkshire
  - bb. (If Yorkshire and Humber) West Yorkshire
7. Which one of the following best describes your ethnic group or background?
- a. White
  - b. Mixed or multiple ethnic groups
  - c. Asian or Asian British
  - d. Black, African, Black British or Caribbean
  - e. Other
  - f. Prefer not to say
8. Which one of the following best describes your ethnic group or background?
- a. (If white) English / Welsh / Scottish / Northern Irish / British
  - b. (If white) Irish
  - c. (If white) Gypsy or Irish Traveller
  - d. (If mixed or multiple ethnic groups) White and Black Caribbean
  - e. (If mixed or multiple ethnic groups) White and Black African
  - f. (If mixed or multiple ethnic groups) White and Asian
  - g. (If Asian or Asian British) Indian
  - h. (If Asian or Asian British) Pakistani
  - i. (If Asian or Asian British) Bangladeshi
  - j. (If Asian or Asian British) Chinese
  - k. (If Black, African, Black British or Caribbean) African
  - l. (If Black, African, Black British or Caribbean) Caribbean
  - m. (If other) Arab
  - n. (If other) Jewish
  - o. (All) Other
  - p. (All) Prefer not to say

9. What is the total annual income of your household (before tax and deductions, but including benefits/allowances)?
- Below £20,000
  - £20,000-£30,000
  - £30,001-£40,000
  - £40,001-70,000
  - Above £70,000
  - Prefer not to say
10. What lung condition(s) do you have?
- Asthma
  - COPD (Chronic Obstructive Pulmonary Disease)
  - Bronchiectasis
  - Interstitial lung disease (ILD)
  - Long covid
  - Mesothelioma
  - Sarcoidosis
  - I don't have a lung condition
  - Other

### Breathlessness and symptoms

11. When do you get out of breath?
- I'm not trouble by being out of breath, except on strenuous exercise
  - I'm short of breath when hurrying on level ground or walking up a slight hill
  - I walk slower than most people on the level, stop after a mile or so, or stop after 15 minutes of walking at my own pace
  - I stop for breath after walking about 100 yards or after a few minutes on level ground
  - I'm too breathless to leave the house, or breathless when dressing and undressing
12. In the last 4 weeks, have you had any usual asthma symptoms such as cough, wheeze, chest tightness or shortness of breath during the day, more than twice a week?
- Yes
  - No
  - Don't remember
13. In the last 4 weeks, have you been woken up during the night because of your asthma?
- Yes
  - No
  - Don't remember
14. In the last 4 weeks, have you needed to use your reliever inhaler more than twice a week?
- Yes
  - No
  - Don't remember
15. In the last 4 weeks, has your asthma interfered with usual daily activities, for example work/housework or taking part in activities?
- Yes
  - No
  - Don't remember

16. Does breathlessness affect your normal day-to-day activities?
- Never
  - Rarely
  - Sometimes
  - Often
  - Very often
  - Always
17. Have you had to give up any of the following because of your breathlessness?
- Hobbies
  - Exercise
  - Ability to care for my family (e.g., parents or children)
  - Meeting friends
  - Work
  - Voluntary roles
  - Sex
  - I have not had to give up or change anything
  - Relationship with partner / spouse
  - Other
18. Which of the following triggers your lung condition?
- Air pollution
  - Alcohol
  - Changes in weather
  - Cleaning products
  - Cold weather
  - Colds and flu
  - Drinks (excluding alcohol)
  - Dust
  - Emotions
  - Exercise
  - Food
  - Hormonal changes
  - Hot weather
  - Moulds and fungi
  - Other people smoking cigarettes
  - Other people using e-cigarettes (vaping)
  - Paint fumes
  - Perfumes and aerosols
  - Pets
  - Pollen
  - Something at work
  - Stress
  - When I use e-cigarettes
  - When I smoke
  - None of the above
  - Other

### Managing your lung condition

19. Do you currently have a written self-management plan for managing your lung condition, to help understand when symptoms are getting worse and what to do about it?
- Yes
  - No

20. Did you have a chance to have a say about what was in the self-management plan?
- Yes
  - No
  - I don't remember
21. Have you had a planned review or planned check-up (sometimes called your annual review) of your lung condition with your doctor, nurse, or a healthcare professional in the last year?
- Yes – face to face
  - Yes – over the phone
  - Yes – via a videocall
  - Yes – via online survey or text
  - No
  - Not sure
22. In the past 12 months, have you discussed any other long-term medical conditions that you have in relation to your lung condition management with a healthcare professional?
- Yes
  - No
  - Don't know
  - I don't have any other long-term conditions
23. In the past 12 months, has a healthcare professional checked how you use your inhaler?
- Yes
  - No
  - Not sure
  - I don't use inhalers
24. How was your inhaler technique checked?
- In a review at a GP surgery
  - With a pharmacist in a pharmacy
  - Remotely (such as on a videocall) with a healthcare professional
  - In hospital, after being admitted
  - In hospital, during an outpatient appointment
  - I don't remember
25. Do you know what your medicines and inhalers for your lung condition are for, and when to take them?
- Yes, I know this about all of them
  - Yes, I know this about some of them
  - No
  - I do not have any medicines or inhalers for my lung condition
26. Have you heard about the impact on the environment of metered dose inhalers?
- Yes
  - No
27. Have you been offered the chance to switch to a dry powder inhaler?
- Yes – and I have switched
  - Yes – I switched, but went back to using an MDI (metered dose inhaler)
  - Yes – but I decided against switching
  - No – I use an MDI, and have not discussed switching inhalers
  - No – I already use a dry powder inhaler
  - No – I do not use an MDI
  - Don't know

28. Why did you decide not to switch your inhaler?
- I didn't want to disrupt my self-management routine
  - I didn't think the dry powder inhaler would work for me
  - I'm happy with my current inhalers
  - I didn't think dry powder inhalers were safe
  - I'm not convinced about the environmental impact of inhalers
  - Other
29. Do you use any digital tools or technology in managing your lung condition?
- Yes
  - No – I have never used technology to manage my lung condition
  - No – I used to, but don't any more
30. What digital tools or technology do you use to manage your lung condition?
- Symptom tracking app
  - Other app
  - Digital peak flow meter
  - Digital spirometer
  - Other
31. What impact has using technology had in managing your lung condition?
- It has improved it
  - It has made no difference
  - It has made it worse
32. Would you be open to using technology to help manage your lung condition?
- Yes
  - No
  - Don't know
33. Why did you stop using technology to manage your lung condition?
- I didn't think it helped me
  - It didn't work very well
  - It was badly designed
  - I was advised to stop using it by a healthcare professional
  - Other
34. Are you on anti-fibrotic medication?
- Yes
  - No

### Getting care for your lung condition

35. Have you ever received emergency/unplanned care at a hospital or out-of-hours centre for your lung condition in the past year?
- Yes
  - No
  - Don't remember

36. The last time you received emergency/unplanned care at a hospital or out-of-hours centre, did you have a follow up appointment for your condition within 2 working days?
- Yes, I had a face-to-face appointment with the doctor/nurse
  - Yes, I had a telephone appointment with the doctor/nurse
  - No, but I had one within 2 weeks
  - No
  - I'm not sure / I can't remember
37. Which one of the following statements apply to you?
- I have previously taken oral steroid tablets / I had a steroid injection for my lung condition, but not in the last year
  - I have had 1 course of oral steroid tablets in the last year
  - I have had 2 courses of oral steroid tablets in the last year
  - I have had 3 or more courses of oral steroid tablets in the last year
  - I take oral steroid tablets everyday
  - In the past, I have taken steroid tablets everyday
  - None of the above
38. Have you ever spoken to your GP/nurse about being referred – or have you been referred – for your lung condition to a specialist doctor or nurse in a hospital?
- I have discussed referral, but not been referred
  - I have discussed referral and been referred
  - I have never discussed referral
  - Not sure
39. Why were you not referred? (Free text)
40. In the past 12 months, have you had a flu jab?
- Yes
  - No
  - Don't know
41. Why did you not get the flu jab?
- I forgot to get it
  - I don't think it works
  - I don't think it is safe
  - I wasn't offered it
  - I don't think I need it
  - I am worried about potential side effects
  - I couldn't afford to pay for it
  - Other
42. Have you had a pneumonia vaccine jab?
- Yes
  - No
  - Don't know
43. Have you had pulmonary rehabilitation as part of your care?
- Yes
  - No
  - I have not heard of pulmonary rehabilitation
44. Have you ever been offered the chance to do pulmonary rehabilitation?
- Yes
  - No



45. Would you consider doing pulmonary rehabilitation, if offered it?
- Yes
  - No
  - Not sure
46. Why did you not do pulmonary rehabilitation, after being offered the chance?
- I didn't think I would be able to complete the programme
  - My other medical problems would make it difficult for me
  - There weren't any classes that were convenient for me
  - I did not feel fit enough to travel to attend
  - I didn't feel like I knew enough about it, so turned it down
  - I didn't want to – or can't – go alone, and have no one to attend with me
  - I didn't attend because the course was online, and I do not have the right equipment at home
  - There is a long waiting list for my local PR course
  - Other
47. Do you smoke?
- Yes
  - I used to, but have given up
  - I used to smoke, and I now use e-cigarettes (vapes)
  - I have never smoked, but I use e-cigarettes (vapes)
  - I have never smoked
48. When did you last have a cigarette?
- 0-6 months ago
  - 7-12 months ago
  - 1-2 years ago
  - 3-5 years ago
  - 6-10 years ago
  - More than 10 years ago
49. In the past 12 months, have you been offered treatment and support from a healthcare professional (i.e., a nurse, doctor, or pharmacist) to stop smoking?
- Yes
  - No
50. Did you accept the offer of treatment and support to quit smoking?
- Yes
  - No
51. Did the treatment and support help you quit smoking?
- Yes
  - No
52. Why did you not use the treatment and support offered to quit smoking?
- I didn't want to quit smoking
  - I didn't think it would work for me
  - I wanted to try another method to quit smoking
  - I've tried before and it didn't work
  - Other

53. Have you tried to access care for your lung condition over the last 6 months?

- a. Yes – at the GP
- b. Yes – at A&E
- c. Yes – with NHS 111
- d. Yes – for an appointment with a hospital specialist
- e. No

54. How long did you have to wait to get care?

- a. I was able to get the care I needed the same day
- b. 1-3 days
- c. 4-7 days
- d. 1-2 weeks
- e. 3-4 weeks
- f. 1-2 months
- g. 3-4 months
- h. 5-6 months
- i. 6-12 months
- j. 12 months+
- k. I have not been able to access care yet

55. Did any of the following happen during your wait for care?

- a. My lung condition got worse
- b. I had an asthma attack / exacerbation
- c. I had to use my inhalers more
- d. I had to borrow inhalers
- e. I paid for private healthcare to get the care I needed
- f. I had to call an ambulance for my lung condition
- g. I had time off work / education
- h. I lost wages
- i. I got advice from elsewhere – from a search engine
- j. I got advice from elsewhere – the NHS website
- k. I got advice from elsewhere – Asthma + Lung UK website
- l. I got advice from elsewhere – Asthma + Lung UK helpline
- m. Other

56. Was this the first time you accessed private healthcare?

- a. Yes
- b. No

## Diagnosis

57. How old were you when you first noticed symptoms of having a lung condition? (Free text)

58. How old were you when you were diagnosed with your lung condition? (Free text)

59. Before you were diagnosed with your lung condition, had you heard of it?

- a. Yes
- b. No

60. How long did you have to wait between talking about your lung condition symptoms with your GP or healthcare professional, to receiving a formal diagnosis?
- a. One month or less
  - b. 1-2 months
  - c. 3-6 months
  - d. 6-12 months
  - e. 1-2 years
  - f. 2 years+
  - g. I don't remember
61. What were the main barriers to getting a diagnosis?
- a. Difficulty in getting appointments
  - b. Diagnosis tests not being available
  - c. Not knowing what the signs of your lung condition were
  - d. Too scared to go to the doctor in case I had a lung condition
  - e. I was misdiagnosed at first, and it took a while to get correctly diagnosed with my lung condition
  - f. My symptoms were dismissed as a cough / chest infection / something else
  - g. My GP thought I had a chest infection or cough at first
  - h. I had to wait a long time for a specialist appointment
  - i. I had trouble getting referred to a specialist
  - j. Concern that I might have lung cancer
  - k. I thought my symptoms were normal with age
  - l. I do not recall there being any barriers
  - m. Other

### Your life with a lung condition

62. Do you think there is a stigma attached to living with a lung condition?
- a. Yes
  - b. No
  - c. Don't know
63. Have you faced any stigma or discrimination due to have a lung condition?
- a. Yes
  - b. No
64. Can you describe what took place? (Free text)
65. Do you feel your lung condition has got worse in the past 12 months?
- a. Yes
  - b. No
66. Do you feel that you need more support to manage your lung condition now than you did 12 months ago?
- a. Yes
  - b. No
67. Has the cost-of-living crisis affected your income level?
- a. Yes
  - b. No

68. How has the cost-of-living crisis affected the following?

- a. Paying your rent/mortgage
- b. Paying to heat my home
- c. Paying other bills
- d. Paying for leisure activities
- e. Paying for food
- f. Paying for prescriptions

Options are:

- i. I could afford this before, but can't now
- ii. I couldn't afford this before, and can't now
- iii. I can afford this
- iv. I don't pay for this
- v. Don't know

69. How would you rate the outdoor air quality in your area? (Scale from 1 being worst to 10 being best)

70. Does air pollution ever impact your health or make your lung condition worse?

- a. It makes me feel breathless
- b. It makes me feel wheezy
- c. It triggers the symptoms of my lung condition
- d. It makes my condition flare up
- e. I have had an asthma attack / flare up because of it
- f. I have been hospitalised because of it

71. How does air pollution impact your daily life?

- a. Air pollution makes me feel low or depressed
- b. I have difficulty breathing when air pollution levels are high
- c. I avoid exercise outdoors when air pollution is worse
- d. I don't leave the house when air pollution is high
- e. I avoid holidays in areas where I know air pollution is higher
- f. I driven when air pollution is high to avoid walking or cycling
- g. I see family and friends less often than I would like to
- h. I have moved house because of air pollution
- i. I use public transport when air pollution is high to avoid walking or cycling
- j. I avoid going to work when air pollution is high
- k. I avoid going to a place of education when air pollution is high
- l. It doesn't affect my daily life
- m. Other

72. What steps would you like to see taken to address air pollution?

- a. More frequent public transport
- b. More reliable public transport
- c. Cheaper public transport
- d. Safer walking and cycling routes
- e. Charging restrictions for driving into city centres
- f. Fewer cars on the roads
- g. Financial incentives to scrap older and more polluting vehicles
- h. More electric car charging points
- i. Greener farming
- j. Cleaner energy
- k. Fewer polluting industries
- l. Restrictions on domestic burning
- m. None of these
- n. Other

73. What is the one thing you would like everyone to know about living with a lung condition? (Free text)