

Prevalence of breathlessness and associated consulting behaviour: results of an online survey

Authors: Amany F. Elbehairy, Jennifer K. Quint, Judith Rogers, Michael J. Laffan, Michael I. Polkey, Nicholas S. Hopkinson

ONLINE SUPPLEMENT

METHODS

The online British Lung Foundation (BLF) Breath Test included 10 simple questions about age, height, body mass, smoking history and Medical Research Council (MRC) breathlessness scale (*table E1*). At the end of the test and based on individual responses, tailored advice was provided. The following tables (*tables E2a, E2b and E2c*) show the report at the end of the test and the tailored advice given to participants based on their responses. The primary medium for promoting the Breath Test was paid Facebook advertising. We used demographic data profiles to display ads to people at likely risk of lung disease. These ads encouraged people to take the online BLF Breath Test. The Breath Test was also promoted widely in the media when it launched. The test was based on a BLF expert consensus as to what were likely to be important questions to ask related to breathlessness around which practical advice could be given – smoking, weight, physical activity, degree of breathlessness seeking medical attention.

Data cleaning: responses that included missing data about subjects' characteristics of height and weight (and so body mass index (BMI)), age or MRC breathlessness score were taken out from the current analysis. Wrong data entry was noticed in body mass values (i.e. values in thousands kilograms or more); these responses were also cleaned from our sample. In total, 8,242 responses were not included in our final analysis which brings a final sample of 356,799 out of 365,043 responses.

A follow-up survey, aimed at assessing the individual behavioural response to the BLF Online Breath Test, was sent by emails only to those who agreed to be contacted again (roughly one year after the initial test) (*table E3*). Of note, only those who remembered taking the online breath test were asked to complete the survey.

RESULTS

BLF Online Breath Test:

Distribution of age category and BMI across MRC breathlessness scores are shown in *figures E1 and E2*. Groups with MRC breathlessness scores ≥ 3 out of 5 showed higher proportion of people with age ≥ 50 years compared with groups with MRC breathlessness score of 1 or 2 (*figure E2*). Additionally, the proportion of physically inactive is increasing as MRC breathlessness score increases (*figure E3*), while the proportion of current smokers is similar across MRC scores (*figure E4*).

BLF Follow-up Survey:

The survey was distributed to the 13,444 subjects who had agreed to be contacted again at the time they completed the online BLF Breath Test. 1072 responses were received; 562 remembered taking the BLF Breath Test and were included in the current analysis (*figure E5*). Overall characteristics: 76% were aged ≥ 60 years, 9% smokers, 30% physically inactive (i.e. not doing at least 20-minutes of daily physical activity) and 69% had BMI ≥ 25 kg/m². *Figure E6* shows the distribution of MRC breathlessness score across the responders. 40% of this sample reported limiting breathlessness (MRC breathlessness score of ≥ 3 out of 5) and the majority of these (73%) already had a diagnosis of a respiratory condition before taking the test (*figure E7*).

Similar to the results of the initial BLF Breath Test, people with limiting breathlessness had higher BMI compared with non-breathless people (29.4 ± 6.9 versus 27.9 ± 6.6 kg/m², $p=0.007$), *figure E8*. Furthermore, the proportion of physically inactive (difference(CI): $18.2(10.4-25.9)$) was

higher in people with limiting breathlessness compared with non-breathless individuals ($p < 0.001$), *figure E9*. The proportions of old age (>60 years) and current smokers were higher in those with limiting breathlessness, but this didn't reach statistical significance *figure E9*.

47% of the subjects reported that taking the online BLF Breath Test increased their awareness that breathlessness can be a sign of a serious disease. *Table E4* summarizes actions taken by subjects in response to the tailored advice they received after taking the BLF Breath Test. Following their test, 33% reported that they had changed their lifestyle and 20% consulted their general practitioner (GP) about their breathlessness. Specifically, 18% increased their exercise level, 17% modified their diet, 6% successfully quit smoking while 3% had tried to quit but failed. As an outcome to the GP visit, 8% got a new diagnosis of a respiratory or cardiac disease condition. Though 9% of responders ($n=49$) were smokers (all visited their GP after the online test), only 4% of them ($n=2$) reported that they had received advice about quitting smoking during their visit to the GP.

The response rate to the follow up email survey (8%) makes it hard to draw firm conclusions but is not in itself particularly unusual.¹ We can only speculate on reasons for non-response, however, it is unlikely to reflect on the question in the Breath Test itself but more general issues and attitudes to surveys. Firstly, individuals had to opt in to leaving a name and email at the end of the Breath Test (they could receive the results of the test by email if they did that). Then they had to opt in to agree to be contacted by the BLF subsequently. Second, a year later about half of the contacted individuals did not recall taking the test, but that is not unexpected given that the test is quick to take.

References

1. Sauermann H, Roach M. Increasing web survey response rates in innovation research: An experimental study of static and dynamic contact design features. *Research Policy* 2013; 42:273-286

Table E1: The online British Lung Foundation (BLF) Breath Test

<p>Feeling short of breath from time to time is healthy and normal – but sometimes it can be a sign of something more serious.</p> <p>Answer these simple questions to see if you should get it checked out. It only takes about 5 minutes, and it's completely confidential.</p> <p>Let's get started</p>	
<p>1. Each day on average, do you do 20 minutes of physical activity? You can count the time you spend walking, cycling, gardening or anything else that makes you breathe faster.</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	
<p>2. Do you worry about getting out of breath?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	
<p>3. When do you get out of breath? Choose the best description:</p> <p><input type="checkbox"/> I'm not troubled by being out of breath except on strenuous exercise <input type="checkbox"/> I'm short of breath when hurrying on the level or walking up a slight hill <input type="checkbox"/> 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 <input type="checkbox"/> I stop for breath after walking about 100 yards or after a few minutes on level ground <input type="checkbox"/> I'm too breathless to leave the house, or breathless when dressing and undressing</p>	
<p>4. Do you smoke?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	
<p>5. What is your height? (We only use this to calculate your BMI)</p>	<input type="text"/>
<p>6. How much do you weigh? (We only use this to calculate your BMI)</p>	<input type="text"/>
<p>7. How old are you?</p> <p><input type="checkbox"/> Less than 40 years-old <input type="checkbox"/> 40–49 years-old <input type="checkbox"/> 50–59 years-old <input type="checkbox"/> 60–69 years-old <input type="checkbox"/> More than or equal years-old</p>	
<p>8. Have you ever seen a doctor, nurse or other health care professional about feeling out of breath?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No [if answered 'No', go to report]</p>	
<p>9. If your doctor, nurse or other health care professional prescribed treatment or suggested things you can do for your breathlessness, has it helped? (for example, breathing techniques, using a fan or opening a window, relaxation techniques, meditation or brain training, yoga)</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No [if answered 'No', go to report]</p>	
<p>10. Do you feel you know enough about your breathlessness to control it and manage it?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No [go to report]</p>	

Table E2: Report

These are the results of your breath test.

These results aren't medical advice. Talk to your doctor or nurse if you're worried about getting out of breath.

Table E2a: Outcome variables

<p>Outcome 1</p> <p>[For everyone who scores 1 on the MRC scale]</p> <p>Based on your results, you don't need to worry about feeling out of breath.</p> <p>Keep on doing exercise that gets you out of breath. But do remember that you're more likely to get breathlessness as you get older, so it is important:</p> <ul style="list-style-type: none">• to keep physically active• to drink and eat healthily• to manage your weight• not to smoke <p>[Show common variables and BMI variables, as outlined below]</p>
<p>Outcome 2</p> <p>[For everyone who scores 2 and above on the MRC scale]</p> <p>Your answers suggest you should ask your doctor or nurse about your shortness of breath.</p> <p>Before you go, have a look at our information about breathlessness to help you prepare for your appointment.</p> <p>[Show common variables and BMI variables, as outlined below]</p>
<p>Outcome 3</p> <p>[For everyone who scores 2 and above on the MRC scale and answers 'No' to Q9 and/or Q10]</p> <p>Although you've already had advice from your doctor, nurse or another health care professional, you need to make another appointment to discuss your breathlessness and how best to manage it.</p> <p>Before you make an appointment, you can read our breathlessness information for lots of information, support and advice. This should also help you prepare for any questions you might be asked.</p> <p>Think about things you might want to say like:</p> <ul style="list-style-type: none">• you've started to do less than you used to• you're finding it difficult to keep up with other people of your age• you avoid doing everyday things you used to so you don't get out of breath• you avoid doing things you used to so you don't have to admit you feel short of breath. This might be stopping unnecessarily to look in shop windows or tie your shoelaces for example <p>[Show common variables and BMI variables, as outlined below]</p>

Outcome 4

[For everyone who answers 'Yes' to Q8, Q9 and Q10]

Your answers suggest that the treatment and management of your breathlessness is going well.

At the moment, you don't need to make another appointment to see your doctor, nurse or other health care professional about your breathlessness.

You should keep following their advice and remember to make an appointment if you start to experience breathlessness that you can't control, other than during exercise or heavy physical activity.

Our [breathlessness information](#) also has lots of information, support and advice that you might find useful.

[Show common variables and BMI variables, as outlined below]

Table E2b: Common variables

[Common variables will appear before BMI variables, unless BMI is within the ideal range; in this case, the BMI variable will appear first, and common variables will follow]

[For everyone who answers 'No' to Q1]

How you can keep active

Every week, do at least 2 hours and 30 minutes of activity that raises your heart rate and makes you breathe faster.

You'll find lots of useful tips and information to get you started on the NHS's [active lifestyle](#) and [fitness](#) information.

[For everyone who answers 'Yes' to Q2]

How you can get help if you worry about getting out of breath

You should tell your doctor or nurse if you feel stressed or anxious about your shortness of breath.

Answer these 4 questions and bring the results along to your appointment. This'll help your doctor or nurse to help you.

Over the last 2 weeks, how often have you been bothered by the following problems? (Make a note of your answers)

	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3

[For everyone who answers 'Yes' to Q4]

How you can get help to quit smoking

If you smoke, you're more likely to get out of breath or develop lung cancer, chronic obstructive pulmonary disease, heart disease and other serious diseases.

Check out our [smoking information](#) for support to help you quit.

Table E2c: BMI variables

[If BMI is within ideal range. This will appear before any common variables]

Your body mass index (BMI) is **[figure here]**.

That's **within** the ideal range. Try to keep a healthy weight because if you become overweight, your breathing can be affected.

The NHS's [BMI information](#) explains how it's calculated, and has lots of information, advice and support for maintaining a healthy weight, keeping fit and eating well.

[For anyone who has common variables, the following will be added:]

However, based on your answers, you should discuss the following with your doctor or nurse:

[If BMI is above ideal range. This will appear **after** any common variables]

How you can lose weight and eat well

Your body mass index (BMI) is **[figure here]**. That's **above** the ideal range.

This suggests you might be overweight or obese, which can affect your breathing.

So it's time to take action.

The NHS's [BMI information](#) explains how it's calculated, and has lots of information, advice and support for maintaining a healthy weight, keeping fit and eating well.

[If BMI is below ideal range. This will appear **after** any common variables]

How to find out more about keeping fit, eating well and maintaining a healthy weight

Your body mass index (BMI) is **[figure here]**. That's **below** the ideal range.

This suggests you might be underweight. This can damage your health, contributing to a weakened immune system, fragile bones and feeling tired.

Being underweight can be caused by diet, or an underlying medical problem such as overactive thyroid, chronic obstructive pulmonary disease (COPD), renal disease, heart failure or cancer, all of which cause breathlessness.

If you're concerned about being underweight you can talk to your GP, practice nurse or other health care professional.

The [NHS's BMI information](#) explains how it's calculated, and has lots of information, advice and support for maintaining a healthy weight, keeping fit and eating well.

Table E3: The British Lung Foundation (BLF) Follow-up Survey

<p>1. Do you remember taking the breath test?</p> <p><input type="checkbox"/> Yes - Proceed <input type="checkbox"/> No Quit</p>
<p>2. Did you have a diagnosis before you took the online breath test?</p> <p><input type="checkbox"/> A lung or respiratory condition that made you breathless <input type="checkbox"/> A heart condition that made you breathless <input type="checkbox"/> Both <input type="checkbox"/> Neither</p>
<p>3. Did you smoke?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>4. Was the breath test easy to use?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>The breath test asked questions about breathlessness, smoking, your weight and how much you exercise and offered some advice. We would like to know if you took any action as a result of taking the test.</p> <p>I changed my lifestyle (diet, exercise level or smoking habits)</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>(If yes, tick all that apply)</p> <p><input type="checkbox"/> I was smoking and tried to quit smoking after taking the test <input type="checkbox"/> I was smoking and succeeded in stopping smoking after taking the test <input type="checkbox"/> I have increased my level of exercise after taking the test <input type="checkbox"/> I have changed my diet after taking the test <input type="checkbox"/> Other [please state]</p>
<p>5. I went to see my general practitioner (GP) as a result of the test</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>(If yes, tick all that apply)</p> <p><input type="checkbox"/> I was sent for further tests <input type="checkbox"/> I got a new diagnosis of a lung or respiratory condition <input type="checkbox"/> I learnt more about my lung health <input type="checkbox"/> I got a new diagnosis of heart disease <input type="checkbox"/> My GP started me on a new medication <input type="checkbox"/> My GP gave me help or advice to quit smoking <input type="checkbox"/> My GP counselled me on weight reduction <input type="checkbox"/> Nothing happened as a result of seeing my GP</p>
<p>6. How has the breath test helped you?</p> <p><input type="checkbox"/> I'm more aware that getting out of breath can be a sign of something more serious <input type="checkbox"/> I understand my breathing better <input type="checkbox"/> I know how to look after my health better <input type="checkbox"/> None of the above</p>

Table E4: Actions in Response to the Advice Received at the end of the BLF Online Breath Test

	n (% of total responders)
General	
▪ Life style changes	187 (33)
▪ I saw my general practitioner (GP)	115 (20)
▪ Life style changes and saw GP	19 (3)
▪ Nothing	241 (43)
Life Style Changes	
▪ I have changed my diet after taking the test	96 (17)
▪ I have increased my level of exercise after taking the test	103 (18)
▪ I was smoking and succeeded to quit after taking the test	36 (6)
▪ I was smoking and tried to quit after taking the test	15 (3)
▪ Others	14 (2)
Outcome of GP visit	
▪ I got a new diagnosis of lung disease	32 (6)
▪ I got a new diagnosis of heart disease	11 (2)
▪ I was sent for further tests	54 (10)
▪ I learnt more about my lung health	29 (5)
▪ My GP gave me help or advice to quit smoking	6 (1)
▪ My GP started me on a new medication	43 (8)
▪ My GP counselled me on weight reduction	13 (2)
▪ Nothing happened as a result of seeing my GP	8 (1)
How has the breath test helped you?	
▪ I know how to look after my health better	178 (32)
▪ I understand my breathing better	222 (40)
▪ I'm more aware that getting out of breath can be a sign of something more serious	265 (47)
▪ None of the above	73 (13)

FIGURES

Figure E1. Data from the online BLF Breath Test (n=356,799) showing body mass index across MRC breathlessness scores. Values in boxes represent the median, 10th, 25th, 75th, and 90th percentiles. *Abbreviations:* MRC= Medical Research Council.

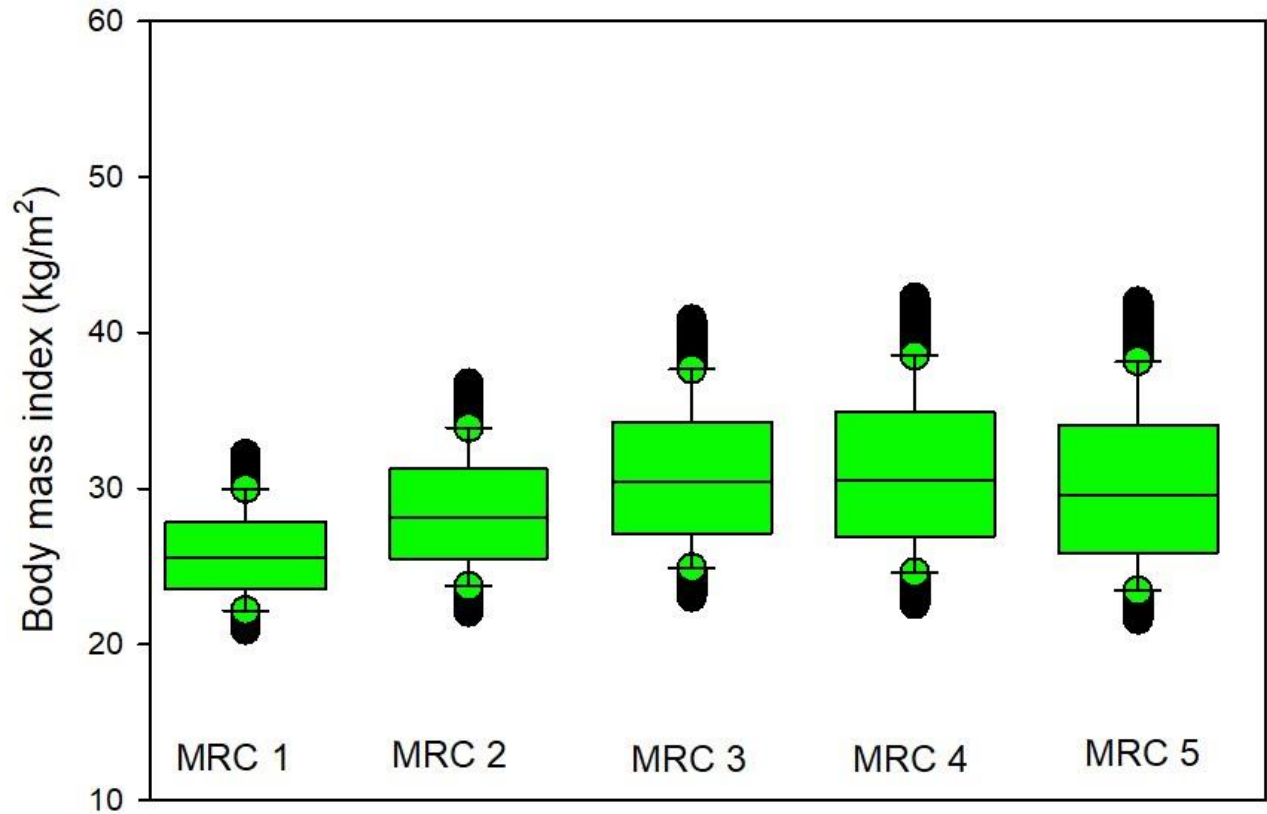


Figure E2. Data from the online BLF Breath Test (n=356,799) showing proportion of age category across MRC breathlessness scores; note the higher proportion of age \geq 50 years as MRC breathlessness score increases. *Abbreviations:* MRC= Medical Research Council.

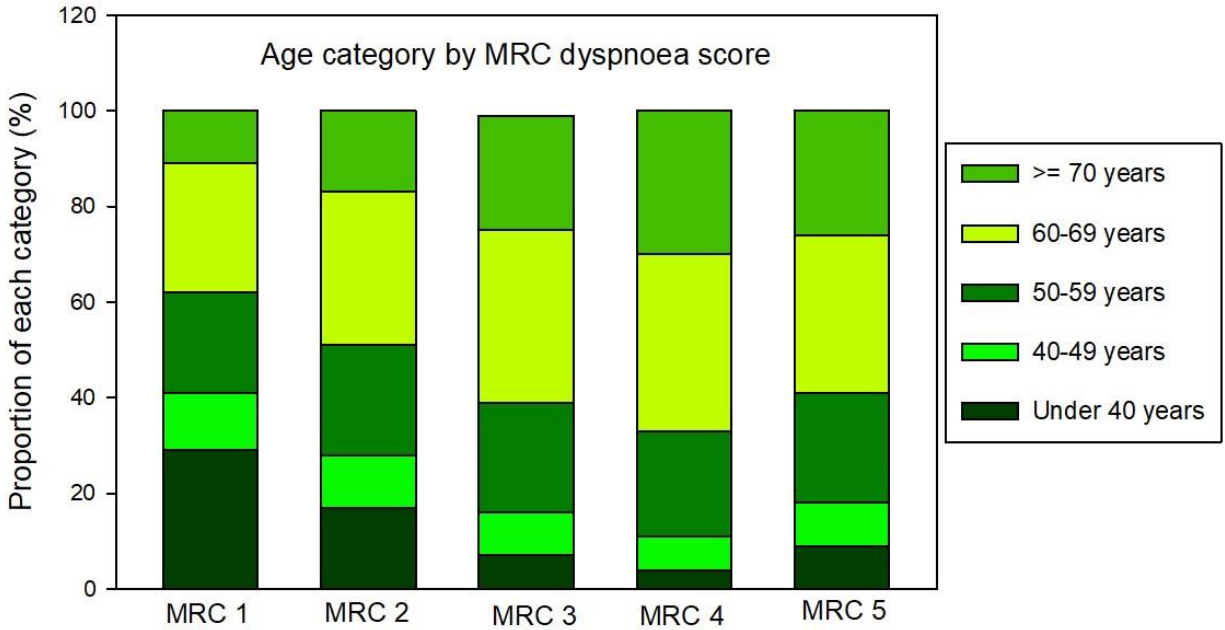


Figure E3. Data from the online BLF Breath Test (n=356,799) showing proportion of physically active and inactive people across MRC breathlessness scores; note the increasing proportion of inactive people as MRC score increases. Physically inactive: those who reported not doing at least 20 minutes of daily activities. *Abbreviations:* MRC= Medical Research Council.

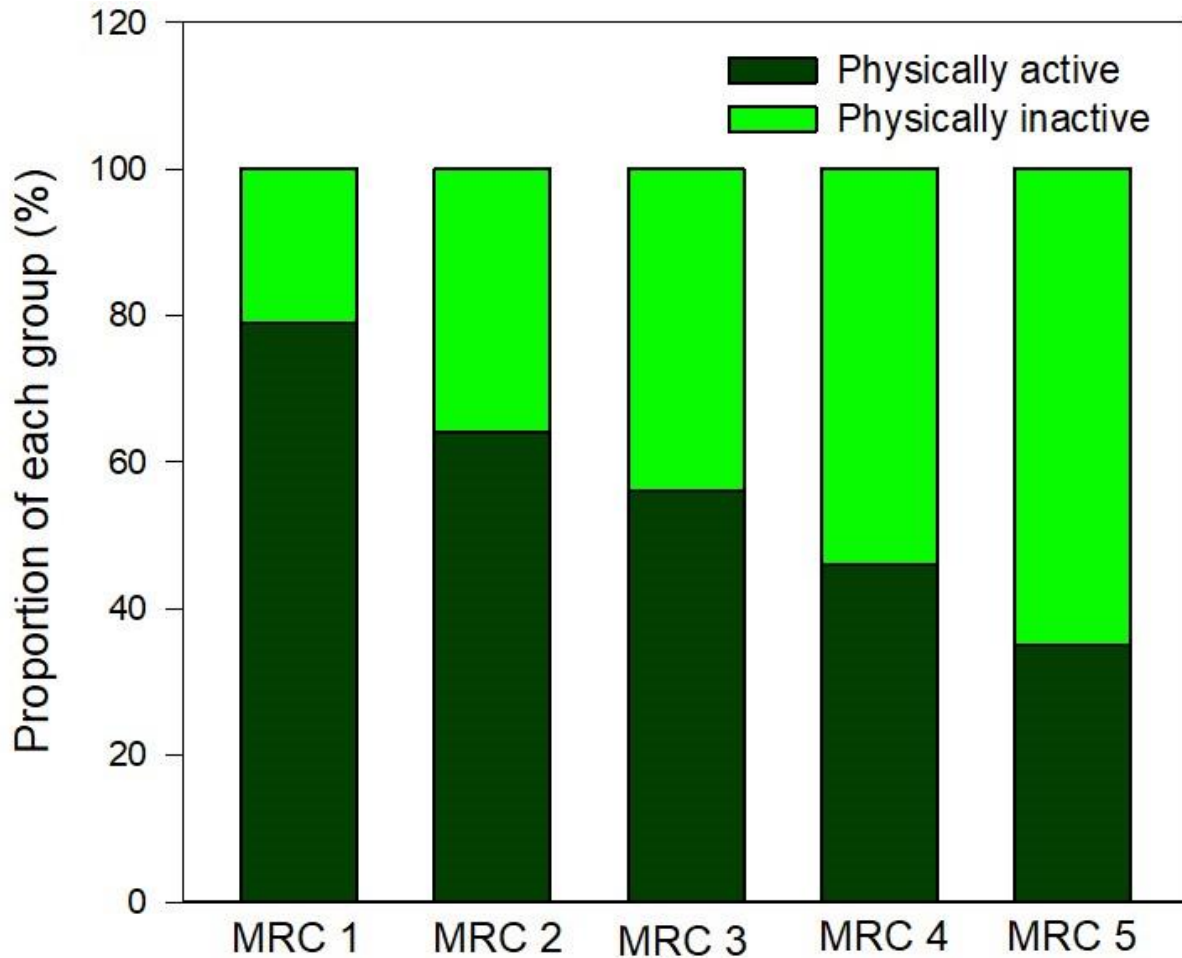


Figure E4. Data from the online BLF Breath Test (n=356,799) showing proportion of current smoker and non-smokers across Medical Research Council (MRC) breathlessness scores.

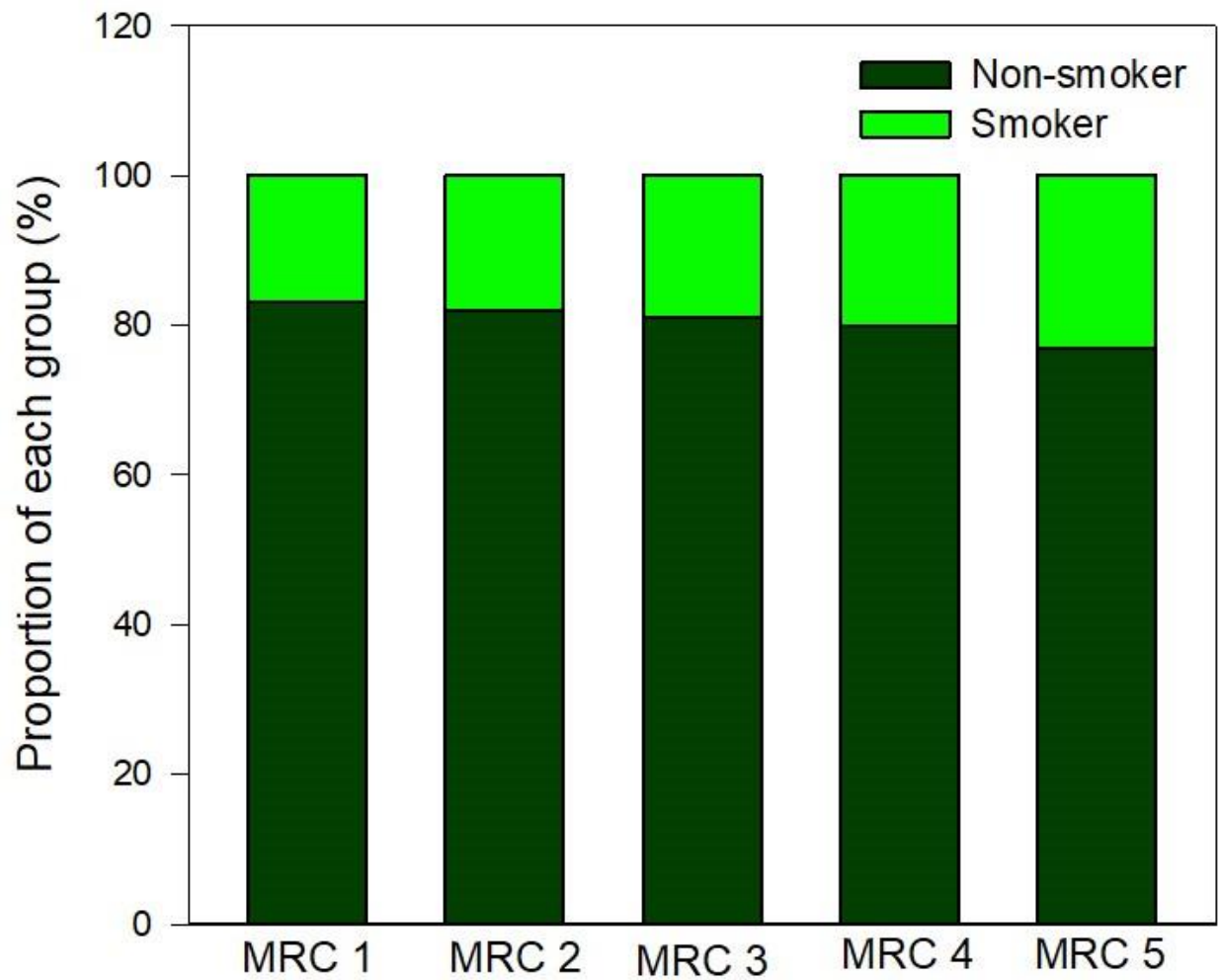


Figure E5. Flow chart of responses to the follow-up BLF survey. Note that only those who remembered taking the first online BLF Breath Test were allowed to complete the survey. *Abbreviations:* BMI= body mass index; MRC= Medical Research Council.

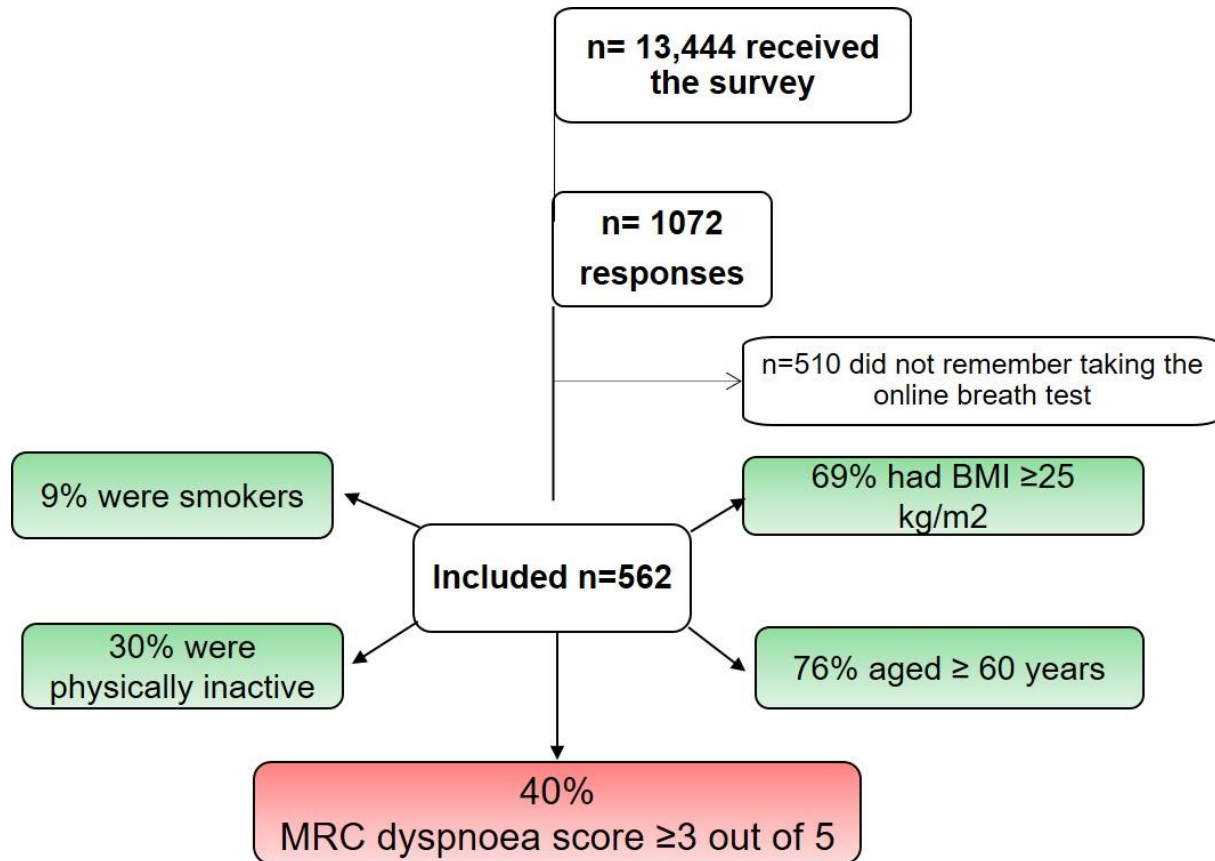


Figure E6. Data from the follow-up BLF survey showing the distribution of MRC breathlessness scores across the sample. *Abbreviations:* MRC= Medical Research Council.

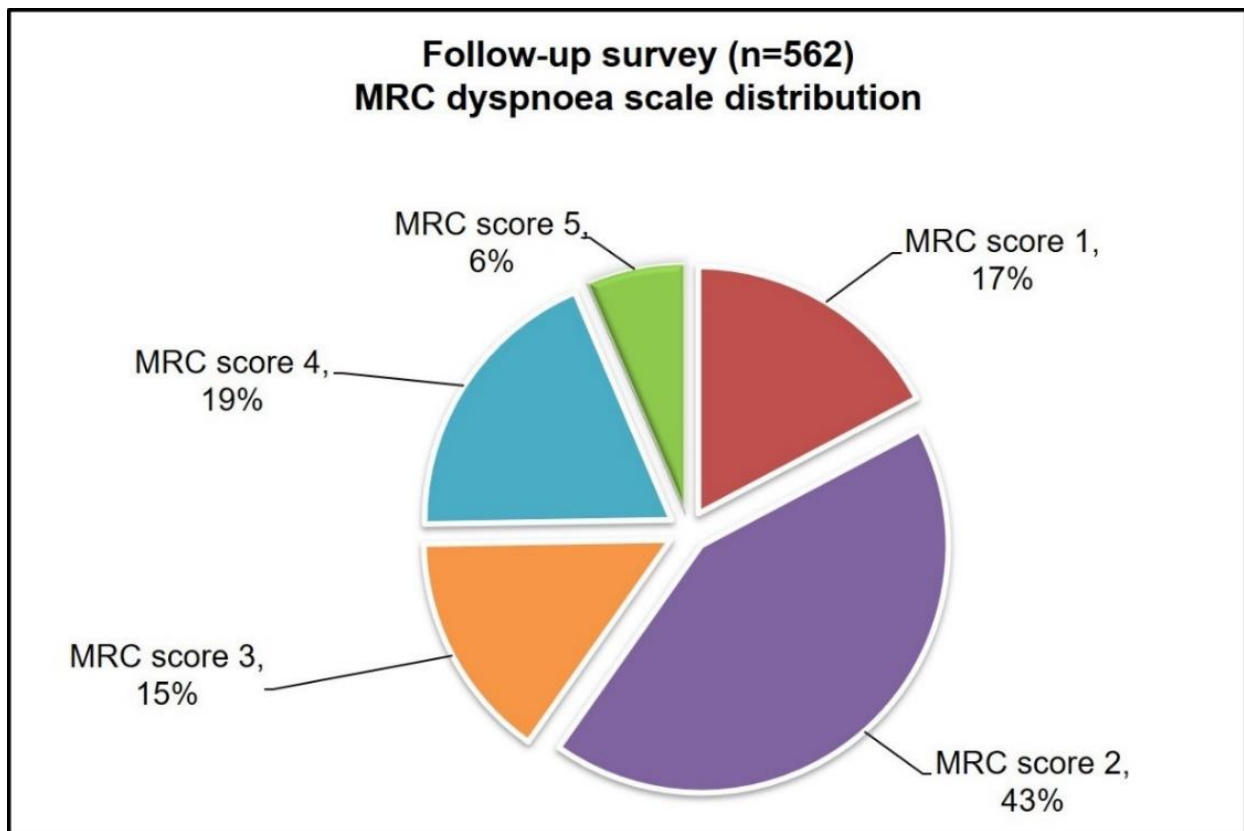


Figure E7. Proportions of disease conditions prior to taking the online BLF Breath Test among people with limiting breathlessness (Medical Research Council (MRC) breathlessness score of ≥ 3 out of 5), showing that respiratory diseases constituted the majority (73%).

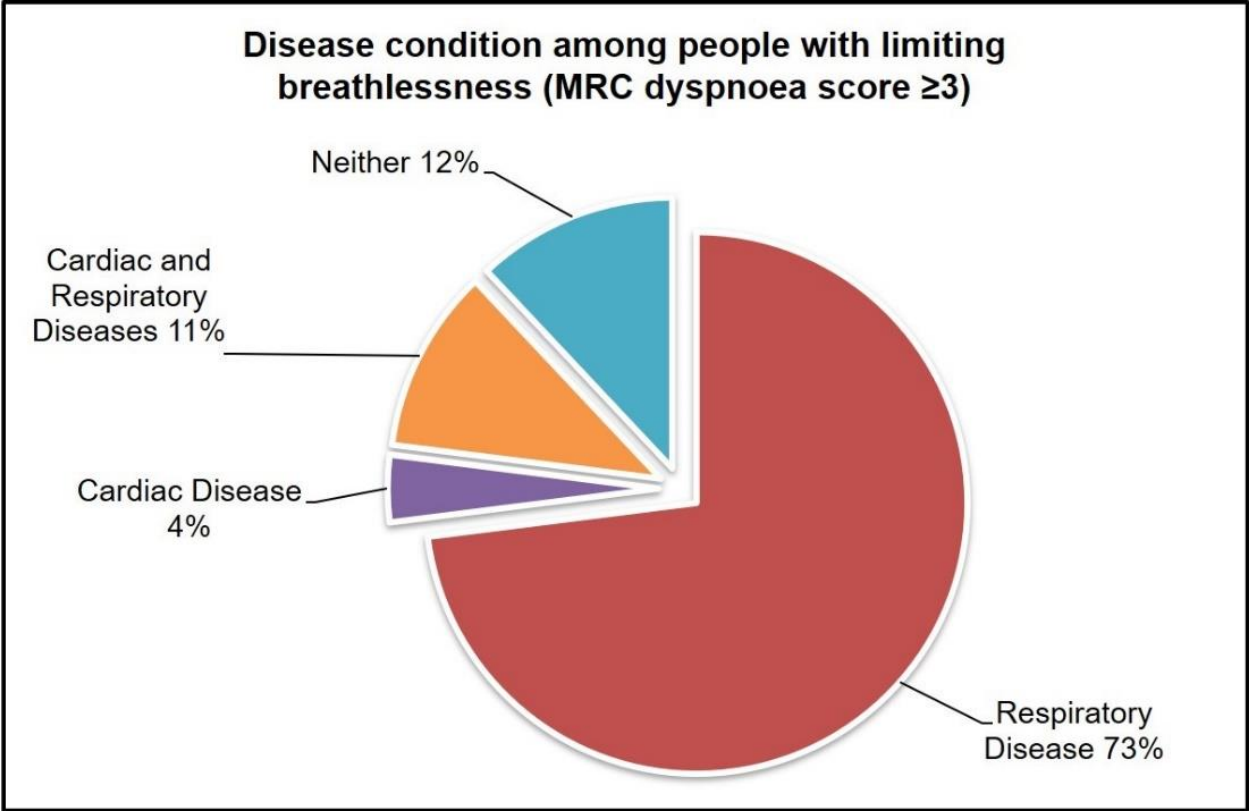


Figure E8. Follow-up BLF survey data showing body mass index in people with limiting breathlessness (Medical Research Council (MRC) breathlessness score ≥ 3 out of 5, n=336) and those who were non-breathless (MRC breathlessness score of 1 or 2, n=226). Values in boxes represent the median, 10th, 25th, 75th, and 90th percentiles. *=p<0.05 people with limiting breathlessness versus non-breathless individuals.

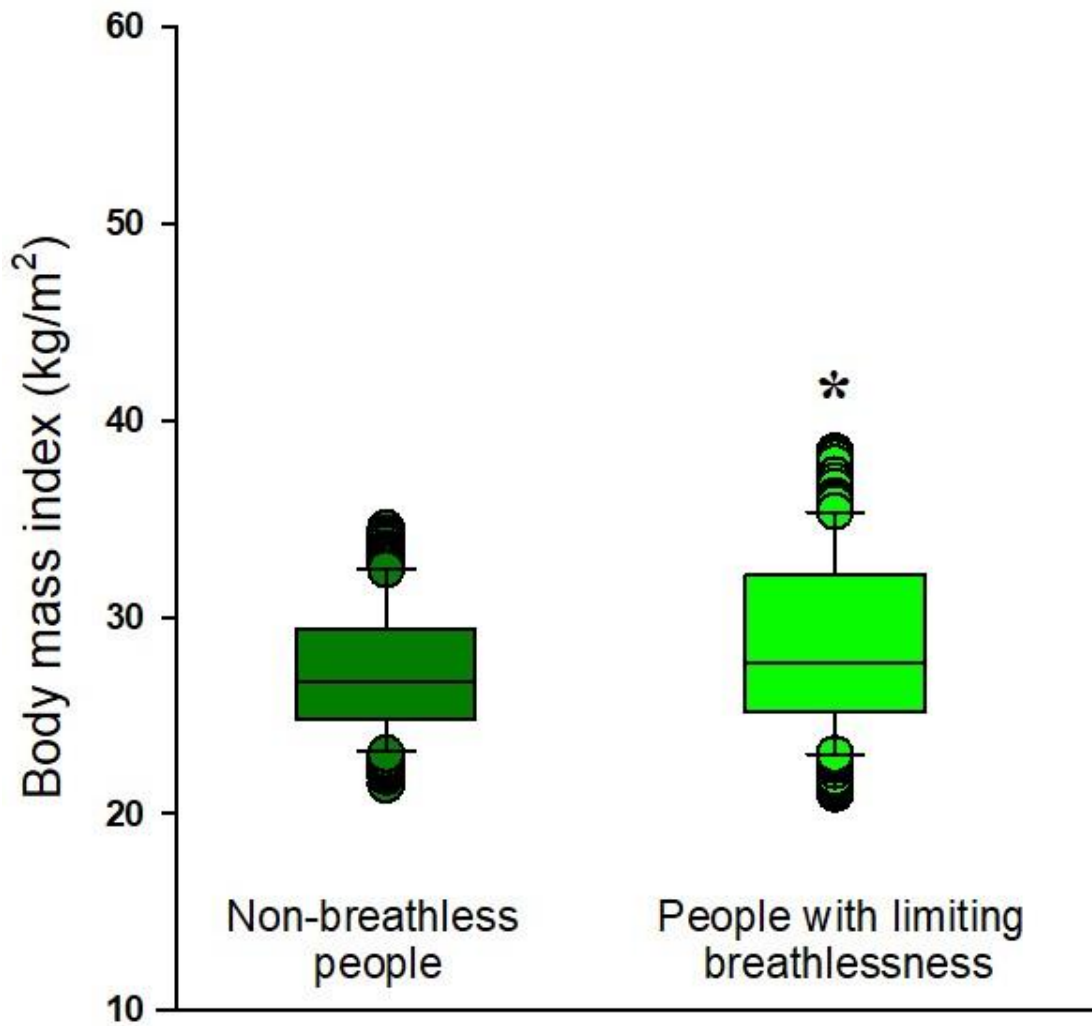


Figure E9. Follow-up BLF survey data showing comparison of proportions of being older >60 years, current smoker and physically inactive between people with limiting breathlessness (Medical Research Council (MRC) breathlessness score ≥ 3 out of 5, n=336) and those who were non-breathless (MRC breathlessness score of 1 or 2, n=226). Values are percentage of subjects within each group. *= $p < 0.05$ people with limiting breathlessness versus non-breathless individuals. Physically inactive: those who reported not doing at least 20 minutes of daily activities.

