

# COPD Patient Web Survey

FINAL – November 17, 2016

We are conducting a survey on how people use online information and would like to include your opinions. We are not selling anything and would simply like to understand your opinions. Your answers and comments will be completely confidential.

## SCREENING AND PROFILING

Q.1 Do you work for a doctor's office, hospital, home care company or other organization that provides medical care?

Yes	1
No	2

**THANK AND END**

Q.2 Have you been diagnosed by a physician with any of the following diseases or conditions? ACCEPT MULTIPLE RESPONSES

Irregular heart beat or arrhythmia	1
Gout	2
High blood pressure or hypertension	3
Chronic obstructive pulmonary disease or COPD (chronic bronchitis, emphysema)	4
Chronic pain	5
Acid reflux or GERD	6
Psoriasis	7
None of the above	10

**IF Q2 ≠ 4, THANK AND END**

Q.3 How frequently do you go online to search for information about medical conditions that you have been diagnosed with or other concerns you have about your health or medical care?

Once a week or more	1
2-3 times per months	2
Once every few months	3
Rarely	4
I've never looked online for medical information	5

**THANK AND END**

Q.4 What is your age?

\_\_\_\_\_

Q.5 Are you:

Male 1

Female 2

Q.6 Which of the following ethnic groups do you identify with?

Caucasian/White	1
African American/Black	2
Asian	3
Native Hawaiian or Other Pacific Islander	4
American Indian or Native Alaskan	5

Q.7 Are you of Latino or Hispanic heritage?

Yes	1
No	2

Q.8 What is the high level of education you have completed?

Some High School	1
High School Graduate	2
Technical school or trade school	3
Some college	4
Associate's degree	5
4 year college degree	6
Graduate school	7

Q.9 What state do you live in?

\_\_\_\_\_

Q.10 How would you describe your overall health status? Would you say it is . . .

Excellent	5
Very Good	4
Average	3
Fair	2
Poor	1

Q.11 How concerned are you about your health?

Very concerned	1
Somewhat concerned	2
Not too concerned	3
Not at all concerned	4

Q.12 Which of the following best describes how COPD impacts your everyday activities?

Not troubled by breathlessness except on strenuous exercising.	0
Shortness of breath when hurrying on level ground or walking up a slight hill.	1
Walk slower than people of the same age on level ground because of breathlessness or have to stop for breath when walking at your own pace on level ground.	2
Stops for breath after walking about 100 yards or after a few minutes of walking on level ground.	3
Too breathless to leave the house or breathless when dressing or undressing.	4

Q.13 What symptoms do you most frequently experience as a result of your COPD? PLEASE CHECK ALL THAT APPLY,

Difficulty sleeping	1
Difficult or labored breathing when performing activities of daily living	2
Experiencing colds more frequently	3
Wheezing	4
COPD symptoms during the night making it difficult to sleep	5

Q.14 Have you had any exacerbations or flare ups of your COPD in the past year?

Yes	1	
No	2	<b>SKIP TO Q16</b>

Q.15 How many exacerbations or flare up have you had in the past year? ENTER A WHOLE NUMBER

\_\_\_\_\_

### DIGITAL HEALTH PROFILE

Q.16 How frequently do you go on the internet?

Less than once a week	1
Once a week	2
2-3 times a week	3
Daily	4
Several times a day	5

Q.17 When you go on the internet, what types of activities do you engage in? PLEASE CHECK ALL THAT APPLY.

Email with family and friends	1
Conduct banking activities (pay bills, transfer funds, manage savings or investments)	2
Shop for and purchase products	3
Watch TV	4
Share photos and videos	5
Read other people's blogs	6
Post on your own blog	7
Read news sites	8
Leave comments on news sites	9
Leave online reviews on products and services you've purchased	10
Go on social media websites to keep in touch with family and friends	11

Q.18 Have you ever “liked” or “followed” on social media . . .

	<u>Yes</u>	<u>No</u>
a. An organization that provides information and advocates on behalf of a disease or medical condition, such as the American Cancer Society or the COPD Foundation?	1	2
b. A company that provides medical products or services, such as a pharmaceutical company or health care provider?	1	2

Q.19 Which of the following online activities have you engaged in related to your health and medical care? PLEASE CHECK ALL THAT APPLY,

Used a website or smart phone to access an electronic medical record maintained by your doctor	1
Paid a medical bill	2
Posted a review about a doctor, hospital, drug or treatment	3
Emailed your doctor or nurse with a question about your health	4
Enrolled in a portal with Medicare (MyMedicare) or with your insurance company in order to access claims and other information about your health insurance coverage	5
Had a visit with your doctor through a secure, online video connection	6

Q.20 Thinking specifically about your COPD, have you ever **gone on the internet** to find information related to your medical care? PLEASE CHECK ALL THAT APPLY.

Information that compares the performance of doctors, hospitals or health plans?	1
Information that compares the costs of different doctors, hospitals or treatment facilities	2
Specific information about COPD	3
Specific information about a medical treatment, procedure or medication that is being recommended to you by your doctor for treatment of your COPD	4
Information that provides online reviews of different drugs or treatments for COPD	5
Blogs or other types of online comments by other people who have been diagnosed with COPD	6

Q.21 When it comes to getting information on how to best keep your COPD under control, to what extent do you turn to the follow information resources?

	<u>Frequently</u>	<u>Sometimes</u>	<u>Rarely</u>
Your doctor	1	2	3
Nurse practitioner/physician's assistant	1	2	3
Other nurse at your doctor's office	1	2	3
Respiratory therapist	1	2	3
Information you find on the internet	1	2	3
Other people who are diagnosed with COPD	1	2	3
Information from your pharmacist	1	2	3
Information from pharmaceutical companies	1	2	3

Q.22 Have you ever posted a question on an "Ask a Doctor" or "Ask a Nurse" website or reviewed responses to questions asked by other people?

Yes	1
No	2

Q.23 Have you ever enrolled in a website that sends you reminders about your health, such as taking your medications, exercising or diet and nutrition?

Yes	1
No	2

Q.24 How often do you bring information related to COPD that you found on the internet to your doctor's appointments in order to discuss that information with him or her? This might include information about different medications, inhalers or other treatment approaches.

All the time	1
Most of the time	2
Some of the time	3
Infrequently	4
Never	5

Q.25 Taking into consideration what you already know about COPD and on how this disease is impacting your life, what are the highest priority information needs you have about COPD? PLEASE CHECK ALL THAT APPLY

Things I can do to keep my COPD symptoms under control	1
Things I can do to minimize the number of times I wake up at night experiencing COPD symptoms	2
Things I can do to reduce the frequency of exacerbations	3
Information on how to use my inhaler the right way	4
Information on how to prevent infections	5
Recommendations on which types of exercises will have the biggest impact on reducing COPD symptoms	6
Understanding how COPD is affecting my body	7
Information about different treatment options that might work better for my COPD	8
Information about natural remedies that might help with my COPD symptoms	9
Information on how to develop a personal emergency response plan for dealing with my COPD	10

#### REACTION TO INDIVIDUAL COPD PATIENT EDUCATION WEBSITES

For the next part of our survey, we are going to ask you to look at some screen shots from two types of websites that provide COPD patients with information that helps them manage their condition. You are not going to be visiting the actual websites, but rather images of what the websites look like.

We want you to look at each of the screen shots so that you can get a sense of what kind of information is available on the website. We have inserted some notations on the screen shots so that you can get a sense of what you might find if you click on the different links. Then, we're going to ask you a few questions about your impressions of that web site.

We are going to do this same exercise for two different websites.

**INSERT SCREENSHOTS FROM FIRST WEBSITE. INSERT TIMER LOCK ON EACH SCREEN SO THAT RESPONDENT CAN'T IMMEDIATELY CLICK THROUGH.**

Q.26 Overall, how would you rate your overall reaction to this website, based on the screen shots that you just reviewed?

Poor				Average				Excellent	
1	2	3	4	5	6	7	8	9	10

Q.27 Why did you rate the website that way? PLEASE BE AS SPECIFIC AS YOU CAN.

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Q.28 Listed below are a series of statements about the content of the website that you just reviewed. Please rate your level of agreement with each of the following statements about this website. RANDOMIZE ORDER OF EXPOSURE

	<u>Strongly Disagree</u>	<u>Slightly Disagree</u>	<u>Neutral</u>	<u>Slightly Agree</u>	<u>Strongly Agree</u>
a. Information appears to be very applicable to me based on the current state of my COPD and how it is affecting my life.	1	2	3	4	5
b. The information seems to be very general.	1	2	3	4	5
c. The information appears to be comprehensive about all facets of COPD.	1	2	3	4	5
d. The information appears to be up to date and includes the latest research on how to best manage COPD.	1	2	3	4	5
e. The information appears to be coming from a person or organization that is a leading authority about COPD.	1	2	3	4	5
f. The information provides me with practical guidance on how to manage my COPD.	1	2	3	4	5
g. The information is attempting to persuade me to try a specific medication.	1	2	3	4	5
h. I think this website is being regularly updated with new information about COPD.	1	2	3	4	5
i. I would probably learn something new about COPD from this website that I probably wouldn't find on other websites.	1	2	3	4	5
j. I would bookmark this website because I'd want to go back to it to learn new things about COPD.	1	2	3	4	5



Q.29 Listed below are a series of statements about the overall look and feel of this website. Please rate your level of agreement with each of the following statements about the look and feel of this website. RANDOMIZE ORDER OF EXPOSURE.

	<u>Strongly Disagree</u>	<u>Slightly Disagree</u>	<u>Neutral</u>	<u>Slightly Agree</u>	<u>Strongly Agree</u>
a. The information is trustworthy.	1	2	3	4	5
b. The information is easy to understand for patients like me.	1	2	3	4	5
c. The website is visually appealing.	1	2	3	4	5
d. The website seems like it would be easy to navigate and find what I'm looking for.	1	2	3	4	5
e. The information is presented in a direct and straightforward manner.	1	2	3	4	5
f. The information is relevant to me.	1	2	3	4	5

Q.30 Based on your impression of this website, what type of organization do you feel is the sponsor of this website? RANDOMIZE ORDER OF RESPONSE EXPOSURE.

A university or medical school	1
A pharmaceutical company	2
A hospital or health system	3
One doctor or a team of doctors that specialize in treatment of COPD	4
A medical journal	5
A for profit website that specializes in providing patient education	6

**REPEAT Q26-30 BATTERY FOR WEBSITES 2. RANDOMIZE ORDER OF ESPOSURE OF WEBSITE/QUESTION BATTERY ACROSS ALL RESPONDENTS.**

**WEBSITE #2 Q31-Q35**

## REACTION TO INDIVIDUAL COPD PATIENT EDUCATION WEBSITES

For the last part of our survey, we'd like you to compare and contrast the two websites that you just reviewed.

Q.36 Which of the websites appealed to you the most?

Website #1	1
Website #2	2

**NOTE: respondents will actually see thumbnail screenshots of the websites with a radio button to make their selection.**

Q.31 Why did you find this website to be most appealing? PLEASE BE AS SPECIFIC AS YOU CAN.

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**Thank you for taking the time to participate in this survey.**

XXXX > WHAT IS COPD > UNDERSTANDING COPD > WHAT IS COPD?

Understanding COPD

What is COPD?

Getting Tested

Living with COPD

COPD Facts

Educational Materials

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## What is COPD?

What is COPD?

Chronic Obstructive Pulmonary Disease (COPD) affects an estimated 30 million individuals in the U.S. **GET SCREENED TODAY!**



**Chronic Obstructive Pulmonary Disease (COPD)** is an umbrella term used to describe progressive lung diseases including emphysema, chronic bronchitis, refractory (non-reversible) asthma, and some forms of bronchiectasis. This disease is characterized by increasing breathlessness.

Many people mistake their increased breathlessness and coughing as a normal part of aging. In the early stages of the disease, you may not notice the symptoms. COPD can develop for years without noticeable shortness of breath. You begin to see the symptoms in the more developed stages of the disease. That's why it is important that you talk to your doctor as soon as you notice any of these symptoms. Ask your doctor about taking a **spirometry** test.

### What are the signs and symptoms of COPD?

- Increased breathlessness
- Frequent coughing (with and without sputum)
- Wheezing
- Tightness in the chest

### How common is COPD?

COPD affects an estimated 30 million individuals in the U.S., and over half of them have symptoms of COPD and do not know it. Early screening can identify COPD before major loss of lung function occurs.

### What are the risk factors and common causes of COPD?

Most cases of COPD are caused by inhaling pollutants; that includes smoking (cigarettes, pipes, cigars, etc.), and second-hand smoke.

Fumes, chemicals and dust found in many work environments are contributing factors for many individuals who develop COPD.

Genetics can also play a role in an individual's development of COPD—even if the person has never smoked or has ever been exposed to strong lung irritants in the workplace.

Here is more information on the top three risk factors for developing COPD:

#### Smoking

COPD most often occurs in people 40 years of age and older who have a history of smoking. These may be individuals who are current or former smokers. While not everybody who smokes gets COPD, most of the individuals who have COPD (about 90% of them) have smoked.

#### Environmental Factors

COPD can also occur in those who have had long-term contact with harmful pollutants in the workplace. Some of these harmful lung irritants include certain chemicals, dust, or fumes. Heavy or long-term contact with secondhand smoke or other lung irritants in the home, such as organic cooking fuel, may also cause COPD.

#### Genetic Factors

Even if an individual has never smoked or been exposed to pollutants for an extended period of time, they can still develop COPD. Alpha-1 Antitrypsin Deficiency (AATD) is the most commonly known genetic risk factor for emphysema. Alpha-1 Antitrypsin related COPD is caused by a deficiency of the Alpha-1 Antitrypsin protein in the bloodstream. Without the Alpha-1 Antitrypsin protein, white blood cells begin to harm the lungs and lung deterioration occurs. The World Health Organization and the American Thoracic Society recommends that every individual diagnosed with COPD be tested for Alpha-1. For more information about AATD and how to get tested, visit the **ALPHA-1 FOUNDATION WEBSITE** or call **1-877-2 CURE-A1**.

Because not all individuals with COPD have AATD, and because some individuals with COPD have never smoked, it is believed that there are other genetic predispositions to developing COPD. Read about the **COPDGENE™ STUDY** to learn about research to find other genetic causes of Chronic Obstructive Pulmonary Disease.

1 Description from the National Heart, Lung, and Blood Institute (NHLBI) available at: [HTTP://WWW.NHLBI.NIH.GOV/HEALTH/DCI/DISEASES/COPD/COPD\\_CAUSES.HTML](http://www.nhlbi.nih.gov/health/dci/diseases/copd/copd_causes.html). Website last accessed 3/18/08.

2 Statistics on Alpha-1-related COPD available on the Alpha-1 Foundation website at: [HTTP://WWW.ALPHAONE.ORG/ALPHAS/?C=01-WHAT-IS-ALPHA-1-ALPHAS](http://www.alphaone.org/alphas/?C=01-WHAT-IS-ALPHA-1-ALPHAS). WEBSITE LAST ACCESSED 3/18/08.

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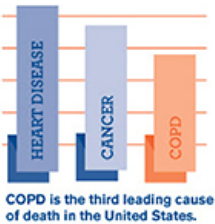
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- COPD Risk Screener
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