COPD

Tracking Perceptions of Individuals Affected, Their Caregivers, and the Physicians Who Diagnose and Treat Them

National Heart, Lung, and Blood Institute

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ABSTRACT

The National Heart, Lung, and Blood Institute (NHLBI) gathered insights about American consumers' and physicians' mindsets around COPD with web-based surveys. American consumers' knowledge and awareness of COPD have increased, with the disease now being recognized by 75% of the respondents. Reflecting the prevalence of COPD among the U.S. population, 4% of the respondents also had the disease and an additional 40% knew or cared for someone with COPD. The fraction of symptomatic patients who disclosed their symptoms to their doctor remained constant at around 73% from 2009 to 2016. Consumers also expressed desire to know more about COPD, its treatment, and the ongoing research. Data from the physicians' survey show that evaluation and diagnosis of COPD continues to rely mainly on patient history, physical examination, and spirometry. Finally, the data confirm pulmonary rehabilitation as an underutilized resource. These data collectively highlight the necessity to: 1) continue awareness campaigns about COPD; 2) increase the communication between patients, their caregivers, and the providers and researchers that treat the disease; and 3) promote and optimize the effective utilization of pulmonary rehabilitation.

BACKGROUND AND OBJECTIVES

Chronic Obstructive Pulmonary Disease, or COPD, is a progressive lung disease that over time makes it hard to breathe. In people with COPD, their air sacs are permanently damaged. The disease can cause coughing that produces large amounts of mucus, wheezing, shortness of breath, chest tightness, and other symptoms. When left untreated, people with COPD gradually lose their stamina and ability to perform daily activities. Other names for COPD include emphysema and chronic bronchitis.

COPD is the third leading cause of death in the U.S., after heart disease and cancer.[1] However, the disease is highly treatable and manageable when detected early.

In the United States, prevalence of COPD in adults 18 years of age and older is 6.5%. More than 15.7 million people are currently diagnosed with COPD and it is estimated that millions more have the disease without realizing it. Part of this may be due to symptoms coming on slowly and worsening over time, causing people affected to make subtle, gradual lifestyle changes to accommodate their changes in health.

The disease is more common than people realize and it disproportionally affects some U.S. ethnic groups, women, and those living in the southern states along the Ohio River Valley.[2] Women are 35% more likely to have COPD than men and more women (52%) die of COPD than men (48%). It is estimated that one of five adults over the age of 45 in the United States suffers from the disease. Smoking is most often associated with COPD, although up to 25% of patients never smoked[3]; other causes may be to blame as well, including long-term exposure to lung irritants—such as dust or fumes in the workplace—second-hand smoke or other air pollutants. In some people, COPD is caused by a genetic condition known as alpha-1 antitrypsin (AAT) deficiency. People with AAT deficiency can get COPD even if they have never smoked or did not have long-term exposure to harmful pollutants. AAT deficiency is an under-recognized condition and estimates suggest that there are currently 100,000 Americans who are homozygotes for the mutation and have the condition but only 15,000 have received the diagnosis. Additionally, studies are underway to address if heterozygotes are susceptible to COPD.[4]

Each year, the National Heart, Lung, and Blood Institute (NHLBI) participates in Porter Novelli's Styles study to gain further understanding of consumer and health care provider mindsets around COPD. The objective of this annual study is to track and gather insights into consumer and health care provider attitudes and behaviors, including disease awareness and knowledge, relationship with the disease, experience of symptoms, patient communication and information, and physicians' approaches to COPD treatment and management. NHLBI uses the information garnered to enhance the outreach activities of its *COPD Learn More Breathe Better®* program, which aims to increase awareness about COPD and encourage people at risk to get diagnosed and treated early.

METHODS

Consumer and physician data for this report were licensed from the Porter Novelli Styles program. ConsumerStyles is an annual series of web-based surveys that gather insights about American consumers, including information about their health attitudes and behaviors. DocStyles is an annual web-based survey conducted among physicians and other health care professionals to gain insight into their attitudes and behaviors concerning a variety of health issues and to assess their use of and trust in available health information sources.

ConsumerStyles 2016

In 2016, the Spring ConsumerStyles wave was conducted among 6,490 adults ages 18 or older who belong to GfK's Knowledge Panel®[5]. The Summer ConsumerStyles survey was sent in June to 6,166 adults who previously completed the spring wave. Respondents were not required to answer any of the questions and could exit the survey at any time. Those who completed the survey received reward points worth approximately $5 and were entered in a monthly sweepstakes. The survey took approximately 30 minutes (median) to complete. A total of 4,203 adults completed the survey for a response rate of 68%. The resulting data were weighted to match the U.S. Current Population Survey proportions for sex, age, household income, race/ethnicity, household size, education level, census region, metro status, and whether or not a respondent had internet access prior to joining the panel.

DocStyles 2016

In June 2016, the DocStyles survey was sent to a random sample of 3,110 health care providers from SERMO's Global Medical Panel[6] which includes over 350,000 medical professionals in the United States. Panelists are verified using a double opt-in sign-up process with telephone confirmation at their place of work. Quotas were set to reach 1,000 primary care physicians (internists and family practitioners), 250 pediatricians, 250 obstetricians/gynecologists, 250 nurse practitioners, and 250 pharmacists. To be eligible to participate, respondents were required to reside in the U.S., see a minimum of 10 patients per week, and have been practicing medicine for at least 3 years. Participation was voluntary and respondents could exit the survey at any time. A total of 2,006 health care providers completed the survey, a response rate of 64%. The sample sizes and response rates per group were: 1,003 primary care physicians (70%), 250 OB/GYNs (71%), 250 pediatricians (68%), 253 nurse practitioners (41%), and 250 pharmacists (70%). Those who completed the survey were paid an honorarium of $21 to $90, depending on the number of questions asked of their specialty.

The primary analyses are based on the 4,203 adult consumers and 1,003 primary care physicians who were asked COPD-related questions in 2016. Where available, trend data is also presented. Methodology, sample sizes, response rates, and demographic characteristics of participants who answered ConsumerStyles from 2008 to 2016 and DocStyles from 2009 to 2016 are provided in Appendix A. Not all columns add to 100% due to rounding or allowance of multiple selections (indicated within each table).

Consumer Awareness and Knowledge of COPD

In 2016, three out of four American adults said that they have heard of chronic obstructive pulmonary disease or COPD. One-fifth indicated they were not aware of COPD and 5% were not sure. Awareness has fluctuated over the past nine years, but has generally increased, from 65% in 2008 to 75% in 2016. Table 1 presents COPD awareness trends.

Table 1. Consumer Awareness 2008-2016

Have you ever heard of a condition called chronic obstructive pulmonary disease or COPD?

	2016	2015	2014	2013	2012	2011	2010	2009	2008
Yes	75%	78%	70%	65%	65%	67%	69%	68%	65%
No	20%	16%	24%	28%	29%	25%	27%	23%	35%
I don't know	5%	6%	6%	7%	6%	8%	4%	9%	NA*

**This answer category was not included in 2008.*

Among the 75% of adults who have heard of COPD in 2016, 86% were accurately categorizing it as a chronic breathing condition when given a list of choices (see Table 2). Only a minority thought it was a heart condition (7%) or blood condition (1%), and 6% were not sure.

Table 2. Consumer Knowledge of COPD

What is COPD? (Asked of those who have heard of COPD)

	2016
A psychological condition	0%
A chronic breathing condition	86%
A heart condition	7%
A blood condition	1%
None of these	1%
Not sure	6%

Consumers' Experience with COPD and its Symptoms

In 2016, four out of ten adults who have heard of COPD reported having personal experience with COPD. While some reported having been diagnosed with COPD themselves (4%), more than a quarter (28%) knew someone who had been diagnosed and 13% knew someone who had died from COPD (see Table 3).

Table 3. Consumers' Relationship with COPD

Which of the following statements describes you?

(Asked of those who have heard of COPD) (Multiple selections allowed)

	2016
I have been diagnosed with COPD	4%
I know someone diagnosed with COPD	28%
I help care for someone with COPD	3%
I know someone who died from COPD	13%
None of the above	60%

It is important to track the presence of COPD symptoms because breathing difficulties represent another way to assess the disease. In 2016, one in ten adults said they have suffered from chronic cough, wheezing, or being too short of breath to do normal activities over the past year. As shown in Table 4, the percentage of adults with symptoms has slightly varied over the past eight years.

Table 4. Symptomatic Adults 2008-2016

Over the past year, have you suffered from chronic cough, wheezing, or being too short of breath to do normal activities?

	2016	2015	2014	2013	2012	2011	2010	2009
Yes	10%	13%	12%	11%	11%	13%	15%	17%
No, I have not suffered from any of these conditions	90%	87%	88%	89%	89%	87%	85%	83%

Patient Communication with Doctors and Information Received

More than seven out of ten adults who suffered from COPD symptoms in 2016 said that they had talked to their doctor about their chronic cough, wheezing, or shortness of breath. The percentage of symptomatic adults who have discussed their symptoms has also fluctuated over the past eight years, with an average of 72.6% (see Table 5).

Table 5. Patient Communication

Have you talked to your doctor about your chronic cough, wheezing, or being too short of breath to do normal activities?

(Among those with symptoms)

	2016	2015	2014	2013	2012	2011	2010	2009
Yes	73%	75%	70%	74%	75%	67%	77%	70%
No, I have not talked to my doctor about these conditions	27%	25%	30%	26%	25%	33%	23%	30%

In 2015, more than half of patients (58%) reported that after talking to their doctors about their symptoms they received a prescription (see Table 6). Four out of ten were given a spirometry test, some said their doctors discussed asthma (38%) or COPD (24%), and 28% were asked about their smoking history. Only one-quarter scheduled a follow-up appointment.

Table 6. Outcomes of Patient-Doctor Discussions

Which of the following happened when you talked to your doctor about your chronic cough, wheezing, or being too short of breath to do normal activities?

(Asked of those who have talked to their doctors about their symptoms) (Multiple selections allowed)

	2015
I received a prescription	58%
I took a test where I blew into a machine	40%
My doctor discussed asthma	38%
My doctor talked to me about my past smoking history/current smoking habit	28%
I scheduled a follow-up with this doctor	25%
My doctor discussed COPD	24%
I received a referral to see another doctor	16%
Nothing changed about my medical care	11%
My doctor told me these were not serious problems	8%
Other	7%

In 2016, half of adults who have personal experience with COPD (have been diagnosed, know someone who has been diagnosed, or care for someone with COPD) indicated that they would be interested in learning about one or more COPD topics. They were most likely to be interested in the effectiveness of new treatments (32%), the availability and effectiveness of current treatments (26%), and what ongoing research is advancing treatments for COPD (24%). Table 7 presents the types of information patients and caregivers are interested in.

Table 7. Desired Patient Information

Choosing from the list below, what would you like to know more about related to COPD?

(Asked among those who have been diagnosed, know someone diagnosed, or care for someone with COPD) (Multiple selections allowed)

	2016
Basic information about COPD/educational materials	23%
Availability/effectiveness of current COPD treatments	26%
The effectiveness of new COPD treatments	32%
Clinical trials for COPD	13%
Emotional support for COPD caregivers and/or patients	10%
Ongoing research to advance treatments for COPD	24%
None of the above	50%

Physicians' Approaches to COPD Evaluation

In 2016, physicians were most likely to assess patients they suspected of having COPD by taking a history and doing a physical examination (77%) and/or using spirometry (71%). Many also used chest imaging (46%) and oximetry (41%). Approximately one-fifth referred patients with COPD symptoms. Table 8 shows that physicians' evaluation practices for COPD from 2009 to 2016 appear to have been rather constant.

Table 8. How Physicians Evaluate COPD: 2009-2016

How do you evaluate patients you suspect of having COPD?

	PCP 2016	PCP 2015	PCP 2014	PCP 2013	PCP 2012	PCP 2011	PCP 2010	PCP 2009
History & physical examination	77%	82%	90%	92%	90%	95%	92%	78%
Spirometry	71%	76%	83%	81%	86%	82%	83%	76%
Chest imaging	46%	46%	64%	NA*	NA	NA	NA	NA
Oximetry	41%	43%	60%	60%	60%	49%	48%	29%
Peak-flow test	37%	39%	46%	46%	36%	36%	31%	24%
A patient questionnaire	28%	26%	35%	37%	28%	28%	17%	17%
Refer patient	18%	16%	24%	22%	18%	21%	18%	10%
None of these	1%	0%	1%	1%	0%	0%	NA	1%

**Answer category was not included where noted.*

Physicians' Perceived Barriers to COPD Diagnosis

In 2015, physicians were asked about the most significant barriers to COPD diagnosis. As shown in Table 9, the key constraints noted by physicians were that patients do not fully report their symptoms (49%) or smoking history (38%), patients have more immediate health issues (41%), and patients are not likely to adhere to treatment (39%). More than a quarter of physicians (26%) noted the cost of testing procedures as an obstacle, while 17% lacked access to diagnostic tests.

Table 9. Perceived Barriers to Diagnosis

Aside from time, which of the following do you see as the most significant issues regarding diagnosis of patients with COPD?

(Up to three selections allowed)

	2015
Patient does not fully report symptoms	49%
Patient has more immediate health issues	41%
Patient is not likely to adhere to treatment	39%
Patient does not fully report smoking history	38%
Cost of testing procedures to patient	26%
Difficult to differentiate COPD from asthma	24%
Lack of access to diagnostic tests	17%
There is no treatment to offer the patient	5%
None of the these	6%

Use of Pulmonary Rehabilitation

More than two-thirds of physicians indicated that there are pulmonary rehabilitation programs available to their patients. Yet only 38% of physicians said that they routinely prescribe pulmonary rehabilitation for their patients diagnosed with COPD. One-third never or rarely did so, and more than a quarter did not prescribe pulmonary rehabilitation because they referred COPD patients to a specialist. Table 10 presents known availability and prescription of pulmonary rehabilitation.

Table 10. Availability and Prescription of Pulmonary Rehabilitation

Are pulmonary rehabilitation programs available to your patients?

	PCP 2016
Yes	68%
No	20%
I don't know	12%

How often do you prescribe pulmonary rehabilitation for patients diagnosed with COPD?

	PCP 2016
Never	5%
Rarely	28%
Most of the time	33%
Always	5%
I don't prescribe this because I refer them to a specialist	28%
I don't treat patients with COPD	1%

DISCUSSION

To gather insights about American consumers and physicians about mindsets around COPD, the National Heart, Lung, and Blood Institute (NHLBI) participates in Porter Novelli's Styles program, an annual series of web-based surveys about health attitudes and behaviors. The data reported here show that American consumers' knowledge and awareness of COPD have increased over time. COPD has progressively become more of a household name from 2008 to 2016 (plus 10%), and most of the respondents now recognize it as chronic breathing condition (86%). Reflecting the latter data and the prevalence of COPD among the >45 U.S. population, 4% of the respondents identified themselves as having the disease and an additional larger fraction as knowing or caring for someone having COPD (40%). Additional data show the proportion of respondents that experience COPD symptoms and have talked to their doctor about them appears, with some fluctuations, to have remained the same during the period 2009-2016 (~13% and ~73%, respectively). Consumers' increase in awareness is clearly accompanied by a desire to know more about the disease, its treatment, and—related to the fact that COPD is so far an incurable disease—the ongoing research that may advance treatments for the disease.

Data from the physicians' survey show that evaluation and diagnosis of COPD relied on patient history, physical examination, and spirometry in the period from 2009 to 2016 (>80% use these tools). Finally, confirming a recent statement from the American Thoracic Society/European Respiratory Society,[7] data show the use of pulmonary rehabilitation remains an underutilized resource, as physicians are aware of programs being available to their patients (68%), but the direct prescription of rehabilitation happens only about 38% of the time.

COPD is the third leading cause of death and the fourth leading cause of disability in the U.S., and disease-associated health care costs are estimated at more than $50 billion annually.[8] The need for awareness and education on the disease remains high. Additionally, the strong levels of personal connections to the disease provide opportunities to reinforce the relevance and reach of COPD to an even wider audience.

The high, and relatively stable, levels of awareness, as well as overall disease knowledge are promising, but one of the major challenges of diagnosing and treating COPD is reflected in the constant number of respondents in the past eight years (Table 5) who have not spoken to their doctor about their symptoms. The doctor-patient communication gap appears to be bilateral: doctors' responses to past DocStyles surveys suggest patients' lack of willingness to report full health symptoms or discuss smoking behaviors contribute to this gap. Patients indicate doctors most often provide a prescription or a test (such as spirometry) but less frequently discuss smoking or asthma, or do nothing. Additional obstacles are represented by the presence in these patients of multi-comorbid conditions and the costs associated with treatments (Table 9).

Survey respondents also indicated a desire for general disease education, and to know more about advancements in COPD research and treatment. At the same time, half of all respondents said they did not want any of the listed resources (Table 7). Additional research could help determine underlying reasons for the responses. People could feel overwhelmed by the disease and opt for less information as a way of avoidance; or could be thinking that finding a cure or a way to prevent the disease all together seem unavailable and out of reach; or the stigma associated to the disease, because of cigarette smoking, could be another possible deterrent.

DISCUSSION

Suffering from COPD is strongly associated with a negative impact on quality of life[9] and patients often cite pulmonary rehab as a key to improving everyday life.[10] While a substantial number of providers are aware of pulmonary rehab in their areas, the percentage of physicians prescribing this type of treatment remains low and just about one third refer their COPD patients to a specialist. The data provide an opportunity to further educate providers and patients and their caregivers on the benefits of intervention.

In summary, these data collectively highlight the necessity to continue campaigns that promote COPD awareness among the U.S. population and point toward two major gaps that need to be filled: 1) increase communication between patients, their caregivers, and the providers and researchers that treat the disease and search for new therapeutic options; and 2) promote and optimize the effective utilization of pulmonary rehabilitation by COPD patients through the help of health care providers.

Limitations

There are several limitations to both the consumer and physician portions of this study. First, all survey data was self-reported and therefore subject to recall and social demand biases. Second, sampling consumers from a web-based panel may have resulted in selection bias. However, research suggests that findings from probability samples reached via random-digit dialing who were invited to join a web-based panel were comparable to surveys conducted via the telephone.[11] Third, while DocStyles is a large, national survey it may not provide a nationally-representative sample in that SERMO only covers 80% of the physicians in the U.S. However, the selection of invited participants using quota sampling has been found to include participants that were demographically comparable (gender, age, average years in practice) with physicians in the AMA Masterfile (unpublished data, Porter Novelli, DocStyles 2016 Methods, Washington DC, 2016). Lastly, for both consumers and physicians, the sampling frames changed over time, which may limit comparability across the total trend span.

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[5]GfK's KnowledgePanel® members are randomly recruited using probability-based sampling and include respondents regardless of whether they have landline phones or Internet access. If needed, households are provided with a web-enabled device and access to the Internet. The panel is continuously replenished and maintains approximately 50,000 panelists.

[6]SERMO is a global market research company. www.sermo.com

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APPENDIX A: TREND DATA METHODS

ConsumerStyles 2008-2016

From 2008 to 2010, ConsumerStyles data was collected using Synovate's mail panel. This opt-in, mail panel of approximately 200,000 households was acquired by Ipsos in 2011. All subsequent ConsumerStyles surveys have been conducted using GfK's Knowledge Panel® which uses probability-based sampling and does not allow opt-in participation. Table 11 shows the unweighted demographic composition of the sample each year as well as the response rates. Non-white participation was higher from 2008 to 2010 because the mail panel surveys specifically oversampled minority respondents as part of the study design.

Table 11: ConsumerStyles Samples 2008-2016 (Unweighted)

	2016	2015	2014	2013	2012	2011	2010	2009	2008
Sample size	4203	4127	4269	4033	4044	4050	4184	4172	5399
Response rate	68%	67%	69%	66%	86%	69%	67%	58%	77%
Gender									
Male	48%	46%	47%	48%	48%	49%	48%	48%	45%
Female	52%	54%	53%	52%	52%	51%	52%	52%	55%
Education									
High school or less	37%	37%	33%	33%	34%	31%	28%	32%	33%
Some college	30%	30%	32%	32%	31%	32%	37%	36%	37%
College degree +	33%	33%	35%	34%	35%	37%	35%	32%	30%
Race/Ethnicity									
White	74%	75%	74%	77%	74%	76%	68%	64%	68%
Black	10%	10%	10%	9%	10%	9%	11%	13%	12%
Hispanic	11%	11%	10%	9%	11%	9%	12%	15%	12%
Other	5%	5%	6%	5%	5%	7%	9%	7%	8%

APPENDIX A: TREND DATA METHODS

DocStyles 2009-2016

From 2009 to 2012, DocStyles was conducted via Epocrates' Honors Panel, an opt-in panel of over 275,000 medical professionals. In 2013 and 2014, DocStyles samples were drawn from World One's Global Medical Panel, which included over 300,000 healthcare professionals in the United States at that time. In 2015, World One's Global Medical Panel was bought by SERMO and renamed SERMO's Global Medical Panel. As of 2016, the SERMO Global Medical Panel has approximately 350,000 medical professionals. Sample sizes, response rates, and demographics for each year are presented in Table 12.

Table 12: DocStyles Primary Care Physician Samples 2009-2016 (Unweighted)

	2016	2015	2014	2013	2012	2011	2010	2009
Sample size	1,003	1,000	1,008	1,006	1,001	1,002	1,000	1,000
Response rate	70%	89%	74%	70%	46%	53%	53%	43%
Gender								
Male	72%	74%	73%	75%	71%	70%	68%	72%
Female	28%	26%	27%	25%	29%	30%	32%	28%
Average age (years)	47.0	45.9	46.0	48.8	46.6	45.4	45.3	45.0
Average years in practice	16.4	15.4	15.3	17.3	15.9	14.5	14.5	14.2
Region								
Northeast	27%	26%	25%	26%	27%	23%	23%	24%
Midwest	21%	23%	23%	23%	22%	24%	21%	22%
South	31%	30%	31%	31%	24%	32%	35%	34%
West	21%	21%	20%	21%	27%	22%	21%	20%

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