COPD NATIONAL ACTION PLAN

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WHY A NATIONAL ACTION PLAN — AND WHY NOW?

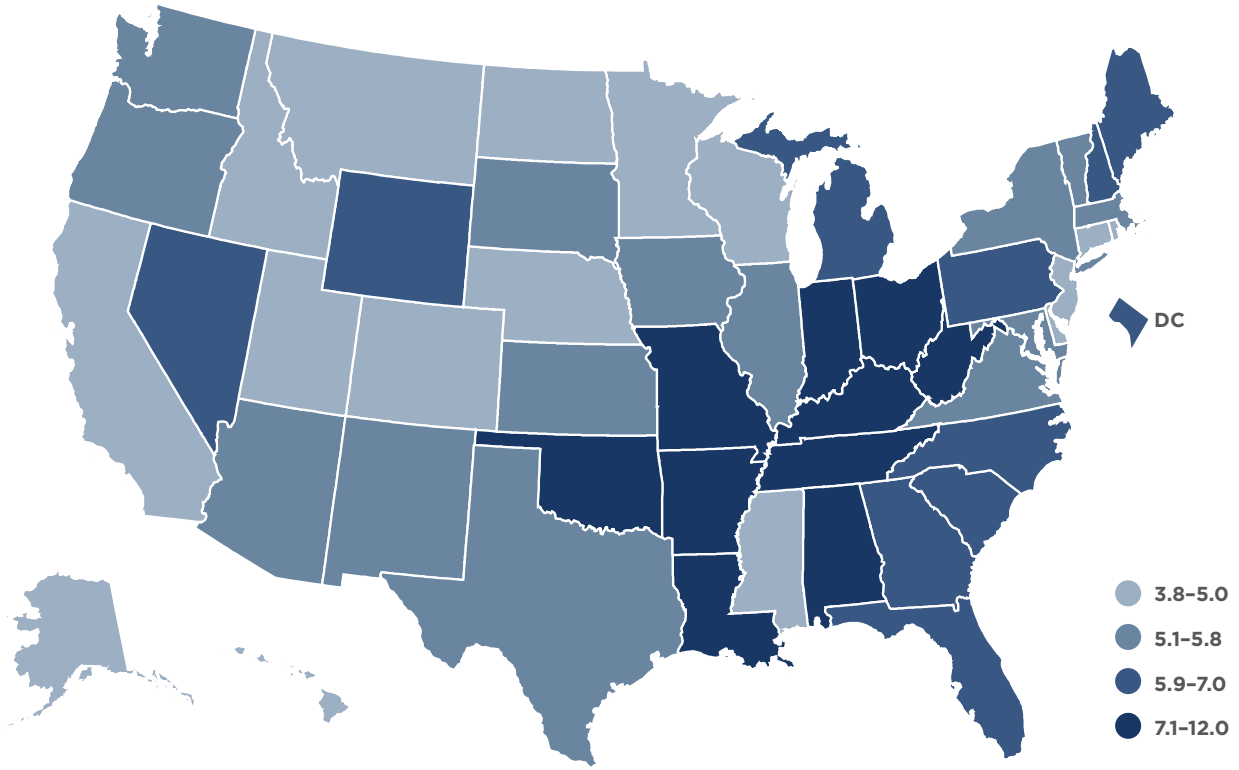
For the 16 million Americans diagnosed with chronic obstructive pulmonary disease (COPD),[2] and the millions of others who do not know they have it,[3] living a normal life can be a daily struggle. The disease not only debilitates; it kills. COPD is the third-leading cause of death in the United States, following heart disease and cancer[1]. Since 1969, the death rate for COPD has doubled, even as the number of deaths for other chronic conditions has declined.[4] COPD is also the fourth main cause of disability in the United States,[5] and it imposes an enormous burden on the nation's health care system. More than $32 billion was spent on COPD-related patient care in 2010, and those costs are projected to increase to $49 billion by 2020.[6]

Addressing the issues around COPD has been difficult. Most COPD cases are preventable, as 8 in 10 COPD deaths are caused by smoking.[7]

Implementing proven strategies to prevent tobacco use (e.g., smoke-free policies, tobacco price increases, and aggressive media campaigns) while increasing smoking-cessation services can reduce smoking and smoking-related COPD. Some states and local communities have developed action plans to improve awareness and treatment of the disease. However, significant differences in the prevalence of the disease — from 11.9 percent in West Virginia to 3.8 percent in Utah[8] — have complicated these and other broader efforts. The bottom line: Despite the work of many and the progress made by some, millions continue to suffer COPD's devastating toll.

A coordinated national approach is now needed to deal with the critical issues around this chronic disease. Along with the steady efforts of researchers seeking a cure and clinicians adopting new tools and therapies for patients, the *COPD National Action Plan* has the potential to change the trajectory of COPD. Developed over the course of a year with input from the COPD community at large, the Action Plan provides a comprehensive, unified framework for action by those affected by the disease and those who care about reducing its burden.

16 MILLION PEOPLE HAVE BEEN DIAGNOSED WITH COPD AND MILLIONS OF OTHERS DO NOT REALIZE THEY MAY HAVE IT.[2,3]



AGE-ADJUSTED PREVALENCE OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) AMONG ADULTS AGED ≥18 YEARS — BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM, UNITED STATES, 2015[8]

For a breakdown of state-by-state data, please see page 58.

MAKING IT HAPPEN

Concerned about the growing incidence of COPD, Members of the Congressional COPD Caucus urged the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) to craft a comprehensive federal plan to tackle the disease.[9] In response, the NIH's National Heart, Lung, and Blood Institute (NHLBI) collaborated with the CDC and other federal partners to organize several interagency workshops that laid the groundwork for a plan. During the workshops, participants discussed and developed several core goals the Action Plan would address. Those initial goals served as the foundation for the national COPD Town Hall Meeting that the NHLBI hosted in early 2016.

During that two-day COPD Town Hall Meeting, federal and nonfederal partners, including patients and their families, participated in breakout groups that informed the development of draft objectives, strategies, and benchmarks for the goals. The comments shared during those breakout groups directly informed the Action Plan as it stands today. Indeed, the engagement of the community remained integral to the Action Plan as its five goals were further refined. Each goal addresses a different aspect of the problems posed by COPD and identifies the various entities in the community that have the capability to deal with those specific issues.

In addition to engaging federal and nonfederal partners and members of the community directly affected by COPD, the NHLBI also invited feedback from the public at large. The latter happened in the fall of 2016, when the NHLBI made a first draft of the *COPD National Action Plan* available for public comment. The NHLBI and other federal partners carefully considered all the comments and used them to finalize the Action Plan, with the understanding that it is a "living" document — subject to revisions as new needs and opportunities to minimize the burden of COPD arise.

GEARING UP

With the completion of this critical first step, the real work can now begin. The community of COPD stakeholders is highly diverse, and its representatives are equipped with different resources because of where they work and the organizations and people they serve. Yet, all can contribute to the successful implementation of the *COPD National Action Plan*. From patients and health care providers to federal partners and advocacy groups, everyone can and must play a role in supporting and moving the *COPD National Action Plan* forward.

THE FIVE GOALS OF THE NATIONAL ACTION PLAN

1. **Empower people with COPD, their families, and caregivers** to recognize and reduce the burden of COPD.
2. **Improve the prevention, diagnosis, treatment, and management of COPD** by improving the quality of care delivered across the health care continuum.
3. **Collect, analyze, report, and disseminate COPD-related public health data** that drive change and track progress.
4. **Increase and sustain research to better understand** the prevention, pathogenesis, diagnosis, treatment, and management of COPD.
5. **Translate national policy, educational, and program recommendations** into research and public health care actions.

WHAT TO KNOW ABOUT COPD

1. How does COPD affect the lungs?

In healthy lungs, the air we breathe goes down bronchial tubes, or airways, that end in tiny air sacs. As these air sacs fill up, they first stretch, then bounce back to their original shape, much like the way a rubber band or balloon might. This elasticity is critical, as it helps move the air in and out of the lungs quickly.

In people with COPD, less air flows in and out of the airways because of one or more of the following:

- The airways and air sacs lose their elastic quality.
- The walls between many of the air sacs are destroyed.
- The airway walls become thick, and airways are narrowed by inflammation.
- The airways make more mucus than usual, which can also clog them.

2. What are the symptoms of COPD?

In some cases, COPD may cause only mild symptoms or no symptoms at all. As a result, people often discount changes in their physical well-being or may adjust their lifestyles to require less breathing (e.g., resting while walking up steps). As the disease progresses, symptoms usually become more severe.

Common signs and symptoms include:

- CONSTANT COUGHING, sometimes called a “smoker’s cough”
- SHORTNESS OF BREATH while doing everyday activities
- INABILITY TO BREATHE EASILY or take a deep breath
- EXCESS MUCUS PRODUCTION coughed up as sputum
- WHEEZING

WHO HAS COPD?

BY ETHNICITY[8]

11% AMERICAN INDIANS/ALASKA NATIVES

10% MULTIRACIAL

6% NON-HISPANIC BLACKS

6% WHITES

3% HISPANICS

3. What are the risk factors associated with COPD?

COPD most often occurs in people with a history of smoking. Approximately 80 percent of COPD deaths are caused by smoking.[7] However, about one-quarter of those affected have never smoked.[2] Exposure to lung irritants — such as air pollution, dust, and chemical or other fumes — in the workplace and exposure to secondhand smoke or air pollutants may contribute to COPD. Genetics can also play a role in the development of COPD; people with a rare condition called alpha-1 antitrypsin (AAT) deficiency are at an increased risk for COPD. Some 20 percent of COPD patients report a history of asthma, which may also be a contributing factor.[10]

The strong association with tobacco use makes COPD highly preventable through interventions that focus on discouraging youth and young adults from starting to smoke, encouraging adults to quit, and providing smoking-cessation support to current smokers. Other efforts include programs and policies aimed at reducing exposure to dust and chemicals in the workplace, as well as exposure to indoor and outdoor air pollutants.

4. How is COPD diagnosed and treated?

A COPD diagnosis is based on signs and symptoms, personal and medical history, and test results.

Lung function tests measure how much air can be breathed in and out, how fast air is breathed out, and how well lungs deliver oxygen to the blood. The main lung function test for COPD is spirometry, but other tests, such as a lung diffusion capacity test, also can be used. Spirometry can detect COPD before symptoms become severe. It is simple and noninvasive — the patient breathes in deeply, then blows as hard as possible into a tube connected to a small machine. The instrument then measures how much air is blown out, and how fast. Other tests to detect and diagnose COPD may include chest X-rays, chest computerized tomography (CT) scans, or oxygen saturation of blood.

While COPD diagnosis and treatment have significantly improved in the past 15 years, developing and implementing effective additional preventive and therapeutic approaches remain the critical focus for the COPD community.

BY GENDER[7]

56% **WOMEN**

44% **MEN**

BY SMOKING HISTORY[2]

38% **CURRENT**

37% **FORMER**

OTHER[2]

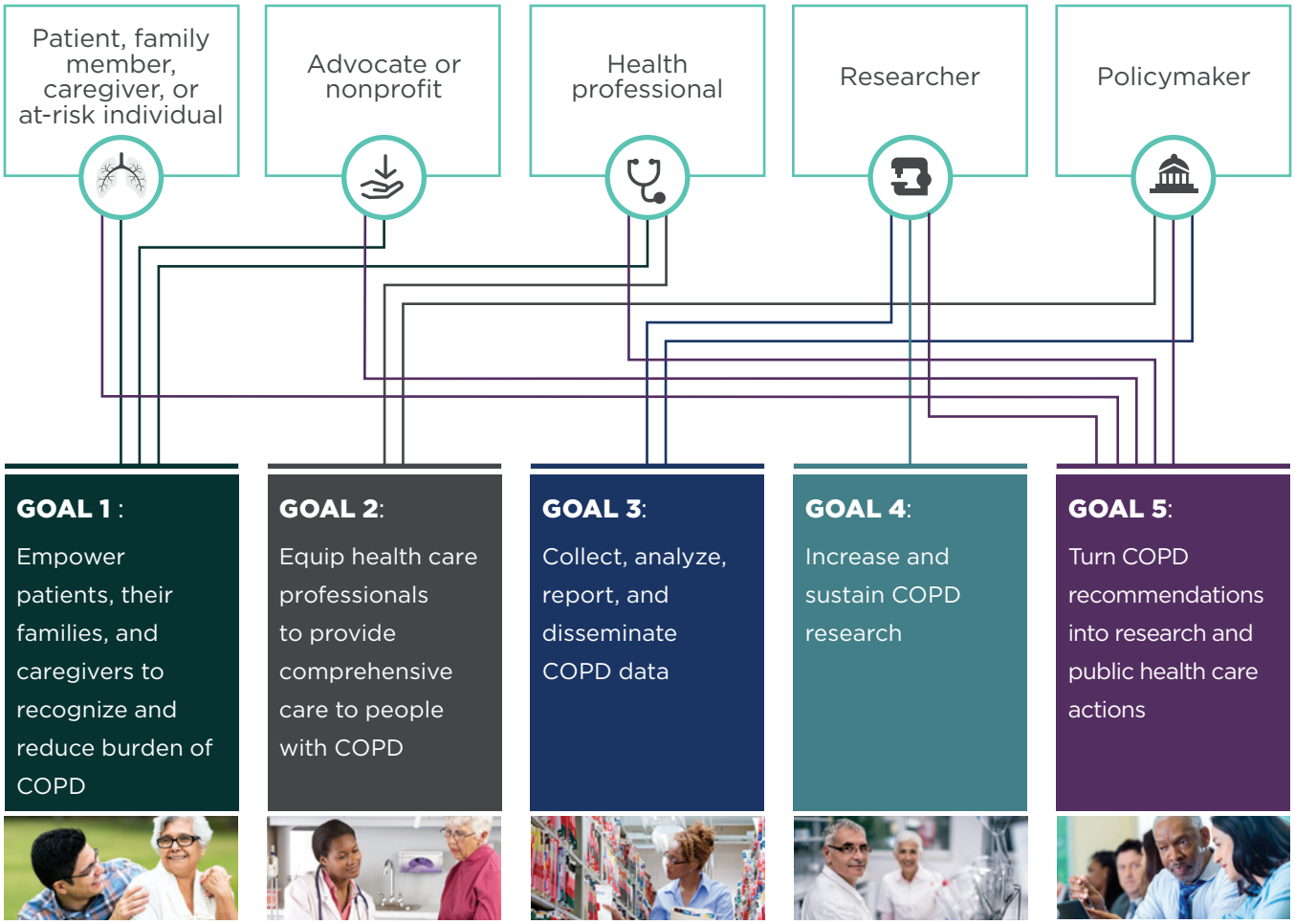
25% **OF CASES** ARE NOT ASSOCIATED WITH DIRECT CIGARETTE SMOKING

HOW YOU MIGHT USE THE COPD NATIONAL ACTION PLAN

To achieve the goals of the *COPD National Action Plan*, it is important that all members of the COPD community get involved.

The chart below can help you identify the Action Plan goals most relevant to you.

WHICH GROUP DO YOU IDENTIFY WITH MOST?



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GOAL 1

Empower people with COPD, their families, and caregivers to recognize and reduce the burden of COPD.

For people with COPD, awareness about this chronic, progressive disease often does not come until well after they have been affected by it. Unfamiliar with the early, nonspecific symptoms, many lose significant lung function before ever seeing a health care provider. It is often not until a hospitalization, a severe respiratory infection, or a noticeable impairment in the ability to perform simple tasks that people living with COPD are diagnosed. As their symptoms worsen, these patients face increasingly difficult challenges carrying on the activities of daily living. They often face daunting emotional challenges, too. Uncertainty about their prognosis and their treatment regimens play a role, as do the anxiety, isolation, depression, and social stigmas — real or perceived — that often come with living with the disease. These challenges affect family members and caregivers alike, and they require attention, care, and understanding.

The first goal of the *COPD National Action Plan* focuses on helping people with COPD, their families, and caregivers recognize the disease through risk and symptom awareness, earlier detection, and diagnosis. It also helps empower these groups by providing information about how best to manage the disease.

1. Increase public awareness of the risk factors and symptoms of COPD so that earlier diagnosis of symptomatic individuals becomes the norm.

a. Review and fully utilize available COPD information and tools, as different organizations may already have resources tailored to their own unique audiences. Create additional resources where gaps exist.

b. Organize information and resources in a range of formats that are culturally relevant to diverse populations, consider health literacy, and ensure the widest possible access.

c. Make the information easily accessible by offering online search capabilities and toll-free access to specially trained operators, peer associates, and experienced COPD health professionals.

d. Expand access to online communities that people with COPD and their caregivers use to share information and support each other.

e. Ensure that health care professionals provide people with COPD and their caregivers multiple avenues that lead to free, reliable, and up-to-date COPD information and resources.

f. Include information to help people with COPD navigate available support programs that provide assistance when they are unable to afford their treatments.

2. Increase the effectiveness and variety of outreach communication campaigns and activities that utilize evidence-based approaches to raise awareness of COPD, particularly among those at high risk, and help people diagnosed with COPD manage the disease.

a. Include messages that focus on risk factors (e.g., smoking, environmental and occupational exposure, and genetic conditions like AAT deficiency), stating what actions should be taken by those at risk and which behavioral interventions (e.g., tobacco cessation, exercise, and nutrition) are available. Include specific messages that help people with COPD and their caregivers manage the disease.

b. Use earned and paid media, online social networks, and other engaging methods to inform individuals and communities at risk for COPD. This could include metrics to measure the communication impact on health care outcomes (e.g., attendance at health fairs, more outlets writing about NIH/CDC-promoted research, and patient narratives).

c. Invest in evaluation research that develops and measures the effectiveness of outreach campaigns. The research should include metrics that measure the scope and health impact of these efforts on patients themselves.

3. Expand opportunities to increase COPD awareness across the public-private spectrum.

a. Identify and engage diverse organizations, including community-based groups, minority health-focused groups, faith-based networks, and groups responsible for public health initiatives, so they can integrate COPD education and awareness activities into their programs.

b. Coordinate existing federal COPD education efforts to ensure that all overarching messages about COPD awareness, prevention, detection, care, and treatment are aligned, comprehensive, and adequately addressed.

c. Increase awareness of the evidence supporting prevention strategies and the value of policies that limit exposure to tobacco and increase access to tobacco-cessation services. These strategies should include but not be limited to:

- Smoke-free policies
- Tobacco-free campuses (businesses, hospitals, etc.)
- Tobacco price increases
- Media campaigns
- Smoking-cessation promotion and outreach

GOAL 1: OPPORTUNITIES FOR ENGAGEMENT AND PARTICIPATION

Share culturally and linguistically appropriate COPD risk assessment tools and educational materials with people with COPD and their families, friends, colleagues, and community members.

Work locally with stakeholders, partners, and communities disproportionately affected by COPD to support disease awareness.

Organize and support local events and activities at hospitals, during community events and activities, and as part of workplace wellness programs; seek local earned media coverage; and utilize existing health observances, including World COPD Day and National COPD Awareness Month.

Develop and execute train-the-trainer programs and distribute educational materials at state and federal levels that have unified messages and calls to action.

Identify and engage new partners who can address COPD, particularly those with the ability to reach populations most affected by the disease, as well as those working on policies aimed at tobacco-use prevention.

GOAL 2

Improve the prevention, diagnosis, treatment, and management of COPD by improving the quality of care delivered across the health care continuum.

Almost every health care professional in the United States is in a position to address the needs of the millions of people at risk for or living with COPD. To achieve Goal 2 of the *COPD National Action Plan*, health care professionals should collaborate to standardize existing training, clinical care tools, and practices and incorporate them into a new set of national standards of care guidelines. These tools and practices should then be used to help provide high-quality, patient-centered, and multidisciplinary, team-based approaches to COPD prevention, care, and treatment, and they should regularly be reviewed and updated. New technologies, tools, and model programs should also be developed and studied to address existing gaps in diagnosis and care.

Tools, practices, and national guidelines should be evidence-based, validated, and culturally appropriate so that every individual with COPD can fully engage in his or her own care. The implementation of these tools should be coordinated across medical disciplines and include training designed to address the needs of people at risk for or living with COPD. The importance of smoking cessation and pulmonary rehabilitation as therapeutic interventions should be made central to evidence-based patient care. Finally, all these recommendations should be translated into research, practice, or public health care actions, as outlined in Goal 5.

An initial review and assessment of care-delivery-focused initiatives, such as new and existing clinical practice guidelines, medical-professional training programs, and quality-improvement programs, will greatly help in achieving this goal, as it will inform the further development of specific COPD programs. The establishment of benchmarks and metrics to monitor accomplishments will help achieve this goal as well.

1. Develop, disseminate, and maintain unified, multidisciplinary, and patient-centric national guidelines for COPD that are accessible and easy to follow.

a. Building upon existing COPD guidelines, like those available from the American Thoracic Society (ATS, *www.thoracic.org/statements/copd.php*) and the Global Initiative for Chronic Lung Disease (GOLD, *www.goldcopd.org*), should create clinical practice guidelines that set consistent national standards for identifying people at risk for COPD as well as diagnosing, caring for, and treating people with COPD across the care continuum.

b. Ensure that all clinical practice guidelines address COPD, reflect the latest evidence-based practices, and meet the Institute of Medicine's Standards for Developing Trustworthy Clinical Practice Guidelines.

c. Ensure that new evidence-based COPD clinical practice guidelines, related summaries, and companion materials are widely available to health care professionals by posting them on the appropriate department websites.

d. Collaborate with federal and nonfederal stakeholders to identify and disseminate current guidelines for best practices for COPD prevention, care, and treatment.

e. Explore ways for the COPD community to broaden its programs to increase awareness and understanding of clinical practice guidelines, with a particular focus on implementation in primary health care settings. In addition, work with specialty medical organizations to develop a national certification program that will support a trained workforce, including primary health care providers, in the medical evaluation, management, and treatment of people at risk for or diagnosed with COPD.

2. Develop a unified, multidisciplinary educational curriculum for health care professionals, including primary health care providers, using harmonized clinical practice guidelines.

a. Assess, create, and distribute educational curricula aimed at improving COPD prevention, care, and treatment. These curricula should be used across multiple health professional disciplines, with a focus on underserved and hard-to-reach populations, and areas with high COPD prevalence.

b. Ensure that the curricula are easy to access and updated regularly to reflect evidence-based best practices for the diagnosis, care, and treatment of COPD, as well as policies related to access to health care services.

c. Develop and disseminate educational programs, materials, and tools in collaboration with primary care organizations, health professional associations, and patient- and community-based groups (e.g., continuing medical education [CME] courses, national certifications, and educational events).

d. Provide COPD training opportunities for federal and state employees working in public health and direct-care programs, including community health workers, pharmacists, and nurses.

3. Develop, in accordance with clinical quality measures, a clinical decision tree and other tools to enable high-quality care for people with COPD.

a. Improve ways to identify people at risk for or living with early COPD and promote the adoption of accurate diagnostic methodologies, including testing for AAT deficiency, as a national standard of care.

b. Collaborate with health insurance plans to ensure their providers and health care professionals are knowledgeable about; are trained in; and, ultimately, adopt the COPD diagnostic recommendations and procedures and use the resources available.

c. Develop a standardized COPD prompt for health care professionals to include in a patient's health assessments and management file, and, ultimately, in the patient's electronic health records (EHRs) and his or her personal health records (PHRs).

d. Create and validate COPD diagnostics with input from federal agencies and their partners, industry, and other organizations. The new diagnostics should distinguish the etiology and pathogenesis of a patient's illness to help tailor treatment and management (personalized medicine) and should be designed for use wherever a patient seeks care.

4. Develop and encourage the use of a written, patient-centric COPD management plan tool, with appropriate cultural and health literacy considerations, which can be customized with input from the patient's health care provider(s). This plan should include the following:

- A patient's daily treatment, such as which medicines to take, when, and why to take them; how to control COPD long term; how to handle worsening COPD or exacerbations; when and how to use oxygen therapy and physical therapy; the importance of medication adherence; and what a patient could expect from optimal therapy and pulmonary-rehabilitation treatments
- An explanation about when to call a health care professional or go to an emergency room; how to recognize the impact of the patient's comorbidities, like lung cancer, cardiovascular disease, and depression/anxiety; and how to treat and manage those comorbidities
- Resources for additional information or assistance, including referrals to patient-support services and customized support for patients who continue to consume tobacco products
- Evidence-based resources that can guide provider and patient conversations, in part by featuring visual aids to help explain COPD, including the signs and symptoms and associated risks, such as exposure to tobacco, environmental and occupational factors, and genetic factors like AAT deficiency

- Information presented in simple, brief formats that are in accordance with health literacy principles, provide culturally appropriate knowledge and understanding for people with COPD, and are medically appropriate for health care professionals
- Information about the appropriate use of spirometry and new diagnostics tools, such as molecular diagnostics and CT scanning, as they are developed

5. Improve access to care for people with COPD, particularly for those in hard-to-reach areas.

a. Create, validate, and implement best practices for the prompt referral of newly diagnosed COPD patients to appropriate services, including pulmonary rehabilitation, smoking-cessation programs, anxiety and depression management, affordable pharmacological treatment, and palliative care.

b. Improve awareness of quality pulmonary-rehabilitation treatment available through Medicare, Medicaid, and private health insurance. Additional recommendations include the following:

   i. Adapt pulmonary-rehabilitation regulations to facilitate broader access to programs outside of the hospital setting.

   ii. Consider opportunities to identify novel ways to help health care providers start and sustain pulmonary-rehabilitation programs and retain patients through the full course of the program — for example, by promoting awareness of best practices and evidence-based guidelines.

c. Improve the affordability of pharmacological treatments for COPD.

   i. Discourage substituting, for nonmedical reasons, one prescription for an inhaled COPD treatment for another.

   ii. Identify novel ways to encourage medication adherence to prescribed treatments.

   iii. Expand access to prescription drug assistance for the uninsured and underinsured, with priority given to those requiring multiple prescriptions per month.

   iv. Facilitate U.S. Food and Drug Administration (FDA) qualification of biomarkers for COPD drug development in order to speed novel treatments to market.

d. Provide coverage and adopt regulations for providing oxygen therapy that meet the full clinical needs of COPD patients and permit ongoing mobility.

e. Encourage the development of COPD-specific technologies (e.g., telemedicine, wearable devices, and mobile technology applications) by federal agencies, their partners, private industry, and other interested organizations. These technologies may improve coordination and personalization of patient care and encourage more effective comprehensive management.

GOAL 2: OPPORTUNITIES FOR ENGAGEMENT AND PARTICIPATION

- **Promote** COPD assessment and treatment guidelines to health care professionals.
- **Incorporate** COPD detection, care, and treatment recommendations into clinical settings.
- **Identify** opportunities to increase health care professionals' awareness and use of existing COPD training, tools, and model programs.
- **Develop** and offer culturally and linguistically appropriate patient resources, including referrals and support services, to further COPD education.
- **Develop,** support, and encourage participation in COPD training programs for health care professionals, particularly primary care practitioners.
- **Use** medical reminders for COPD risk detection during patients' health care visits.
- **Educate** health care professionals about national COPD detection, treatment, and care guidelines.
- **Ask** health care professionals to assess patients for COPD, including the use of spirometry, as appropriate, and then develop a personalized, written (or digital, if preferred) management plan.

GOAL 3

Collect, analyze, report, and disseminate COPD-related public health data that drive change and track progress.

Reliable data are critical for informed decision-making. This is especially so when creating health care resources and when measuring the success of new risk-identification methods, early detection methods, health care policies, and care-delivery efforts. Health data that measure the prevalence and characteristics of COPD, patterns of treatment, and patient outcomes form the basis for the effective prevention and diagnosis of COPD as well as for the treatment of people at risk for or living with the disease.

Goal 3 of the *COPD National Action Plan* addresses the need to close data gaps by encouraging increased and coordinated data collection, validation, analyses, sharing, and real-world application of these data as they are collected. The adoption of secure health information technology (HIT), the use of EHRs/PHRs, and the creation of large-scale patient registries can greatly enhance the ability to capture and collect patient-level data. The National Center for Health Statistics (NCHS), part of the CDC, conducts the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES), the National Ambulatory Medical Care Survey (NAMCS), the National Hospital Ambulatory Medical Care Survey (NHAMCS), and the National Hospital Care Survey (NHCS). NCHS also collects mortality records through the National Vital Statistics System. These data-collection systems represent the foremost sources of population surveillance data.[11] Other population data, including data from U.S. Census Bureau surveys, the Behavioral Risk Factor Surveillance System (BRFSS), and NCHS provider surveys, could also reveal trends that spur new policies, resource allocations, or budget modifications.

Data needs may be addressed if federal and nonfederal partners consider developing new infrastructures and alliances within their existing organizations. This kind of development could have a far-reaching effect, inspiring new ways to assess COPD prevalence and engage in predictive modeling more broadly. The stakeholders involved in these efforts also must ensure widespread and meaningful dissemination of data analyses.

1. Enhance and optimize our capacity to collect and aggregate data from multiple sources, including at local, regional, and national levels, and turn them into actionable information.

a. Develop standardized data-collection methods using harmonized definitions and core indicators to monitor the prevalence, care, and treatment of people with COPD, including those with AAT deficiency.

   i. Strengthen the surveillance and reporting capacity of state and local health departments by urging primary care providers to collect and report COPD surveillance data to these authorities.

   ii. Improve the accessibility of EHRs/PHRs, claims data, pharmacy-benefit data, patient reported-outcomes data, and other electronic data for use in COPD surveillance and measurement efforts.

   iii. Upgrade surveillance information technology as a way to improve the exchange of data among reporting entities, such as health systems; state and local health departments; and agencies such as the CDC, the Centers for Medicare & Medicaid Services (CMS), and the Veterans Health Administration (VHA).

   iv. Conduct surveys and special studies designed to investigate populations at risk, occupational and environmental factors, geographic variations (e.g., rural versus urban), disease attributes (e.g., lung function and physical function), demographic factors (e.g., gender, age, and ethnicity), access to care, and other disparities in health services for people with COPD.

b. Improve data compatibility for aggregation and analyses.

   i. Enlist federal and nonfederal partners to develop protocols for the collection, storage, and sharing of COPD data from various sources; to help ensure that the data analyses draw from these sources, including clinical-trial data, observational data, and patient-registry data, as well as protocols and algorithms, in the collection efforts.

   ii. Utilize aggregated data to describe how COPD and related prevention, care, and treatment programs influence health and morbidity.

   iii. Incorporate International Classification of Diseases (ICD) codes into COPD surveillance, and ensure that COPD diagnostic codes (ICD-9, ICD-10, and thereafter) are required for EHR certification.

c. Capture and analyze surveillance data from people with COPD, identify trends to better predict the prevalence and burden of COPD, and accurately describe the public health impact.

   i. Comprehensively and regularly monitor the prevalence and incidence of COPD at the national, state, and local levels.

   ii. Monitor the use and impact of validated assessment tools to detect and diagnose COPD, particularly in at-risk populations.

   iii. Assess the national availability and use of pulmonary-rehabilitation services using CMS, VHA, and commercial-payer data; this can assist with interventions designed to target underserved areas.

   iv. Monitor the delivery and impact of COPD care and treatment, including pulmonary rehabilitation.

   v. Monitor and assess the relationship between comorbidities and COPD morbidity and mortality.

2. Facilitate dissemination of data and analyses.

a. Report findings of federal COPD surveillance initiatives in a biannual report on the national burden of COPD in the United States, including prevalence, mortality, related health indicators, and care-delivery measurements.

   i. Regularly report COPD surveillance data through established federal channels (e.g., CDC surveillance reports and Agency for Healthcare Research and Quality [AHRQ] briefs) then make that data available to the public in an easily accessible format.

   ii. Proactively disseminate the findings of COPD surveillance studies to diverse stakeholders.

   iii. Encourage federal and nonfederal partners to publish outcomes of COPD data analyses using scientific-exchange (e.g., peer-review) opportunities.

b. Conduct studies that assess all aspects of existing and new models of detection, care, and treatment for people living with COPD, including studies addressing barriers to care and rehabilitation services.

GOAL 3: OPPORTUNITIES FOR ENGAGEMENT AND PARTICIPATION

Report the prevalence of COPD in accordance with the requirements of public health and health care organizations.

Work with public health authorities to improve the thoroughness and quality of COPD surveillance data.

Use EHR/PHR technology to assess and evaluate the capacity to monitor and control COPD and related services.

Collect detailed information about population-specific health disparities in COPD prevention, diagnosis, care, and treatment.

Promote research that tracks the prevalence and incidence of COPD, including its phenotypes.

Create or continue to build existing COPD patient registries that help evaluate and improve patient management, clinical care, and treatment.

Support surveillance projects and epidemiological investigations to help understand the characteristics and needs of people at risk for and living with COPD.

Create a common portal database and make its use publicly accessible in order to evaluate and enable predictive modeling.

GOAL 4

Increase and sustain research to better understand the prevention, pathogenesis, diagnosis, treatment, and management of COPD.

With this goal, the *COPD National Action Plan* focuses on the need to characterize the many contributing risk factors and underlying mechanisms in COPD. This goal aims to improve understanding of the causes and progression of COPD; the different forms of the disease; and its prevention, diagnosis, and treatment. Translation of basic research to clinical applications can yield improved methods of diagnosis and symptom management, as well as treatments that are health-preserving and disease-arresting or -reversing. Of particular importance is research aimed at improving the identification of people at risk for COPD and those in the early stages of COPD development, since early detection provides the best opportunity for disease management.

Despite what is known about the association between smoking and COPD, other, lesser-known and unknown causes of COPD do exist. Because COPD develops, progresses, and manifests in different ways, many factors likely influence how people with COPD respond to treatment. Therefore, research supported by the Precision Medicine Initiative, and NHLBI COPD efforts like the COPDGene and SPIROMICS projects, could help unravel the underlying biology and, coupled with advanced imaging, allow for a better understanding of the different COPD clinical phenotypes, the role of comorbidities, and the efficacy and safety of interventions and treatments at an individual level. Such patient-powered research holds promise for the acceleration of COPD discoveries and will provide health care professionals with new tools, knowledge, and targeted therapies that make it easier to choose the treatments best suited for each individual with COPD.

1. Help expand, coordinate, and optimize COPD research efforts.

a. Advance short- and long-term priorities across all phases of COPD research. This should leverage synergistic partnerships and include the following:

   i. Characterization of the biological basis of COPD, including genetic, environmental, and occupational risk factors; molecular and cellular systems involved in pathobiology; and the pathophysiological mechanisms of symptom development, disease progression, and comorbidities.

   ii. Identification of biomarkers and clinical measures useful for the early detection, prognosis, and targeting of precise therapeutics.

   iii. Development and testing of therapies, especially those involving novel molecular targets or specific groups of patients.

   iv. Implementation of effective approaches for diagnosis and treatment in ways that maximize the impact on public health and are accessible to everyone in the United States.

b. Encourage more patients and underrepresented populations to participate in all types of research, including patient registry efforts and clinical trials.

c. Improve access to databases and patient-centered registries for use in research.

   i. Use aggregated patient EHRs and real-world observational data to monitor how patients with COPD are diagnosed, cared for, and treated.

   ii. Share secure, anonymized clinical trial data (culled from shared data repositories) for use in secondary analyses.

   iii. Facilitate cross-communication among scientists, practicing health care professionals, and patients throughout the research process (research planning, participant recruitment, study execution, and dissemination and adoption of results).

2. Improve methods for earliest detection and diagnosis and develop effective strategies for preventing the onset and progression of COPD.

a. Improve the quality of COPD detection and diagnostic technologies, and increase the use of validated technologies as alternatives to spirometry, in clinical and other settings. This can be done by developing and defining performance measures for COPD risk identification and earliest detection. These efforts would be informed by scientific evidence and with input from patients, professional and medical organizations, private industry, and other relevant stakeholders.

b. Encourage the development of new, highly sensitive and rapid diagnostics tools, such as those that identify biomarkers, and encourage their use in molecular diagnostics. Additionally, enable the submission of biomarkers for FDA approval so they can be used in clinical trials and practice.

c. Improve the quality of COPD prevention strategies for people at risk.

   i. Develop and test models for detecting COPD that can be adapted and used in different health care settings and with diverse populations; these models will help identify and reach people at risk for COPD, including nonsmokers and those with a genetic predisposition, such as AAT deficiency, those being screened for lung cancer, and those with concurrent asthma.

   ii. Develop and test COPD interventions, including those related to nutrition and behavior, in home and routine care settings; this can help determine how to modify risk factors for COPD, reduce the frequency or severity of exacerbations, and prevent the progression of the disease.

   iii. Use community-based research to pilot-test the effectiveness of detection and prevention programs designed to reach underserved and culturally diverse populations and those at risk for COPD.

3. Define and characterize the pathogenesis of COPD heterogeneity.

a. Facilitate and encourage basic science research about the underlying mechanisms that contribute to the development of different COPD clinical phenotypes.

   i. Develop and apply new animal models, cell models, and human-tissue resources to explore the full range of causes of COPD.

   ii. Collect and analyze genomic and biomarker data to further characterize COPD phenotypes.

4. Develop personalized medicine for COPD based on the pathogenesis and clinical heterogeneity.

a. Facilitate and encourage the translation of basic science COPD etiology and pathogenesis studies into epidemiology and clinical research involving patients with different COPD phenotypes.

   i. Develop and validate new diagnostic tests to screen people by COPD phenotype who are at risk for or already diagnosed with the disease; this will help refine personalized care and treatment programs.

   ii. Develop and test new precision medicine treatments for people diagnosed with COPD based on COPD phenotypes.

   iii. Develop new care programs for people diagnosed with COPD based on COPD phenotypes for their use in health care and other settings.

   iv. Include the full spectrum of people with COPD, comprehensive of AAT-deficient patients, in clinical studies.

5. Promote research that can lead to strategies that help prevent the onset and progression of COPD and improve the quality of COPD care and management.

a. Investigate how access to care affects the treatment for people diagnosed with COPD.

   i. Study the clinical effectiveness of patient-centered treatments, including quality of life and functionality as outcome measures.

   ii. Conduct research on the progression of subclinical disease to overt disease.

   iii. Conduct research to identify the most effective structure and components of a pulmonary-rehabilitation program, including the most effective length and number of sessions, the effects of different educational components and delivery strategies, and the most effective way to provide rehabilitation in rural areas.

b. Support clinical effectiveness and treatment-outcomes research to obtain findings that can be translated into models of care that then can be tested and adapted for use in different health care and clinical settings (T3/T4 space).

c. Conduct research on the effectiveness of COPD-focused policies and programs.

   i. Evaluate COPD-focused policies, public health interventions, and programs by using predefined, evidence-based performance metrics.

   ii. Develop value-based return-on-investment models using research that describes the effectiveness of current COPD programs and policies.

GOAL 4: OPPORTUNITIES FOR ENGAGEMENT AND PARTICIPATION

Invest in, facilitate, and promote basic, clinical, and applied research to improve the diagnosis and treatment of people with COPD; assess the impact of the home environment on patient management and treatment.

Create COPD patient registries that help evaluate and improve patient management, clinical care, and treatment.

Invest in, facilitate, and promote the development, regulatory review and approval, and use of new technologies to improve the COPD care continuum.

Investigate the biological effects of nicotine and its delivery devices and products to better understand emerging threats to lung health that may modify the onset or progression of COPD.

Promote the inclusion of information relevant to COPD in programs for training medical professionals and the next generation of biomedical scientists.

Identify risk factors and targets for preventive interventions for chronic lung disease using ongoing NHLBI-supported cohort studies. Test the feasibility of strategies for the prevention of COPD and demonstrate proof of principle in early phase clinical studies.

Leverage NHLBI-funded programs, such as LungMAP, to develop novel approaches for cell-based therapies and lung regeneration that could be applied in late-stage emphysema.

Leverage observational cohorts, such as the NHLBI-supported COPDGene and SPIROMICS studies, to identify subgroups of patients with COPD in which particular molecular pathways or pathophysiological mechanisms are critical in pathogenesis. Develop and test panels of biomarkers that can be used to identify individual patients within these subgroups.

Conduct clinical trials for COPD that are designed to allow analysis of efficacy in predefined subgroups of subjects, thereby providing an evidence base for precision medicine. This applies both to trials of drugs that target particular molecular pathways and to trials of other interventions, such as pulmonary rehabilitation.

Design and test novel approaches for better implementation of effective strategies for the case finding, diagnosis, and treatment of COPD in the community, home, and primary medical care environments.

Investigate the prevalence and incidence of COPD in nonsmokers to contrast and compare them — and their responsiveness to currently available therapeutics — to patients with cigarette-smoke-induced COPD.

GOAL 5

Translate national policy, educational, and program recommendations into research and public health care actions.

This goal calls for federal and nonfederal partners to collaborate to meet the objectives of the *COPD National Action Plan* and translate its recommendations into actions.

All involved need to work together to make funding available for a variety of activities and allow all interested to participate.

1. Put into action prevention strategies that are proven effective in addressing the 80 percent of COPD deaths due to smoking.[7]

a. Support initiatives and activities that promote a tobacco-free society. Evidence-based approaches already exist and include, but are not limited to, smoke-free and tobacco-free policies, large-scale, strategically-placed media campaigns, and tobacco price increases.

2. Create a collaborative official entity that implements, prioritizes, and tracks activities in accordance with the *COPD National Action Plan*'s goals and objectives.

a. Create an official entity tasked to oversee and support the implementation and tracking of the *COPD National Action Plan*. This entity should be established with the following considerations:

   i. Hosted and supported by the Department of Health and Human Services (HHS) and include representatives from federal and nonfederal partners, including patients; and permit regular engagement to foster the collaboration and coordination of efforts.

   ii. Charged with prioritizing and tracking the five goals of the *COPD National Action Plan* through biannual reporting; implementation of tactics will be the responsibility of federal and nonfederal partners, as outlined in the *COPD National Action Plan.*

iii. Encumbered with an equal governance role for patients and caregivers affected by COPD.

iv. Composed of, minimally, representatives from the CDC (including its National Centers for Chronic Disease Prevention and Health Promotion [NCCDPHP] and the National Institute for Occupational Safety and Health [NIOSH]), CMS, NIH (NHLBI), the Department of Defense (DoD), VHA, the Health Resources and Services Administration (HRSA), and AHRQ.

3. Identify and publicize funding opportunities that advance the implementation of the *COPD National Action Plan*.

a. Develop an easily accessible resource guide to COPD research-funding opportunities offered by federal and nonfederal partners, including patient registries and other channels that speed access to clinical trials. In particular, increase the awareness and visibility of investigator-initiated research about COPD, including AAT deficiency.

b. Develop and implement a process for including new nonfederal funding partners, such as public-private advisory boards, in the resource guide.

c. Develop a mechanism to regularly share resources and funding opportunities with all interested parties (e.g., via a dedicated website or newsletter).

4. Develop and implement COPD quality measures into national care delivery.

a. Use existing and still-developing performance-quality measures that are informed by scientific evidence and input from various COPD stakeholders (e.g., payers, professional associations, medical organizations, private industry, and patient advocacy organizations). Then work with federal agencies to encourage the adoption of those measures to improve COPD detection, care, and treatment in health care settings and payer programs.

   i. Define, validate, and disseminate performance-quality measures for the COPD continuum of care, including measurements for patient services in private and public health plans, pulmonary rehabilitation, and associated reimbursements.

   ii. Encourage health systems to incorporate COPD into current health and community assessments, such as the Community Health Needs Assessment Surveys.

   iii. Obtain patient input when developing new quality measures and new alternative-payment models and treatment guidelines. This feedback will help ensure that care remains patient-centered and tailored to help patients achieve their goals.

5. Strengthen the public health infrastructure for addressing COPD.

a. Support all 50 states, the District of Columbia, and U.S. territories in the development of comprehensive, statewide COPD action plans that include public health interventions, patient education efforts, and the creation of public-private partnerships to implement the initiatives specified within the individual state plans and the *COPD National Action Plan*.

b. Incorporate COPD into state and local health department programs that focus on chronic disease prevention, tobacco prevention, general health promotion and education, and other relevant health initiatives.

c. Improve the delivery and coordination of community services to support COPD patients.

d. Use the Whole School, Whole Community, and Whole Child Model to address tobacco use and other risk factors for COPD.

e. Create a formal, standardized national certificate program for COPD peer coaches and health educators.

f. Incorporate COPD into prevention, awareness, surveillance, and management programs that encompass the range of risk factors and common comorbidities of COPD.

GOAL 5: OPPORTUNITIES FOR ENGAGEMENT AND PARTICIPATION

- **Create** quality-control performance metrics for COPD detection, care, and treatment.
- **Encourage** the adoption and use of performance metrics for COPD detection, care, treatment, and prevention.
- **Assess** the progress of the *COPD National Action Plan*'s initiatives biannually.
- **Share** information about the *COPD National Action Plan*'s performance.

ORGANIZATIONS

The organizations below represent groups that have an interest in COPD and the *COPD National Action Plan*, including federal partners and those organizations that attended the COPD Town Hall Meeting or provided comments during the public comment period.

NAME	DESCRIPTION
Agency for Healthcare Research and Quality Government	The Agency for Healthcare Research and Quality strives to make health care safer, better, and more accessible. The agency works with the U.S. Department of Health and Human Services and partners to ensure that evidence-based research is used to improve the delivery of health care in the United States. In addition to funding health delivery system research, the agency offers resources that support people with chronic health conditions and that help empower patients and families through shared decision-making. › *www.ahrq.gov*
All About You Homecare Services Health Care Organization	All About You Homecare Services is a nurse-owned and -operated agency offering skilled nursing, physical therapy, occupational therapy, respiratory therapy evaluation, and home health aides. All About You specializes in caring for patients with respiratory disease using a pulmonary pathway. It offers referrals for outpatient pulmonary rehabilitation, support groups, and 90-day follow up phone calls to those in treatment. › *www.aayct.com*
Alpha-1 Foundation Nonprofit	The Alpha-1 Foundation promotes research and the development of new therapies for improving the quality of life for those diagnosed with alpha-1 antitrypsin (AAT) deficiency. The foundation is committed to finding a cure for AAT deficiency and improving the lives of people affected worldwide. › *www.alpha1.org*
American Academy of Family Physicians Health Care Professional Association	The American Academy of Family Physicians advocates for high quality standards for family doctors. It is one of the world's largest medical organizations, with nearly 125,000 members in 50 states and abroad. The association was founded in 1947. › *www.aafp.org*
American Association for Respiratory Care Health Care Professional Association	The American Association for Respiratory Care advances the science and practice of respiratory care, encourages and promotes professional excellence, and serves as an advocate for patients and their families, the public, and the respiratory care profession. › *www.aarc.org*
American Association of Cardiovascular and Pulmonary Rehabilitation Health Care Professional Association	The American Association of Cardiovascular and Pulmonary Rehabilitation is composed of health professionals who work in the field of cardiac and pulmonary rehabilitation. Members include cardiovascular and pulmonary physicians, nurses, exercise physiologists, physical therapists, behavioral scientists, respiratory therapists, dieticians, and nutritionists. › *www.aacvpr.org*

NAME	DESCRIPTION
American College of Allergy, Asthma, and Immunology Health Care Professional Association	The American College of Allergy, Asthma, and Immunology advocates for those suffering from asthma and allergies, and educates the public about symptoms and allergist care and treatment. › *www.acaai.org*
American College of Chest Physicians Health Care Professional Association	The American College of Chest Physicians seeks to advance best patient outcomes through innovative chest medicine education and clinical research. › *www.chestnet.org*
American College of Preventive Medicine Health Care Professional Association	The American College of Preventive Medicine focuses on the health of communities, individuals, and populations through the work of physicians dedicated to prevention. Its goal is to protect, promote, and maintain health and well-being, and to prevent disease, disability, and death. › *www.acpm.org*
American Lung Association Nonprofit	The American Lung Association is committed to supporting those affected by COPD. The association offers a variety of resources and information about the disease. Resources include Better Breathers Clubs, COPD Management Plan, and a Living with COPD Online Support Community for those affected and their families. The association is a source for lung health education, lung disease research, support, programs, services, and advocacy. › *www.lung.org*
American Thoracic Society Health Care Professional Association	The American Thoracic Society is dedicated to understanding pulmonary diseases, critical illnesses, and sleep-related breathing disorders. Founded in 1905, the society has grown into an international society with more than 15,000 members. › *www.thoracic.org*
Ascension Health Care Organization	Ascension is the largest nonprofit health system in the United States and the world's largest Catholic health system, operating 2,500 sites of care — including 141 hospitals and more than 30 senior living facilities — in 24 states and the District of Columbia. Ascension is committed to delivering compassionate, personalized care to all, with special attention to persons living in poverty and others in vulnerable situations. › *www.stagnes.org*
AstraZeneca Industry	AstraZeneca counts respiratory disease as one of its main therapy areas, as evidenced by its growing portfolio of respiratory medicines. In 2015, those treatments reached more than 17 million patients. AstraZeneca aims to transform asthma and COPD treatment through inhaled combinations for those needing basic care, biologics for the unmet needs of specific patient populations, and scientific advancements that help with disease modification. › *www.astrazeneca.com*
Atlantic General Hospital Health Care Organization	Atlantic General Hospital is a nonprofit community hospital in Berlin, Md., that offers acute care and specialty services. With a network of more than 30 family physicians, internists, and specialists with offices in 10 locations throughout the region, the hospital and its health system serve the health care and wellness needs of residents and visitors across the Eastern Shore. › *www.atlanticgeneral.org*

NAME	DESCRIPTION
Boehringer Ingelheim Industry	Boehringer Ingelheim has been committed for nearly a century to researching the science of serious respiratory diseases and providing therapies to help people living with them. To treat COPD, Boehringer Ingelheim has developed six FDA-approved medicines and is committed to doing more research that could help and support the COPD community further. › *www.boehringer-ingelheim.com*
Breathe Easy Home Industry	Breathe Easy Home educates homeowners and contractors on ways to improve homes for people with respiratory issues. It developed the Breathe Easy Home Indoor Air Quality System, which helps remove allergy and asthma triggers, along with other irritants and pollutants, from a home's indoor environment. › *www.breatheeasyhome.org*
BREATHE LA Advocacy	BREATHE LA, founded in 1903, promotes clean air and lungs through research, education, and technology. BREATHE LA aims to eliminate causes of lung disease and reduce the pain and discomfort of those affected by lung diseases in California. › *www.breathela.org*
Breathe New Hampshire Nonprofit	Breathe New Hampshire focuses on issues related to lung health, such as tobacco use, COPD, asthma, air quality, and lung cancer. It provides educational programs and supports public health advocacy and scientific research focused on preventing, eliminating, and treating lung disease. › *www.breathenh.org*
Carolina Diagnostic Solutions Industry	Carolina Diagnostic Solutions provides pulmonary diagnostic equipment, testing supplies, and asthma and COPD management tools to the health care industry. Additionally, Carolina Diagnostic Solutions' respiratory therapists provide a wide range of diagnostic testing, patient education, and specialized disease management in multiple settings. › *www.carolinadiagnosticsolutions.com*
Carolinas HealthCare System Health Care Organization	Carolinas HealthCare System serves nearly 12 million patients each year throughout the Southeast. It has some 900 locations, ranging from hospitals and freestanding emergency departments to home health agencies and outpatient centers. › *www.carolinashealthcare.org*
Carroll Hospital Health Care Organization	Carroll Hospital is a portal of health and wellness, serving the greater Baltimore area. The hospital aims to improve the health of patients through care management and delivery of high-quality, low-cost services in the most appropriate settings. Carroll Hospital is a division of LifeBridge Health and is advancing in areas such as cardiovascular, cancer, surgery, and outpatient services. › *www.carrollhospitalcenter.org*
Case Western Reserve University School of Medicine Academic	Case Western Reserve University School of Medicine, in Cleveland, Ohio, is dedicated to enhancing human health in the fields of medical education and biomedical research and development. Founded in 1843, the school trains more than 800 students each year. › *www.case.edu*

NAME	DESCRIPTION
Centers for Disease Control and Prevention Government	The Centers for Disease Control and Prevention increases the health security of Americans and works to protect citizens from health threats. As the nation's health protection agency, the CDC conducts surveillance of chronic diseases, including COPD, to better understand the extent of health risk behaviors, preventive care practices, disease prevalence, disability, and death; to monitor the progress of prevention efforts; and to help public health professionals and policy makers make more timely and effective decisions. › *www.cdc.gov*
Centers for Medicare & Medicaid Services, U.S. Department of Health and Human Services Government	The Centers for Medicare & Medicaid Services administers Medicare, Medicaid, the Children's Health Insurance Program, and the Health Insurance Marketplace, all of which aim for more affordable, better care. › *www.cms.gov*
Children's National Medical Systems Health Care Organization	The Children's National Health System is a children's health care system in the Washington, D.C., area that focuses on clinical care, advocacy, research, and education for children. The system is dedicated to caring for children, their families, and the community with primary and specialty health professionals. › *www.childrensnational.org*
Clear Lungs Adventure Nonprofit	Clear Lungs Adventure raises awareness for early screening and diagnosis of progressive lung diseases, while demonstrating the power of older athletes to be role models and ambassadors for healthy and active living. Clear Lungs Adventure sponsors a series of 12 climbs in seven destinations for people affected by COPD. › *www.clearlungsadventure.com*
Cleveland Clinic Respiratory Institute Health Care Organization	The Cleveland Clinic Respiratory Institute provides patient care through clinical expertise, research, and education. With more than 100 pulmonologists, allergists, immunologists, and critical care specialists, Cleveland Clinic treats a wide range of lung, allergy and breathing-related conditions. › *www.clevelandclinic.org*
Colorado COPD Coalition Advocacy	The Colorado COPD Coalition was founded in 2006 and is made up of Colorado health professionals, patients, research scientists, industry representatives, state officials, and caregivers. Its mission is to address the health crisis of COPD by increasing awareness, prevention, and screening. › *www.coloradocopdcoalition.org*
Columbia University Academic	Columbia University Medical Center provides leadership in scientific research, health and medical education, and patient care. The center has more than 40 active research and clinical programs. › *www.cumc.columbia.edu*
COPD Foundation Nonprofit	The COPD Foundation was established to improve the lives of those affected by COPD and is the only U.S. health care nonprofit solely dedicated to preventing and curing the disease. Founded in 2004, the foundation focuses on helping those with COPD through research, education, and advocacy programs. It helps speed innovations that provide more effective and affordable treatments to those with COPD. › *www.copdfoundation.org*

NAME	DESCRIPTION
Culpeper Medical Center Health Care Organization	The Culpeper Medical Center partners with pediatric and adult pulmonologists who specialize in treating respiratory disorders. Culpeper Memorial Hospital is part of the University of Virginia Health System and provides services in all areas of health care. › *www.uvaculpeperhospital.com*
Department of Veterans Affairs Government	The Department of Veterans Affairs (VA) operates the nation's largest integrated health care system, with more than 1,700 hospitals, clinics, community living centers, readjustment counseling centers, and other facilities. The VA provides COPD resources and treatment for people with the disease. › *www.va.gov*
Dorney-Koppel Family Charitable Foundation, Inc. Nonprofit	The Dorney-Koppel Family Charitable Foundation, founded in 1999, is named for Grace Dorney-Koppel, wife of television newsman Ted Koppel. Dorney-Koppel, who was diagnosed with COPD more than 16 years ago, has become a national spokesperson for those with chronic breathing conditions. The foundation has helped fund the creation of pulmonary and cardiac rehabilitation clinics in Maryland, West Virginia, Louisiana, and North Carolina. › *N/A*
Duke University Health System Academic	The Duke University Health System combines educational, research, policy, and patient care programs. Duke Health helps manage COPD symptoms through an experienced personal care team and actively conducts research on COPD treatments. › *www.dukehealth.org*
Emphysema Foundation For Our Right To Survive Nonprofit	The Emphysema Foundation For Our Right To Survive (EFFORTS) is a nonprofit organization that seeks to support individuals who suffer with emphysema, a chronic obstructive pulmonary disease. › *www.emphysema.net*
Erlanger Health Health Care Organization	Erlanger Health's pulmonary rehabilitation program aims to help people with restrictive lung impairments lead more active lives. The certified program involves exercise, education, and support tailored to meet each patient's needs. › *www.erlanger.org*
Evidera Industry	Evidera is dedicated to advancing research and consultation in the life sciences industry and has worked with 20 biopharmaceutical companies. Evidera scientists and consultants publish more than 150 peer-reviewed articles each year and have more than 1,100 studies in progress across all major therapeutic areas. › *www.evidera.com*
Fremont Health Health Care Organization	Fremont Health is a health system with six clinics throughout Nebraska. More than 100 active members of its medical staff practice in nearly every medical specialty. › *www.fremonthealth.com*
FutureCare Health Care Organization	FutureCare is a short-term rehabilitation and nursing care center with 14 facilities throughout Maryland. Its staff of 3,800 health care professionals serves both patients and families. FutureCare provides respiratory care to residents through its BreatheStrong pulmonary rehab program. › *www.futurecare.com*

NAME	DESCRIPTION
George Mason University Academic	George Mason University is the largest public research university in Virginia. Partnering with the National Institutes of Health, researchers from across the university are working to develop advanced diagnostics and treatments for major life-threatening illnesses, including COPD. › *www.gmu.edu*
Georgetown University Hospital Academic	MedStar Georgetown University Hospital is a nonprofit, acute-care teaching and research hospital in Washington, D.C. Its Division of Pulmonary, Critical Care and Sleep Medicine provides resources and treatments for people with COPD. › *www.medstargeorgetown.org*
Glaxo Smith Kline Industry	Glaxo Smith Kline is a global health care company committed to the research and development of pharmaceutical medicines, vaccines, and consumer health care products. Glaxo Smith Kline seeks to widen access to their products regardless of where patients live. › *www.gsk.com*
Grifols Industry	Grifols is a global health care company whose mission is to improve the health and well-being of people around the world. Grifols has been working in the fields of transfusion, blood banking, protein therapeutics, and laboratory analysis for more than 75 years. › *www.grifolsusa.com*
Hawaii COPD Coalition Nonprofit	The Hawaii COPD Coalition is a nonprofit dedicated to advocacy, education, support, and resources for those at risk for or suffering from COPD. Formed in 2007, the coalition also offers practical training and resources for families, caregivers, and health care professionals. › *www.hawaiicopd.org*
Health Resources and Service Administration, U.S. Department of Health & Human Services Government	The Health Resources and Services Administration is the primary federal agency tasked with improving health and achieving health equity through access to quality services, a skilled health workforce, and innovative programs. Its programs provide health care to people who are geographically isolated and economically or medically vulnerable. › *www.hrsa.gov*
Holy Cross Hospital Health Care Organization	Holy Cross Hospital is a full-service, nonprofit, teaching hospital based in South Florida, with more than 600 physicians on staff in nearly every specialty in medicine. The hospital offers inpatient, outpatient, and community outreach services and clinical trials. It also offers a certified cardiovascular/pulmonary rehabilitation program. › *www.holy-cross.com*
Hospital for Special Care Health Care Organization	The Hospital for Special Care is a long-term acute-care hospital in Connecticut that serves both adults and children. The hospital is recognized for advanced care and rehabilitation in highly specialized areas, including pulmonary care. › *www.hfsc.org*
HumanKind Nonprofit	HumanKind, founded in 1903 in Virginia, aims to strengthen individuals and families through care, counseling, and education. › *www.humankind.org*

NAME	DESCRIPTION
Indian Health Service, U.S. Department of Health and Human Services Government	The Indian Health Service is the principal federal health care provider and health advocate for Indian people and Alaska Natives. The Indian Health Service provides a comprehensive health service delivery system for approximately 2.2 million American Indians and Alaska Natives who belong to 567 federally recognized tribes in 36 states. › *www.ihs.gov*
Inova Health Care Organization	Inova is a nonprofit health care system that serves more than 2 million people each year throughout the Washington, D.C., metro area and beyond. Based in Northern Virginia and governed by a volunteer board of community members, Inova has grown from one hospital in 1956 to a nationally recognized, comprehensive network of hospitals, outpatient services and facilities, primary and specialty care physician practices, and health and wellness initiatives. › *www.inova.org*
J. Craig Venter Institute Health Care Organization	The J. Craig Venter Institute was formed in October 2006 through the merger of several affiliated and legacy organizations — the Institute for Genomic Research (TIGR) and the Center for the Advancement of Genomics (TCAG), the J. Craig Venter Science Foundation, the Joint Technology Center, and the Institute for Biological Energy Alternatives (IBEA). Today, all these organizations have become one large multidisciplinary genomic-focused organization. › *www.jcvi.org*
JFK Medical Center Health Care Organization	The JFK Medical Center is based in Atlantis, Fla., and was established in 1966. The medical center has evolved into a multi-campus medical center with four locations. › *www.jfkmc.com*
Johns Hopkins University Hospital Academic	The Johns Hopkins University Hospital is the teaching hospital and biomedical research arm of the Johns Hopkins School of Medicine, located in Baltimore, Md. › *www.jhu.edu*
Kaiser Permanente Health Care Organization	Kaiser Permanente provides health care to more than 9 million people with multiple plans. For more than 60 years Kaiser Permanente has been committed to reaching the community and promoting health and wellness through its plans and facilities. › *www.kaiserpermanente.org*
Kindred Healthcare Health Care Organization	Kindred Healthcare's Nursing and Rehabilitation Centers provide pulmonary care to help patients breathe easier. Kindred Healthcare treats a variety of conditions, including COPD, and offers patients individualized care and access to nurses trained in respiratory management and healthy lifestyle programs. › *www.kindredhealthcare.com*
Lincoln Health Foundation Nonprofit	The Lincoln Health Foundation, located in Lincoln Parish, La., seeks to improve the quality of life for patients and develop initiatives and programs that facilitate health and wellness. › *www.lincolnhealth.com*
Living Healthy Health Care Organization	Living Healthy seeks to change behavior through education. It provides nurse consulting services, workshops, CPR training, and health and safety inspections. Living Healthy partners with organizations to equip and inform them on health and safety. › *www.livinghealthyinc.com*

NAME	DESCRIPTION
MD/DC Society for Respiratory Care Health Care Professional Association	The MD/DC Society for Respiratory Care provides support, educational opportunities, and legislative monitoring for respiratory care professionals in Maryland and the District of Columbia. › *www.mddcsoc.org*
Medical University of South Carolina Academic	The Medical University of South Carolina (MUSC) is a hospital and academic medical center in South Carolina. MUSC seeks to provide quality health care through its dedication to patient care, academics, and research. › *www.musc.edu*
MedStar Family Choice Health Care Organization	MedStar Family Choice is a provider-sponsored managed care organization servicing Medicaid programs in the District of Columbia and the state of Maryland. With 42,000 members, the MedStar network consists of 3,000 physicians and health care providers. › *www.medstarfamilychoice.com*
Monadnock Community Hospital Health Care Organization	Monadnock Community Hospital, founded in 1923, is a 25-bed critical access hospital offering medical, surgical, and intensive care services, including pulmonary care. › *www.monadnockcommunityhospital.com*
Mount Sinai Health System Health Care Organization	Mount Sinai Health System is a group practice offering the experience of more than 100 physicians with personalized and integrated treatment for patients. Mount Sinai specializes in clinical services, and offers a pulmonary rehabilitation program that helps patients manage and improve their COPD, learn more about their disease, and increase their endurance and ability to enjoy daily living. › *www.mountsinai.org*
Mylan Industry	Mylan is a generics and specialty pharmaceutical company, with sales in approximately 165 countries and territories. Mylan was founded in 1961 and seeks to provide new generics to the market. › *www.mylan.com*
National Cancer Institute, Division of Cancer Prevention Government	The National Cancer Institute's Division of Cancer Prevention focuses on cancer prevention research. Providing funding and administrative support to clinical and laboratory researchers, its goal is to detect changes and intervene early to prevent cancer in major organs. › *www.prevention.cancer.gov*
National Center on Addiction and Substance Abuse Nonprofit	The National Center on Addiction and Substance Abuse is a research organization focused on improving the understanding, prevention, and treatment of substance use and addiction. › *www.centeronaddiction.org*
National Development and Research Institutes Nonprofit	The National Development and Research Institutes, Inc. was founded in 1967 to advance the understanding of factors that affect the health of individuals, communities, and other populations. › *www.ndri.org*

NAME	DESCRIPTION
National Emphysema Foundation Nonprofit	The National Emphysema Foundation aims to improve the quality of life in patients with emphysema and their caregivers by providing educational, advocacy, and research initiatives to the medical community and the general public. The foundation is dedicated to reducing the toll emphysema takes on people around the globe. › *www.emphysemafoundation.org*
National Heart, Lung, and Blood Institute Government	The National Heart, Lung, and Blood Institute, part of the National Institutes of Health, plans, conducts, and supports research related to the causes, prevention, diagnosis, and treatment of heart, blood vessel, lung, and blood diseases; and sleep disorders. The Institute also administers national health education campaigns on women and heart disease, COPD, and other topics. › *www.nhlbi.nih.gov*
National Institute of Environmental Health Sciences Government	The National Institute of Environmental Health Sciences is a research institute that is part of the U.S. Department of Health and Human Services. Its mission is to discover how the environment affects people and to educate the public on how to live healthier lives. › *www.niehs.nih.gov*
National Institute of Nursing Research Government	The National Institute of Nursing Research seeks to improve the health and health care of Americans through the funding of nursing research and research training. Its mission is to promote and improve the health of all individuals. › *www.ninr.nih.gov*
National Institute on Aging, Division of Geriatrics and Clinical Gerontology Government	National Institute on Aging is dedicated to understanding aging, supporting the health and well-being of older adults, and helping people live longer, healthier, and more active lives. The National Institute on Aging is focused on discovering the factors that contribute to healthy aging, as well as to understanding and addressing some of the diseases and disabilities associated with growing older. › *www.nia.nih.gov*
National Jewish Health Health Care Organization	The National Jewish Health is a hospital in Denver, Co., where every doctor on staff is also a researcher. The hospital treats pulmonary diseases using a program customized for each patient. › *www.nationaljewish.org*
National Oceanic and Atmospheric Administration Government	The National Oceanic and Atmospheric Administration seeks to understand and predict climate changes and conserve coastal ecosystems. It uses cutting-edge research and high-tech instrumentation to provide citizens, planners, and emergency managers reliable information when they need it. › *www.noaa.gov*
National Rural Health Association Nonprofit	The National Rural Health Association is a national membership organization with more than 20,000 members. The association's goal is to provide leadership on rural health issues through advocacy, communications, education, and research. › *www.ruralhealthweb.org*
New York-Presbyterian Health Care Organization	New York-Presbyterian is an academic health care delivery system that seeks to provide compassionate care and service to patients in the New York metropolitan area. › *www.nyp.org*

NAME	DESCRIPTION
North Carolina COPD Taskforce Advocacy	The North Carolina Taskforce is composed of groups across the Carolinas. Together they provide resources to health professionals and individuals working on behalf of COPD patients. The Taskforce annually sponsors a COPD Symposium focused on implementing a state COPD strategic plan. › *www.uscopdcoalition.org/StateCoalitions/NorthCarolina.aspx*
Northwest Hospital Health Care Organization	Northwest Hospital is a community hospital that serves the health care needs of northwest Baltimore in Maryland. Northwest Hospital's Division of Pulmonary Medicine offers broad-based consultation, diagnosis, and treatment in pulmonary diseases. › *www.lifebridgehealth.org*
Novartis Industry	Novartis is a health care company based in Switzerland that works to find health care solutions for patients worldwide. It uses science-based innovation to improve areas of health care and the practice of medicine. › *www.novartis.com*
Olmsted Medical Center Health Care Organization	Olmsted Medical Center offers cardiopulmonary rehabilitation services that are certified by the American Association of Cardiovascular and Pulmonary Rehabilitation. The center has been providing care to patients for 65 years. › *www.olmmed.org*
Pen Bay Medical Center Health Care Organization	Pen Bay Medical Center is the largest community hospital in Midcoast Maine. Providing patient care in multiple medical settings, including clinics and a retirement community, the nonprofit center has a staff of more than 100 physicians and 1,500 health care professionals. › *www.penbayhealthcare.org*
Propeller Health Industry	Propeller Health aims to help people with asthma and COPD live better lives by minimizing the daily impact of their symptoms and connecting them to their physicians, environment, and community. With sensor-connected inhalers, digital interfaces, mobile spirometers, and real-time education, participants can receive personal guidance to improve self-management, and clinicians can receive data to inform selection of the optimal therapy for each individual. › *www.propellerhealth.com*
Pulmonary Horizons, Inc. Health Care Organization	Pulmonary Horizons provides patient-centered education in its treatment and management of those diagnosed with COPD. The organization partners with the National Lung Health Education Program and Right2Breathe. › *www.pulmonaryhorizons.org*
Pulmonary Wellness Rehabilitation Center Health Care Organization	The Pulmonary Wellness Rehabilitation Center was founded in 1998 to provide wellness, rehabilitation, and education programs for people living with pulmonary disease. The Center helps empower patients by teaching them how to lessen and reverse the effects of their respiratory disease and to effectively manage associated symptoms. › *www.pulmonarywellness.com*
Reading Health System Health Care Organization	Reading Health System provides health care to the community, promotes health and education, and participates in clinical research. › *www.readinghealth.org*

NAME	DESCRIPTION
Respiratory Health Association Nonprofit	The Respiratory Health Association specializes in asthma, COPD, and air quality through research, education, and advocacy activities. Founded in 1906 in Chicago, the group promotes ways to keep lungs healthy, fights lung disease, and hosts educational events for health care providers. › *www.lungchicago.org*
Right2Breathe® Nonprofit	Right2Breathe® was created by two automotive enthusiasts to help improve the quality of life for those who live with respiratory diseases. Right2Breathe® provides awareness campaigns, education, and free COPD screenings at events across the country. › *www.right2breathe.org*
Sanford Health Health Care Organization	Sanford Health is a network of 43 hospitals and nearly 250 clinics in nine states and three countries. Its pulmonology division specializes in diagnosing and treating respiratory tract and lung disease. The staff works with primary care specialists to provide advanced diagnosis and treatment and management of lung conditions and diseases. › *www.sanfordhealth.org*
Social Security Administration Government	The Social Security Administration provides financial benefits, tools, and information to help support people through all stages of life. › *www.ssa.gov*
Society for Women's Health Research Health Care Professional Association	The Society for Women's Health Research is a nonprofit based in Washington, D.C., that is dedicated to improving women's health through science, advocacy, and education. › *www.swhr.org*
Temple Lung Center Academic	Temple Lung Center's team of pulmonary specialists offers advanced treatment options for respiratory conditions, including COPD. Temple Lung Center is located in Philadelphia. › *www.pulmonary.templehealth.org*
Teva Industry	Teva is a pharmaceutical company that seeks to increase access to high-quality health care for people across the globe by developing, producing, and marketing generic drugs. Based in Israel, Teva was established in 1901 and produces more than 64 million prescription tablets at 66 manufacturing facilities in 60 countries. › *www.tevapharm.com*
The UNC Medical Center Academic	The UNC Medical Center is an academic medical center and part of the University of North Carolina, Chapel Hill. The center's pulmonary care program addresses a wide range of conditions and treatments, including COPD. UNC has an Obstructive Lung Diseases Clinical and Translational Research Center, where specialists care for COPD patients and conduct clinical research on COPD. UNC also provides pulmonary rehabilitation and smoking cessation support to patients suffering from pulmonary diseases. › *www.med.unc.edu*
The University of Chicago Asthma and COPD Center Academic	The University of Chicago Asthma and COPD Center is dedicated to the care of asthma and COPD patients. Its respiratory disease specialists provide a range of services to help manage asthma and COPD. › *asthma.bsd.uchicago.edu*

NAME	DESCRIPTION
The University of Illinois Hospital & Health Sciences System Academic	The University of Illinois Hospital & Health Sciences System is an academic facility that is part of the University of Illinois at Chicago. It has a pulmonary outpatient clinic for the treatment and care of patients with respiratory diseases. › *www.hospital.uillinois.edu*
The University of Kentucky Medical Center Academic	The University of Kentucky Medical Center is an academic health care center established in 1957 on the Lexington campus of Kentucky's flagship university. The faculty, students, and staff strive for excellence in education, patient care, research, and community service. › *www.mc.uky.edu*
The University of Michigan Health System Academic	The University of Michigan Health System is a health care system and academic medical center made up of hospitals, health care centers, and clinics throughout Michigan. Its vision is to achieve excellence in medical education and research and provide quality patient care. › *www.med.umich.edu*
Theravance Biopharma Industry	Theravance Biopharma is a biopharmaceutical company with the mission to create medicines that make a difference in the lives of patients suffering from serious illness like COPD. Theravance has a history of commitment to the respiratory and COPD community and has active research programs in the respiratory arena. › *www.theravance.com*
U.S. COPD Coalition Advocacy	The U.S. COPD Coalition is a nonprofit organization made up of patient organizations, health professional organizations, individuals, and government agencies that work together to improve the care of individuals affected by COPD. › *www.uscopdcoalition.org*
University of Texas Medical Branch Academic	The University of Texas Medical Branch, opened in 1891, is an academic health and sciences center with schools for medical, nursing, and health professionals; a research facility; and a network of clinics. The University of Texas Medical Branch is part of the Texas Medical Center and provides a range of primary and specialized care. › *www.utmb.edu*
Washington Hospital Center Health Care Organization	The Washington Hospital Center is a nonprofit, 926-bed academic medical center in Washington, D.C. Its team of pulmonary experts treats patients with a range of pulmonary conditions, from acute illnesses to chronic respiratory diseases like COPD. › *www.medstarwashington.org*
Weill Cornell Medicine Academic	Weill Cornell Medicine is a clinical and medical research center affiliated with New York-Presbyterian Hospital. Founded in 1898, the center is known for its breakthrough discoveries in biomedical research and patient care. It is a major hub for state-of-the-art technologies and the pursuit of scientific discovery and life-saving therapies. It offers access to internationally recognized physicians from all fields of medicine. › *www.weill.cornell.edu*
Western Michigan University Homer Stryker M.D. School of Medicine Academic	Western Michigan University Homer Stryker M.D. School of Medicine is a collaboration between Western Michigan University and Kalamazoo's two teaching hospitals, Borgess Health and Bronson Healthcare. › *www.wmich.edu*

GLOSSARY

TERM	DEFINITION
Access to care	Access to care means having the timely use of personal health services to achieve the best health outcomes.
Adherence	Adherence, or taking medications correctly, is generally defined as the extent to which patients take medication as prescribed by their doctors. This involves factors such as getting prescriptions filled, remembering to take medication on time, and understanding the directions.
Agency for Healthcare Research and Quality (AHRQ)	The Agency for Healthcare Research and Quality's (AHRQ) mission is to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used.
Agency for Healthcare Research and Quality's National Guideline Clearinghouse (AHRQ NGC)	The National Guideline Clearinghouse (NGC) supports AHRQ's mission to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable by providing objective, detailed information on clinical practice guidelines, and to further their dissemination, implementation, and use in order to inform health care decisions.
Air sacs	Air sacs, also called alveoli, are a part of the lung that form at the end of the bronchioles. When air reaches the air sacs, oxygen passes through the air sac walls into the blood in the capillaries. The airways and air sacs are elastic (stretchy). When you breathe in, each air sac fills up with air like a small balloon. When you breathe out, the air sacs deflate and the air goes out. There are about 300 million alveoli in a normal lung.
Alpha-1 antitrypsin (AAT) deficiency	Alpha-1 antitrypsin (AAT) deficiency is an inherited condition that raises the risk for lung and liver disease. AAT is a protein produced by the liver that protects the lungs. If the AAT proteins are not the correct shape, they get stuck in the liver cells and cannot reach the lungs.
Arterial blood gas test	Arterial blood gas tests measure how much oxygen and carbon dioxide are in the blood. They also determine the pH, or how acidic or basic, the blood is.
Behavioral Risk Factor Surveillance System (BRFSS)	The Behavioral Risk Factor Surveillance System (BRFSS) is the nation's premier system of telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 states, the BRFSS now collects data in all 50 states, as well as the District of Columbia and three U.S. territories. The BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world.
Biomarker	A biomarker refers to a broad subcategory of medical signs — that is, objective indications of medical states observed from outside the patient — which can be measured accurately and reproducibly. Medical signs stand in contrast to medical symptoms, which are limited to those indications of health or illness perceived by patients themselves.

TERM	DEFINITION
Bronchial tubes	The bronchial tubes, or bronchi, are two tubes that branch off the trachea, or windpipe. Bronchial tubes carry air to the lungs. The most common problem with the bronchi is bronchitis, an inflammation of the tubes.
Bronchitis	Bronchitis is an inflammation of the bronchial tubes. It causes a cough that often brings up mucus and can also cause shortness of breath, wheezing, a low fever, and chest tightness. There are two main types of bronchitis: acute and chronic.
Care continuum	Care continuum is a concept involving an integrated system of care that guides and tracks a patient over time through a comprehensive array of health services.
Centers for Disease Control and Prevention (CDC)	The Centers for Disease Control and Prevention (CDC) is the nation's health protection agency. The CDC conducts critical science and provides health information that protects the U.S. against expensive and dangerous health threats, and responds when these arise.
Centers for Medicare & Medicaid Services (CMS)	The Centers for Medicare & Medicaid Services (CMS) is part of the Department of Health and Human Services (HHS). Its programs include Medicare, Medicaid, the Children's Health Insurance Program, and the Health Insurance Marketplace.
Chest CT scan	A chest CT scan is a more detailed type of chest X-ray. This painless imaging test takes many detailed pictures, called slices, of the lungs and the inside of the chest. Computers can combine these pictures to create three-dimensional (3D) models to help show the size, shape, and position of the lungs and structures in the chest. A chest CT scan can also help determine the cause of lung symptoms such as shortness of breath or chest pain, or check to see if a patient has certain lung problems such as a tumor, excess fluid around the lungs (called pleural effusion), pulmonary embolism, emphysema, tuberculosis, and pneumonia.
Chest X-ray	A chest X-ray is a fast and painless imaging test that uses certain electromagnetic waves to create pictures of the structures in and around the chest. This test can help diagnose and monitor conditions such as pneumonia, heart failure, lung cancer, tuberculosis, sarcoidosis, and lung tissue scarring, called fibrosis. Doctors may use chest X-rays to see how well certain treatments are working and to check for complications after certain procedures or surgeries.
Chronic conditions	Chronic conditions are a condition, disease, sign, or symptom that lasts persistently, recurs frequently, or worsens progressively over a long time.
Chronic lower respiratory disease	Chronic lower respiratory disease is a disease that affects the lungs, including COPD.
Clinical quality measures (CQMs)	Clinical quality measures (CQMs) are tools that help measure and track the quality of health care services provided by eligible professionals, eligible hospitals, and critical access hospitals within our health care system. These measures use data associated with providers' ability to deliver high-quality care or relate to long-term goals for quality health care.
Community health needs assessment (CHNA) survey	Community health needs assessment (CHNA), or a community health assessment (CHA), refers to a state, tribal, local, or territorial health assessment that identifies key health needs and issues through systematic, comprehensive data collection and analysis.

TERM	DEFINITION
Comorbidity	Comorbidity describes two or more disorders or illnesses occurring in the same person. They can occur at the same time or one after the other. Comorbidity also implies interactions between the illnesses that can worsen the course of both.
Continuing medical education (CME)	Continuing medical education (CME) is the process by which family physicians and other health professionals engage in activities designed to support their continuing professional development. Activities are derived from multiple instructional domains, are learner centered, and support the ability of those professionals to provide high-quality, comprehensive, and continuous patient care and service to the public and their profession.
COPDGene	COPDGene is a multicenter observational study designed to identify genetic factors associated with COPD.
Culturally appropriate	Culturally appropriate is broadly defined as care and services that are respectful of and responsive to the cultural and linguistic needs of all individuals.
Department of Defense (DoD)	The mission of the Department of Defense (DoD) is to provide the military forces needed to deter war and to protect the security of the United States.
Disability	A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).
Disparities	Disparities refers to when a health outcome is seen to a greater or lesser extent between populations. Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health.
Dyspnea	Dyspnea is shortness of breath, breathlessness, or difficulty breathing.
Elasticity	Elasticity refers to the "stretchy" quality of the airways and air sacs that allows them to retain their shape.
Electronic health record (EHR)	An electronic health record (EHR) is a digital version of a patient's paper chart. EHRs are real-time, patient-centered records that make information available instantly and securely to authorized users.
Emphysema	Emphysema is a type of COPD involving damage to the air sacs (alveoli) in the lungs. As a result, the body does not get the oxygen it needs. Emphysema makes it hard for an individual to catch their breath. It may also cause chronic coughing and trouble breathing during exercise.
Epidemiology	Epidemiology is the study of the distribution (frequency, pattern) and causes and risk factors of health-related states and events (not just diseases) in specified populations, including neighborhoods, schools, cities, states, countries, and global.
Etiology	Etiology is the cause or origin of disease.
Evidence-based practices	Evidence-based practices are the conscientious, explicit, and judicious use of current best evidence when making decisions about the care of the individual patient. This involves integrating individual clinical expertise with the best available external clinical evidence from systematic research.

TERM	DEFINITION
Exacerbations	Exacerbations of COPD cause morbidity, hospital admissions, and mortality, and strongly influence health-related quality of life. Some patients are prone to frequent exacerbations, which are associated with considerable physiologic deterioration and increased airway inflammation. About half of COPD exacerbations are caused or triggered primarily by bacterial and viral infections (colds, especially from rhinovirus), but air pollution can also contribute to the beginning of an exacerbation.
Genomics	Genomics is the study of genes and their functions, and related techniques.
Guidelines-based care	Guidelines-based care is care based on clinical guidelines that are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.
Health care cost: direct vs. indirect	Direct costs are those costs borne by the health care system, community, and patients' families in addressing an illness. Indirect costs are mainly productivity losses to society caused by the health problem or disease.
Health care providers	Any organization (including an HMO, preferred provider organization, or group medical practice) that provides health care services and follows a formal peer-review process for the purpose of furthering quality health care.
Health indicators	Health indicators are measures of the health of people in a community, including rates of disease such as COPD.
Health information technology (HIT)	Health information technology (HIT) is a broad concept that encompasses an array of technologies to store, share, and analyze health information.
Health literacy	Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.
Health Resources and Services Administration (HRSA)	The Health Resources and Services Administration (HRSA) is an agency of the U.S. Department of Health and Human Services (HHS) and is the primary federal agency for improving health and achieving health equity through access to quality services, a skilled health workforce and innovative programs. HRSA's programs provide health care to people who are geographically isolated and economically or medically vulnerable.
Heterogeneity	Heterogeneity refers to something made up of elements or ingredients that are not alike.
Inhaled treatments	Inhaled treatments for COPD patients refers to the two main methods of using inhaled medications, including the use of an inhaler or the use of a nebulizer.

TERM	DEFINITION
International Classification of Diseases (ICD)	The International Classification of Diseases (ICD) is designed to promote international comparability in the collection, processing, classification, and presentation of mortality statistics. This includes providing a format for reporting causes of death on the death certificate. The reported conditions are then translated into medical codes through use of the classification structure and the selection and modification rules contained in the applicable revision of the ICD, published by the World Health Organization (WHO). These coding rules improve the usefulness of mortality statistics by giving preference to certain categories by consolidating conditions and by systematically selecting a single cause of death from a reported sequence of conditions. The single selected cause for tabulation is called the underlying cause of death, and the other reported causes are the non-underlying causes of death. The combination of underlying and non-underlying causes is the multiple causes of death. The ICD is currently in the Tenth Revision (ICD-10). The International Classification of Diseases codes for COPD include: chronic bronchitis (ICD-9 codes 490-491), emphysema (ICD-9 code 492), bronchiectasis (ICD-9 code 494), and chronic airway obstruction (ICD-9 code 496).
Linguistically appropriate services	Linguistically appropriate services are broadly defined as care and services that are respectful of and responsive to the cultural and linguistic needs of all individuals.
Lower pulmonary function	Lower pulmonary function is a measure of how much air an individual exhales, and how quickly they exhale.
Lung function tests	Lung function tests, or pulmonary function tests (PFTs), measure how well the lungs work. They include tests that measure lung size and air flow, such as spirometry and lung volume tests. Other tests measure how well gases, such as oxygen, get in and out of the blood. These tests include pulse oximetry and arterial blood gas tests. Another pulmonary function test, called fractional exhaled nitric oxide (FeNO), measures nitric oxide, which is a marker for inflammation in the lungs. One or more of these tests may be used to diagnose lung and airway diseases, compare lung function to expected levels of function, monitor if a patient's disease is stable or worsening, and see if a treatment is working.
Medicaid	Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults, and people with disabilities. Medicaid is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.
Medicare	Medicare is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with end-stage renal disease (ESRD), permanent kidney failure requiring dialysis or a transplant.
Medicare doughnut hole	The "doughnut hole" refers to a gap in prescription drug coverage under Medicare Part D.

TERM	DEFINITION
Mortality rate	A mortality rate is a measure of the frequency of occurrence of death in a defined population during a specified interval.
Multidisciplinary team-based approach	Multidisciplinary team-based approach broadens delivery of care by expanding the health care team to include several types of health care professionals. Collaborative teams vary according to patients' needs, patient load, organizational constraints, resources, clinical setting, geographic location, and professional skills.
National Ambulatory Medical Care Survey (NAMCS)	The National Ambulatory Medical Care Survey (NAMCS) is a national survey designed to meet the need for objective, reliable information about the provision and use of ambulatory medical care services in the United States. Findings are based on a sample of visits to nonfederal employed, office-based physicians who are primarily engaged in direct patient care.
National Center for Health Statistics (NCHS)	The National Center for Health Statistics (NCHS) compiles statistical information to guide actions and policies to improve health.
National Health and Nutrition Examination Survey (NHANES)	The National Health and Nutrition Examination Survey (NHANES) is a program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey is unique in that it combines interviews and physical examinations.
National Health Interview Survey (NHIS)	The National Health Interview Survey (NHIS) has monitored the health of the nation since 1957. NHIS data includes a broad range of health topics that are collected through personal household interviews.
National Heart, Lung, and Blood Institute (NHLBI)	The National Heart, Lung, and Blood Institute, part of the National Institutes of Health, plans, conducts, and supports research related to the causes, prevention, diagnosis, and treatment of heart, blood vessel, lung, and blood diseases; and sleep disorders. The Institute also administers national health education campaigns on women and heart disease, COPD, and other topics.
National Institute for Occupational Safety and Health (NIOSH)	The National Institute for Occupational Safety and Health (NIOSH) is part of the U.S. Centers for Disease Control and Prevention (CDC), in the U.S. Department of Health and Human Services (HHS). It has the mandate to assure "every man and woman in the Nation safe and healthful working conditions and to preserve our human resources."
Online communities	Online communities are Internet-based platforms that unite either a group of patients, a group of professionals, or a mixture of both. Members interact using modern communication technologies such as blogs, chats, forums, and wikis.
Palliative care	The goal of palliative care is to help people with serious illnesses feel better. It prevents or treats symptoms and side effects of the disease and treatment. Palliative care also treats emotional, social, practical, and spiritual problems that illnesses can bring up. When the person feels better in these areas, they have an improved quality of life. Palliative care can be given at the same time as treatments meant to cure or treat the disease. Palliative care may be given when the illness is diagnosed, throughout treatment, during follow-up, and at the end of life.

TERM	DEFINITION
Pathogenesis	The pathogenesis of a disease describes the mechanisms by which it develops, progresses, and either persists or is resolved.
Patient registries	A patient registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure and that serves predetermined scientific, clinical, or policy purpose(s).
Patient-centered care	Patient-centered care is defined as health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences, and that patients have the education and support they need to make decisions and participate in their own care.
Patient-centric	Patient-centric health care is health care that is relationship-based with an orientation toward the whole person. Partnering with patients and their families requires understanding and respecting each patient's unique needs, culture, values, and preferences.
Pharmacological	Pharmacological refers to the science of drugs, including their composition, uses, and effect, or the characteristics or properties of a drug, especially those that make it medically effective.
Phenotype	A phenotype is an individual's observable trait, such as height, eye color, and blood type. The genetic contribution to the phenotype is called the genotype. Some traits are largely determined by the genotype, while other traits are largely determined by environmental factors.
Polypharmacy	Polypharmacy is an increase in the number of medications or the use of more medications than are medically necessary. Polypharmacy is common in older ambulatory care, hospital, and nursing home patients. Polypharmacy increases the risk of numerous negative health consequences in the elderly.
Population surveillance	Population surveillance is the ongoing scrutiny of a population (general population, study population, target population, etc.), generally using methods distinguished by their practicability, uniformity, and frequently their rapidity, rather than by complete accuracy.
Precision Medicine Initiative®	Precision medicine is an emerging approach for disease prevention and treatment that takes into account people's individual variations in genes, environment, and lifestyle. The Precision Medicine Initiative® will generate the scientific evidence needed to move the concept of precision medicine into clinical practice. Near term goals are focused on innovative clinical trials of targeted drugs for adult and pediatric cancers, the use of combination therapies, and the expansion of knowledge to overcome drug resistance. Longer term goals are the focus of the AllofUs effort to create a research cohort of >1 million American volunteers. Participants will provide genetic data, biological samples, and other information about their health. These data will be used by researchers to study a large range of diseases, with the goals of better predicting disease risk, understanding how diseases occur, and finding improved diagnosis and treatment strategies.
Prevalence	Prevalence is the proportion of a population which has (or had) a specific characteristic in a given time period — in medicine, typically an illness, a condition, or a risk factor, such as depression or smoking.

TERM	DEFINITION
Prognosis	The prognosis of a genetic condition includes its likely course, duration, and outcome. When health professionals refer to the prognosis of a disease, they may also mean the chance of recovery; however, most genetic conditions are lifelong and are managed rather than cured. COPD is measured in stages with Stage 1 being very mild and Stage 4 being very severe.
Public health nurse	A public health nurse works to assess the health and health care needs of a population in order to identify subpopulations, families, and individuals who would benefit from health promotion or who are at risk of illness, injury, disability, or premature death.
Pulmonary rehabilitation	Pulmonary rehabilitation, also called pulmonary rehab or PR, is a broad program that helps improve the well-being of people who have chronic (ongoing) breathing problems. For example, PR may benefit people who have COPD, sarcoidosis, idiopathic pulmonary fibrosis, or cystic fibrosis.
Smoker's cough	Smoker's cough is a type of coughing that may produce large amounts of mucus.
Smoking cessation	Smoking cessation is the process of quitting smoking tobacco products.
Spirometry	Spirometry measures the rate of air flow and estimates lung size. For this test, a person breathes multiple times, with regular and maximal effort, through a tube that is connected to a computer. Some people feel lightheaded or tired from the required breathing effort.
Sputum	Sputum is mucus and other matter brought up from the lungs by coughing.
Subphenotype	A subphenotype identifies a subset of phenotype.
Subpopulations and Intermediate Outcome Measures in COPD Study (SPIROMICS)	Subpopulations and Intermediate Outcome Measures in COPD Study (SPIROMICS) is a multi-center observational study of COPD designed to guide future development of therapies for the disease. This is done by providing robust criteria for sub-classifying COPD participants into groups most likely to benefit from a given therapy during a clinical trial, thereby improving the chances of successful outcome; and by identifying biomarkers/phenotypes that can be used as intermediate outcomes to reliably predict clinical benefit during therapeutic trials, thus reducing costs.
T3/T4 Space[12]	Refers to a type of translational research. With T3 translational research, investigators explore ways of applying recommendations or guidelines in general practice. T3 research yields knowledge about how interventions work in real-world settings. In T4 translational research, investigators study factors and interventions that influence the health of populations. T4 research ultimately results in improved public and global health.
Telemedicine	Telemedicine allows health care providers to examine, diagnose, and treat patients using technology like a phone, computer, or other device.
The Global Initiative for Chronic Obstructive Lung Disease (GOLD)	The Global Initiative for Chronic Obstructive Lung Disease (GOLD) is an initiative that works with health care professionals and public health officials around the world to raise awareness of COPD and to improve prevention and treatment of the disease.

TERM	DEFINITION
The Health and Medicine Division (HMD) (Formerly Institute of Medicine)	The Health and Medicine Division (HMD) is a division of the National Academies of Sciences, Engineering, and Medicine (the National Academies). HMD aims to help those in government and the private sector make informed health decisions by providing evidence upon which they can rely.
Tobacco products	Tobacco products are defined as cigars, cigarettes, smokeless tobacco, pipe tobacco, and roll-your-own tobacco. Smokeless tobacco refers to any snuff or chewing tobacco.
Trans-governmental	Trans-governmental refers to cooperation based on loosely-structured, peer-to-peer ties developed through frequent interaction rather than formal negotiation involving specialized domestic officials directly interacting with each other.

REFERENCES

1. Centers for Disease Control and Prevention (US), National Center for Health Statistics, *Deaths: final data for 2014*, by Kenneth D. Kochanek, Sherry L. Murphy, Jiaquan Xu, and Betzaida Tejada-Vera, National Vital Statistics Reports, 65 (4), (June 30, 2016), https://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65_04.pdf

2. Anne G. Wheaton, Timothy J. Cunningham, Earl S. Ford, MD, and Janet B. Croft., "Employment and activity limitations among adults with chronic obstructive pulmonary disease — United States, 2013," *Morbidity and Mortality Weekly Report (MMWR)*, 64 (11), pp. 289-295 (March 7, 2015), Centers for Disease Control and Prevention (CDC)

3. David M. Mannino, Robert C. Gagnon, Thomas L. Petty, and Eva Lydick., "Obstructive lung disease and low lung function in adults in the United States: data from the National Health and Nutrition Examination Survey 1988-1994." *Archives of Internal Medicine*, 160 (11), pp. 1683-1689 (June 12, 2000)

4. Jiemin Ma, Elizabeth M. Ward, Rebecca L. Siegel, and Ahmedin Jemal., "Temporal trends in mortality in the United States, 1969-2013." *JAMA,* 314 (16), pp.1731-1739 (October 27, 2015)

5. MW Brault, J Hootman, CG Helmick, KA Theis, and BS Armour., "Prevalence and most common causes of disability among adults — United States, 2005," *Morbidity and Mortality Weekly Report (MMWR)*, 58 (16), pp. 421-426 (May 1, 2009), Centers for Disease Control and Prevention (CDC)

6. Earl S. Ford, Louise B. Murphy, Olga Khavjou, Wayne H. Giles, James B. Holt, and Janet B. Croft., "Total and state-specific medical and absenteeism costs of COPD among adults aged ≥ 18 years in the United States for 2010 and projections through 2020," *Chest*, 147 (1), pp. 31-45 (January 2015)

7. Earl S. Ford, Janet B. Croft, David M. Mannino, Anne G. Wheaton, Xingyou Zhang, and Wayne H. Giles, "COPD surveillance — United States, 1999-2011," *Chest*, 144 (1), pp. 284-305 (July 2013)

8. BRFSS Prevalence & Trends Data [Internet]. Atlanta (GA): Centers for Disease Control and Prevention (US); [reviewed 2017 Jan 3; cited 2017 Apr 11]. Available at: https://www.cdc.gov/brfss/brfssprevalence/

9. John Lewis, David P. Joyce, and Carol Shea-Porter (U.S. House of Representatives)., Letter to: Dr. Thomas R. Frieden (Director, Centers for Disease Control and Prevention, Atlanta, GA) and Dr. Francis S. Collins (Director, National Institutes of Health, Bethesda, MD). 2014 Nov 24. 1 leaf

10. Nicole M. Kosacz, Antonello Punturieri, Thomas L. Croxton, Monique N. Ndenecho, James P. Kiley, Gail G. Weinmann, Anne G. Wheaton, Earl S. Ford, Letitia R. Presley-Cantrell, Janet B. Croft, and Wayne H. Giles., "Chronic obstructive pulmonary disease surveillance among adults-United States, 2011," *Morbidity and Mortality Weekly Report (MMWR)*, 61 (46), pp. 938-943 (November 23, 2012), Centers for Disease Control and Prevention (CDC)

11. The NAMCS, NHAMCS, and NHCS are beginning the process of collecting EHRs, which will greatly increase the number and content of available records.

12. Harvard Catalyst, The Harvard Clinical and Translational Science Center; [reviewed and cited 2017 May] Available at: http://catalyst.harvard.edu/pathfinder/t3detail.html.

AGE-ADJUSTED PREVALENCE OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) AMONG ADULTS AGED ≥18 YEARS — BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM, UNITED STATES, 2015

State	COPD Prevalence
Alabama	9.9%
Alaska	4.1%
Arizona	5.8%
Arkansas	9.1%
California	4%
Colorado	4.2%
Connecticut	4.6%
Delaware	6.3%
District of Columbia	5.9%
Florida	6%
Georgia	6.7%
Hawaii	4.1%
Idaho	4.5%
Illinois	5.4%
Indiana	7.4%
Iowa	5.2%
Kansas	5.8%
Kentucky	11.2%
Louisiana	7.1%
Maine	7%
Maryland	5.8%
Massachusetts	5.3%
Michigan	6.9%
Minnesota	4.2%
Mississippi	7.2%
Missouri	7.9%

State	COPD Prevalence
Montana	5%
Nebraska	5%
Nevada	6.2%
New Hampshire	6.1%
New Jersey	4.6%
New Mexico	5.5%
New York	5.3%
North Carolina	7%
North Dakota	4.8%
Ohio	7.1%
Oklahoma	8.2%
Oregon	5.1%
Pennsylvania	6.2%
Rhode Island	5.7%
South Carolina	6.7%
South Dakota	5.2%
Tennessee	8.9%
Texas	5.1%
Utah	3.8%
Vermont	5.6%
Virginia	5.5%
Washington	5.8%
West Virginia	12%
Wisconsin	4.2%
Wyoming	6.8%

THANK **YOU**

WE WOULD LIKE TO ACKNOWLEDGE THE CONTRIBUTIONS OF THE ENTIRE COPD COMMUNITY IN DEVELOPING THIS *COPD NATIONAL ACTION PLAN*. COLLABORATION ACROSS THIS COMMUNITY IS ESSENTIAL TO THE SUCCESSFUL IMPLEMENTATION OF THE PLAN.

TO LEARN MORE ABOUT THE *COPD NATIONAL ACTION PLAN*, VISIT

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National Institutes of Health
National Heart, Lung, and Blood Institute

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