For the 16 million Americans living with chronic obstructive pulmonary disease (COPD), and for millions more who do not know they have it, 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. It also is the fourth leading cause of disability, and it imposes an enormous burden on the nation’s health care system: Americans spent more than $32 billion on COPD-related patient care in 2010, and those costs are projected to increase to $49 billion by 2020.

Yet, despite the steady work of researchers seeking a cure and clinicians adopting new patient tools and therapies, addressing the issues around COPD — a preventable disease caused mainly by smoking — has been difficult. It is why a coordinated national effort is needed to deal with the problem and why the COPD National Action Plan came to be.

Requested by Congress and guided by the National Heart, Lung, and Blood Institute, the Plan was developed over the course of a year in collaboration with the Centers for Disease Control and Prevention, other federal partners, and the COPD community at large, including patients and their families. It provides a comprehensive, unified framework for action by those who are affected by the disease and those who care about reducing its burden.

Each of the five goals in the Plan addresses a different aspect of the challenge posed by COPD and identifies the various entities best capable of dealing with those specific issues. The Plan, however, is a “living” document — subject to revisions by the entire COPD community as new needs and opportunities arise.
Goal 1

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

For people with COPD, awareness about the chronic, progressive disease often does not come until well after they have been affected by it. Unfamiliar with the early, non-specific 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 get diagnosed. Goal 1 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. It specifies ways to do this.

1. Increase public awareness of the risk factors and symptoms of COPD, so that earlier diagnosis of symptomatic individuals becomes the norm.
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.
3. Expand opportunities to increase COPD awareness across the public-private spectrum.

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. Goal 2 calls on health care professionals to work together 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, 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. This goal suggests how to do this.

1. Develop, disseminate, and maintain unified, multidisciplinary, patient-centric national guidelines for COPD that are accessible and easy to follow.
2. Develop a unified, multidisciplinary educational curriculum for health care professionals, including primary health care providers, using harmonized clinical practice guidelines.
3. Develop, in accordance with clinical quality measures, a clinical decision tree and other tools to enable high-quality care for people with COPD.
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).
5. Improve access to care for people with COPD, particularly for those in hard-to-reach areas.
Goal 3
Collect, analyze, report, and disseminate COPD-related public health data that drive change and track progress.

Reliable data are critical to informed decision-making. This is especially true 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. Goal 3 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. It encourages the adoption of secure health information technology, the use of electronic health records and personal health records, and the creation of large-scale patient registries that can greatly enhance the ability to capture and collect patient-level data.

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

• 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 alpha-1 antitrypsin (AAT) deficiency.

• Improve data compatibility for aggregation and analyses.

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

2. Facilitate dissemination of data and analyses.

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

• Conduct studies that assess all aspects of existing and new models of disease detection, care, and treatments for people living with COPD, including studies that address barriers to care and rehabilitation services.

Goal 4
Increase and sustain research to better understand the prevention, pathogenesis, diagnosis, treatment, and management of COPD.

This goal focuses on the need to characterize the many contributing risk factors and underlying mechanisms in COPD. It aims to improve understanding of the causes and progression of COPD; the different forms of the disease; and its prevention, diagnosis, and treatment. It calls for translating basic research to clinical applications in order to improve methods of diagnosis and symptom management, as well as treatments that are health-preserving and disease-arresting or -reversing.

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

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

3. Define and characterize the pathogenesis of COPD heterogeneity.

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

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.
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.
2. Create a collaborative official entity that implements, prioritizes, and tracks activities in accordance with the COPD National Action Plan’s goals and objectives.
3. Identify and publicize funding opportunities that advance the implementation of the COPD National Action Plan.
4. Develop and implement COPD quality measures into national care delivery.
5. Strengthen the public health infrastructure for addressing COPD.

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