

Goal 1: Empower people with COPD, their families, and caregivers to recognize and reduce the burden of COPD.

For people diagnosed with COPD, the physical impairments of the disease all too often come with significant challenges to daily living: uncertainty and worry about the prognosis, social stigmatization due to behaviors such as tobacco consumption, and social isolation. This sense of isolation may stem from concerns that are both mental and physical. Whether it is the embarrassment that comes from being seen wearing a cannula or the difficulty that comes from traveling with necessary oxygen equipment, the results can set off loneliness and distress.

Goal 1 of the *COPD National Action Plan* focuses on helping people with COPD, their families, and caregivers recognize the disease through risk and symptom awareness, early detection, and diagnosis. It also helps empower these groups by providing information about how best to manage this chronic, progressive disease.

1) Offer every person at risk for and living with COPD, as well as their caregivers and family members, ready access to free, reliable, and up-to-date COPD information and resources.

1.A Encourage existing networks, including but not limited to federal and state agencies, professional associations, and nonprofit organizations, to collaborate to review available COPD information and update or create additional resources.

1.A.1. Encourage these existing networks to 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.

1.A.2. Encourage these existing networks to make the information easily accessible by offering online search capabilities and/or toll-free access to specially trained operators and experienced COPD health professionals.

1.A.3. Encourage these existing networks to create or offer access to online communities that allow people with COPD and their caregivers to share information and support each other.

1.A.4. Encourage health care professionals to provide people with COPD and their caregivers education and resources as well as multiple avenues to access them.

2) Increase the effectiveness and expand the range of outreach communication campaigns designed to decrease the burden of COPD.

2A. Conduct public education and awareness activities that use messages and tools geared to all audiences.

2.A.1. Ensure that those messages focus on risk factors (e.g., smoking, environmental exposure, genetic conditions), behavioral interventions (e.g., dieting, exercise), and the care and treatment of people with COPD.

2.A.2. Encourage and support the use of earned and paid media, online social networks, and other engaging methods to get those messages to individuals and communities at risk for COPD.

2.A.3. Invest in evaluation research that develops and measures the effectiveness of outreach communication programs.

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

3.A. Identify and engage diverse organizations, including community-based groups, that can enhance and incorporate COPD education and awareness activities into their programs.

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

3.C. Support all 50 states and the District of Columbia in the development of statewide COPD education efforts and encourage the creation of public-private partnerships to spread the word.

Opportunities for Engagement and Participation

- Share culturally and linguistically appropriate COPD risk assessment tools and educational materials with COPD patients 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 and community health fairs and 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 on 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 impacted by the disease.

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Goal 2: Improve the prevention, diagnosis, treatment, and management of COPD by promoting and sustaining the education and training of health care professionals.

Almost every health care professional in the U.S. 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 must work collectively to standardize existing training, clinical care tools, and policies and incorporate them into national standards of care guidelines. Those tools and policies should then be used to help provide high-quality, 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, policies, and national guidelines should be evidence based, validated, and culturally competent so that any 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 a therapeutic intervention tool should be central to patient care and offered as a fully medically reimbursable health program to every person with COPD who qualifies.

An initial review and assessment of awareness initiatives will greatly help in achieving this goal, as it will inform the further development of targeted programs. The establishment of benchmarks and metrics to monitor accomplishments will help with this goal as well.

1) Develop and maintain unified, multidisciplinary, patient-centric national guidelines for COPD.

1.A. Encourage excellence in clinical practices through the development and dissemination of national COPD guidelines.

1.A.1. Encourage the creation of clinical practice guidelines that set consistent national standards for identifying people at risk for COPD as well as diagnosing, caring, and treating people with COPD across the care continuum.

1.A.2. Encourage professional medical associations to ensure that practice guidelines address COPD, reflect the latest evidence-based practices, and meet the Institute of Medicine's standards for trustworthy clinical practice guidelines.

1.A.3. Encourage the routine posting of new evidence-based COPD clinical practice guidelines, related summaries, and companion materials by the Agency for Healthcare Research and Quality's National Guideline Clearinghouse. This posting will ensure the information is widely available to health care professionals.

1.A.4. Promote guidelines and help incorporate them in primary health care settings. In addition, work with specialty medical organizations to develop a 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.

1.A.5. Collaborate with federal and nonfederal stakeholders to identify and disseminate current guidelines for best practices and new options for COPD prevention, care, and treatment.

2) Using the guidelines, develop a unified, multidisciplinary educational curriculum for health care professionals, including primary health care providers.

2.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.

2.B. 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 and educational events).

2.C. Provide COPD training opportunities for federal and state employees working in public health and direct-care programs.

2.D. Ensure that the curricula are updated regularly to reflect evidence-based best practices for the diagnosis, care, and treatment of COPD as well as policies related to reimbursement and the efficient use of health care spending. Easy access to the curricula should also be ensured.

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

3.A. Improve ways to identify people at risk for or living with early COPD and promote the adoption of accurate diagnostic methodologies as a national standard of care.

3.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.

3.C. Develop a standardized COPD prompt for health care professionals to include in a patient's health assessments and, ultimately, in the patient's electronic health records (EHRs).

3.D. Create new COPD diagnostics with collaborative 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 a written, patient-centric COPD management plan tool, with appropriate health and cultural literacy considerations, which can be customized with input from the patient's health care provider(s).

4.A. Every person with COPD should have a written, patient-centered COPD management plan that includes a patient's daily treatment, such as which medicines to take and when to take them. The plan should describe how to control COPD long term; how to handle worsening COPD or exacerbations; and when and how to use oxygen therapy, physical therapy, and pulmonary rehabilitation treatments. The plan also should explain when to call a health care professional or go to an emergency room, recognize the impact of the patient's comorbidities, and include how to treat and manage those comorbidities.

4.B. The COPD management plan should encourage open conversations between the patient and the patient's family, caregivers, and the health care team. This increases the likelihood that the patient will understand — and own — his or her responsibilities for self-care, and families will understand how best to play a supportive role.

4.C. The plan should offer resources for additional information or assistance, including referrals to patient support services.

4.D. The plan should contain evidence-based resources that can guide provider and patient conversations. These resources could feature visual aids to help explain COPD,

including the signs and symptoms and associated risks, such as exposure to tobacco, environmental factors, and genetics.

4.E. The plan should present information in a simple, brief format that provides culturally appropriate information for people with COPD as well as medically appropriate information for health care professionals.

4.F. The plan should include information about and an explanation of the appropriate use of spirometry and new diagnostics tools, such as molecular diagnostics and computerized tomography (CT) scanning, as they are developed.

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

5.A. Develop a comprehensive public health strategy to promote and implement policies that match respiratory care resources to each patient's respiratory needs.

5.B. Create, validate, and implement best practices for the prompt referral of newly diagnosed COPD patients to services that offer proper care and treatment, including pulmonary rehabilitation, smoking cessation programs, anxiety and depression management, and palliative care.

5.C. Adopt and promote policies that give people with COPD access to quality pulmonary rehabilitation treatment as recommended by evidence-based data under Medicaid and Medicare and private health insurance benefit programs in a variety of public (inpatient/outpatient) and private (home-care) settings. These policies should ensure full coverage for the recommended treatment.

5.D. Adopt and promote, when indicated, the use of oxygen therapy customized to the needs and lifestyle of people diagnosed with COPD.

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

Opportunities for Engagement and Participation

- Promote guidelines to health care professionals on COPD assessment and treatment.
- 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 screening during patients' health care visits.
- Educate health care professionals about national COPD detection and related treatment and care guidelines.
- Ask health care professionals to assess patients for COPD, including using spirometry as appropriate, and then develop a personalized, written management plan.

Goal 3: Collect, analyze, disseminate, and report COPD-related public health data that drive change and track progress.

Reliable data are critical to informed decision-making — when creating resources and also when measuring the success of new risk-identification methods, early detection methods, and the delivery of care. Health data that measures the prevalence and characteristics of COPD, treatment patterns, and patient outcomes are the basis for the effective prevention, diagnosis, and 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 better data collection, validation, analyses, sharing, and real-world application of these data. The adoption of secure health information technology (HIT) and the use of EHRs may greatly enhance the ability to capture and collect patient-level data. Population surveillance efforts, like the U.S. Census and the Behavioral Risk Factor Surveillance System (BRFSS), could also reveal trends that necessitate new policies, resource allocations, or modifications. While using and enhancing existing programs, federal and nonfederal partners should develop new infrastructures and alliances to address data needs. This could inspire new ways to measure COPD prevalence and engage in predictive modeling. Stakeholders also must ensure widespread and meaningful dissemination of data analyses.

1) Collect and aggregate data from multiple sources, including at local, regional, and national levels, and turn them into actionable information.

1.A. Enhance the ability of the existing infrastructure to monitor the public health impact of COPD.

1.A.1. Develop standardized data-collection methods using harmonized definitions and core indicators to monitor the prevalence, care, and treatment of people with COPD.

1.A.2. 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.

1.A.3. Expand COPD surveillance through the assessment of EHRs, claims data, and other electronic data sources.

1.A.4. 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 the U.S. Centers for Disease Control and Prevention (CDC).

1.A.5. Conduct surveys and special studies designed to investigate populations at risk, occupational and environmental factors, disease attributes (e.g., lung function), access to care, and disparities in health services for people with COPD.

1.B. Ensure data compatibility for aggregation and analyses.

1.B.1. 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, include clinical trial and observational data, as well as protocols and algorithms, in the collection efforts.

1.B.2. Utilize aggregated data to describe how COPD and related prevention, care, and treatment programs influence health and morbidity.

1.B.3. Incorporate International Classification of Diseases (ICD)-10 codes into COPD surveillance and ensure that COPD diagnostic codes (ICD-9, ICD-10, and thereafter) are required for EHR certification.

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

1.C.1. Comprehensively and regularly monitor the prevalence and incidence of COPD at national, state, and local levels.

1.C.2. Monitor the use and impact of assessment tools to diagnose COPD, particularly in at-risk populations.

1.C.3. Monitor the delivery and impact of COPD care and treatment, including pulmonary rehabilitation.

1.C.4. Monitor and assess the relationship between comorbidities and their linkage to COPD morbidity and mortality.

2) Facilitate dissemination of data and analyses.

2.A. Report findings of federal COPD surveillance initiatives on a regular basis.

2.A.1. Encourage the regular reporting of COPD surveillance data via established federal infrastructures — e.g., CDC surveillance reports.

2.A.2. Encourage federal and nonfederal partners to be proactive in disseminating the findings of COPD surveillance studies to diverse stakeholders. This could be accomplished by disseminating culturally sensitive materials through a variety of social network platforms (e.g., Facebook and Twitter).

2.A.3. Encourage federal and nonfederal partners to publish outcomes of COPD data analyses using scientific exchange (e.g., peer-review) opportunities.

2.B. Encourage studies that assess the efficacy, risks, and costs of existing and new models of detection, care, and treatment for people living with COPD.

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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 technology to assess and evaluate the impact of 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.
- Contribute to COPD research and the development of improved COPD assessment procedures and technologies.
- Support surveillance projects and epidemiological investigations to help understand the characteristics and needs of people at risk for and living with COPD.
- Support the creation of 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 examine the many contributing risk factors and underlying mechanisms in COPD. This goal aims to improve the understanding of the different forms of the disease, along with its diagnosis and treatments. Translation of basic research to clinical applications can help yield improved methods of diagnosis, symptom management, and treatments that are health preserving and disease arresting or reversing. Of particular importance is the improved identification of people at risk for COPD and those in early COPD development stages, as this will provide the best opportunities for disease prevention and modification.

Because COPD presents, progresses, and manifests in differing ways, many factors influence how people with COPD respond to treatment. Therefore, research supported by the Precision Medicine Initiative could help identify the underlying biology and, coupled with advanced imaging, allow for a better understanding of COPD clinical phenotypes, the role of comorbidities, and the efficacy and safety of interventions and treatments. Such patient-powered research holds promise for the acceleration of COPD discoveries and provides health care professionals with new tools, knowledge, and targeted therapies that will make it easier to choose the treatments best suited for individuals with COPD.

1) Advance research to detect and diagnose COPD.

1.A. Develop and define performance measures for COPD risk identification and early detection, informed by scientific evidence and with input from professional medical organizations.

1.B. Promote basic, clinical, and applied research that improves the diagnosis of people with COPD, leveraging potential synergistic opportunities.

1.B.1. Create a research agenda to 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.

1.B.1.a. Encourage the development of new highly sensitive and rapid diagnostics tools, such as those that identify biomarkers, and their use in molecular diagnostics.

1.B.1.b. Validate biomarkers and pursue their Food and Drug Administration (FDA) qualification for clinical trials and practice.

1.B.2. Create a research agenda that will lead to improvements in the quality of COPD prevention strategies for people at risk.

1.B.2.a. 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, those being screened for lung cancer, and those with concurrent asthma.

1.B.2.b. Develop and test COPD interventions in home- and routine-care settings to determine how to modify risk factors for COPD, reduce the frequency or severity of exacerbations, and prevent the progression of the disease.

1.B.2.c. 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.

2) Define and characterize the pathogenesis of COPD heterogeneity.

2.A. Facilitate and encourage basic science research into the underlying mechanisms that contribute to the development of different COPD clinical phenotypes.

2.A.1. Promote and apply new animal models, cell models, and human-tissue resources to explore the full range of causes of COPD.

2.A.2. Promote the identification of genomic and biomarker data to further characterize COPD phenotypes.

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

3.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.

3.A.1. 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.

3.A.2. Develop new precision medicine treatments for people diagnosed with COPD based on COPD phenotypes.

3.A.3. Develop new care programs for people diagnosed with COPD based on COPD phenotypes for the use in health care and other settings.

3.A.4. Investigate and validate the repurposing of existing drugs approved to treat other diseases.

3.A.5. Include the full spectrum of people with COPD in clinical studies.

3.B. Enhance and monitor the diagnosis, care, and treatment of people with COPD, capturing data by COPD phenotypes.

3.B.1. Develop clear diagnostic categories for each phenotype of COPD and incorporate them into national clinical care guidelines and existing health care delivery plans — e.g., ICD-10 codes.

3.B.2. Create well-characterized patient registries for each COPD phenotype and facilitate their use with applicable technologies and supportive communications.

4) Develop strategies to prevent the onset and progression of COPD.

4.A. Promote research and its findings to improve the quality of COPD care and management.

4.A.1. Support research that studies how access to care impacts the treatment for people diagnosed with COPD.

4.A.1.a. Encourage research on clinical effectiveness and patient-centered treatment outcomes that includes quality-of-life and functionality measures.

4.A.2. Encourage research that studies the progression of subclinical disease to overt disease.

4.B. Develop and test models of care that can be adapted and used in different health care and clinical settings.

4.B.1. Support clinical effectiveness and treatment outcomes research that focuses on the translation of findings from research in controlled environments to general clinical practice and population health (T3/T4 space).

4.C. Improve access to data bases and patient registries for the use in research.

4.C.1. Use aggregated patient EHRs to monitor the use of tools for the detection, diagnosis, care, and treatment of COPD.

4.C.2. Encourage the development and use of real-world observational data for patient care and treatments.

4.C.3. Encourage the sharing of anonymized patient data from diagnostic and treatment clinical trials for the use in secondary analyses. This can be done by capitalizing on data-sharing opportunities made possible by the creation of data repositories from all sources, including pharmaceutical sponsors.

4.C.4. Facilitate cross-communication between scientists and practicing health care professionals.

4.D. Promote research that studies the effectiveness of COPD-focused policies and programs.

4.D.1. Evaluate COPD-focused policies, public health interventions, and programs by using predefined, evidence-based performance metrics.

4.D.2. Develop value-based return-on-investment (ROI) models using research that describes the effectiveness of current COPD programs and policies.

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.

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Goal 5: Translate national policy, educational, and program recommendations into legislative, 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 legislative and public health care actions. All involved need to work together to make funding opportunities for a variety of activities available and allow all interested to participate.

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

1.A. Create an official entity to oversee and support the implementation and tracking of the *COPD National Action Plan*.

1.A.1. This official entity must include representatives from federal and nonfederal partners and permit regular engagement to foster the collaboration and coordination of efforts.

1.A.2. This official entity will assist in prioritizing and tracking the five goals of the *COPD National Action Plan* through annual reporting. Implementation of tactics will be the responsibility of federal and nonfederal partners, as outlined in the *COPD National Action Plan*.

2) Identify and support opportunities to further COPD research and education at national and local levels.

2.A. Develop an easily accessible resource guide to COPD research and outreach funding opportunities offered by federal and nonfederal partners. In particular, increase the awareness and visibility of investigator-initiated research in COPD.

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

2.C. Develop a mechanism to regularly share opportunities with all interested parties (e.g., via a dedicated website or newsletter).

3) Develop and implement COPD quality measures into national care delivery.

3.A. Use existing and still-developing performance quality measures that are informed by scientific evidence and input from professional medical organizations and work with federal agencies to encourage the adoption of those measures for COPD detection, care, and treatment in health care settings.

3.A.1. Define, validate, and disseminate quality performance measures for the COPD continuum of care, including patient services in private and public health plans, pulmonary rehabilitation, and associated reimbursements.

3.A.2. Encourage health systems to incorporate COPD into current health and community assessments, such as the Community Health Needs Assessment Surveys, as described in the Affordable Care Act.

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Opportunities for Engagement and Participation

- Advise in the creation of 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.
- Engage in the annual assessment of *COPD National Action Plan* initiatives.
- Share information about the *COPD National Action Plan's* performance.

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