National Campaign Development: COPD

Les Rencontres de Santé publique France

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National Institutes of Health (NIH)
USA





CONFLICTS

- US government employee
- I will be discussing US government programs.



Outline

- Why COPD? Why now?
- Learn More Breathe Better Awareness®
 Campaign
 - Goals
 - Target Audiences
 - Methods
 - Metrics
- COPD National Action Plan
 - Charge
 - Goals
 - Methods

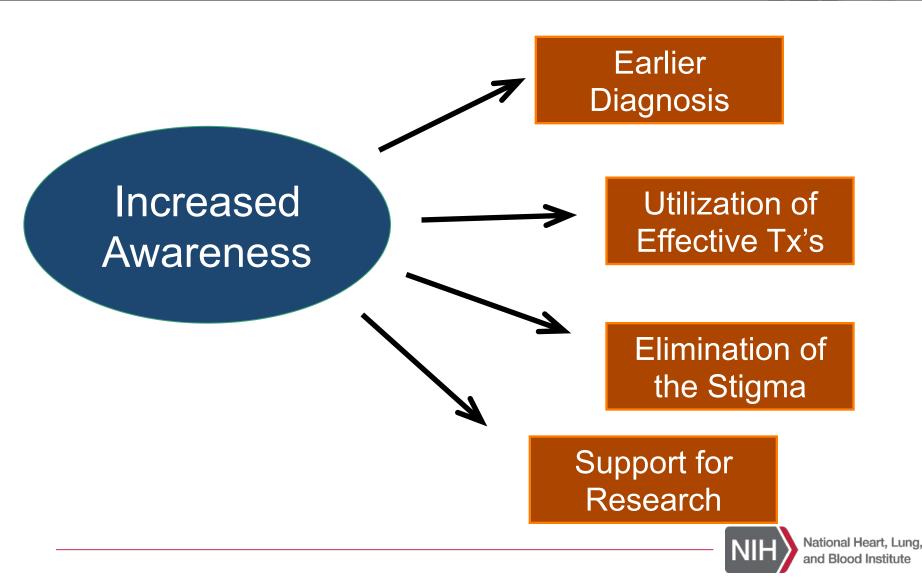


Why COPD? COPD Is a Serious Public Health Problem

- 4th leading cause of death in the U.S., following heart disease and cancer
- Nationwide prevalence is 6.5%
 - 16 million people have diagnosis of COPD
 - Millions more don't know they have it
 - More common in elderly, poor, and women
- 4th main cause of disability costing nearly \$32 billion went to COPD-related care in 2010



Why COPD? Serious underdiagnosis and misconceptions



Learn More, Breather Better® Campaign

Objective

To increase awareness and understanding of COPD and its risk factors among target audiences, and to underscore the benefits of early detection and treatment.

Audiences

- At-risk men and women (smokers and former smokers age 45+)
- Patients with COPD diagnosis and their caregivers
- Health care providers



Strategic Approach

- Fact-based
- "Brand" COPD "It has a name"
- Emphasize diagnosis and treatment, not causes
- Building partnerships as key to success



Core Campaign Components



National Campaign Launch

- January 18, 2007 press conference
- 175 partners, media, health professionals & patients
- More than 20 partner organizations represented
- Patient spokesperson



Dr. Elizabeth Nabel, NHLBI Director, speaking at press conference, 2007



COPD Launch Media Coverage

 Television: 142 airings on 96 TV stations, ~ 3 million views

• Radio: 3,128 airings on 1,688 stations: 14.4 million listener impressions

- Print: 14 original print or online stories appearing on over 500 outlets
- Total: 28 million impressions



PLUS: 10 Top Power Foods

Develop Materials

CHRONIC OBSTRUCTIVE PULMONARY DISEASE **Breathing Better** With a COPD Diagnosis

DID YOU KNOW?

COPD is the 4th leading cause of death in the United States and causes serious, long-term disability. The number of people with COPD is increasing. More than 12 million people are currently diagnosed with COPD and an additional 12 million likely have the disease and don't even know it.

But there is reason for hope. You've taken the first step by being aware of your symptoms and seeing your doctor for testing and diagnosis. Now that you know you have COPD, your doctor

WHEN YOU ARE DIAGNOSED WITH COPD

There are many things that you can do to make living with COPD easier:

Ouit Smoking

If you smoke, the best thing you can do to prevent more damage to your lungs is to quit. Ask your doctor about new options for quitting. Many resources to help you quit are available online. Visit www.smokefree.gov; www.lungusa.org; or call 1-800-QUIT NOW for more information.

EDUCATIONAL VIDEO

CHRONIC OBSTRUCTIVE PULMONARY DISEASE COPD: Are You at Risk?

COPD is the 4th leading cause of death in the United States. The disease kills more than 120,000 Americans each year—that's 1 death every 4 minutes—and causes serious, long-term disability. The number of people with COPD is increasing. More than 12 million people are diagnosed with COPD and an additional 12 million likely have the disease and don't even know it.

WHAT IS COPD?

EDUCATIONAL VIDEO

COUGHING - IT HAS A NAME - DIFFIC

When COPD is severe, shortness of breath and other symptoms can get in the way of doing even the most basic tasks, such as doing light housework, taking a

walk, and even bathing and getting dressed. COPD develops slowly, and can worsen over time, so be sure to report any symptoms you might have to your doctor as soon as possible, no matter how mild they may seem.

ARE YOU AT RISK?

a history

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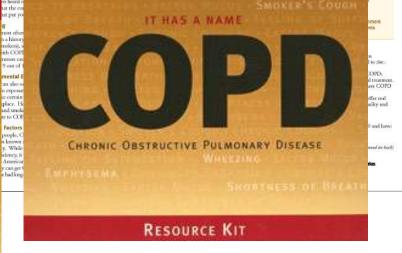
CHRONIC OBSTRUCTIVE PULMONARY DISEASE

ABOUT THIS VIDEO

Profiling the personal experiences of three people diagnosed with COPD (chronic obstructive pulmonary disease), this DVD answers basic questions about the disease and its risk factors, and demonstrates how real people took Steps to manage the disease and breathe easier. A useful tool for educating those at-risk for the disease, the video can be utilized in settings such as community-based information seminars, health and wellness events and shows, and in health care provider offices or waiting rooms. Running time is approximately 9 minutes. Companion guide for moderators also included. www.LearnAboutCOPD.org

COPD IN TO.







CHRONIC OBSTRUCTIVE PULMONARY DISEASE

COPD Essentials

for Health Professionals

· Primary care providers have a key role in

the diagnosis and management of COPD.

. Consider diagnosis of COPD in adults with

Risk factors other than digarette emoking history are important. Ten to 20 percent of

cases may be due to environmental and

occupational exposures.

shortness of breath, with or without symptoms of cough and sputum production:

Health-related Partners













Promoting Health & Preventing Disease











Partnership: Breathe Better Network

By 2013, 80+ partners in 50 states

- Breathe Better Network members conduct COPD education and outreach in their communities
- Membership includes organizations at the national level

Breathe Better Network









A CDC-NHLBI partnership put COPD on the map

Center for Disease Control and Prevention (CDC) collects regional data about U.S. residents regarding their health, using a telephone survey, the Behavioral Risk Factor Surveillance System (BRFSS).

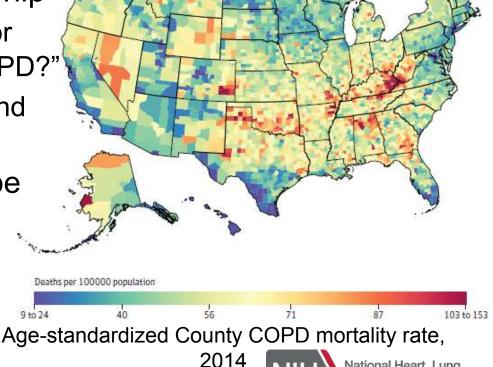
CDC BRFSS–NHLBI partnership

Added a question: "Has a doctor ever told you that you have COPD?"

 Provided COPD data at state and local levels

 Enabled outreach efforts to be targeted on areas with high COPD prevalence

 Provided foundation to build focused state action plans



Act Locally: Contracts at State Level

Western Michigan U. School of Medicine

Going beyond traditional health care settings to provide COPD care.

Respiratory Health Association

Working to empower COPD caregivers with information and effective strategies.

COPD Foundation

Providing training to improve understanding of COPD among rural health care professionals.

Breathe New Hampshire

Bolstering tobacco-use treatment in state & enhancing national collaboration to reduce burden of COPD.

Atrium Health

Harnessing the power of children to advance COPD awareness & education.

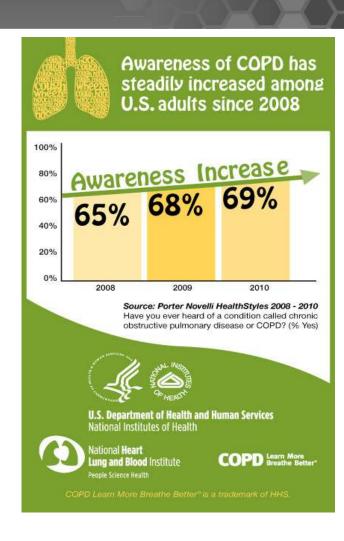
South Carolina Tobacco-Free Collaborative

Targeting rural health clinics with COPD education program to improve diagnosis & treatment outcomes.



Program Evaluation

- Collect data annually on COPD awareness, COPD symptoms, and health care provider interactions:
- Key findings among consumers (2018 data):
 - **7/10** Americans are aware of COPD---steady since 2014.
 - 1 6 percentage points 2009 2014.
 - 1/10 Americans experiences
 COPD symptoms
 - 1/4 of these has not spoken to a health care provider





Materials Continue to Evolve Based upon Data

- Designed to address barriers to diagnosis
- Designed to appeal to patients & providers



More social media





COPD: BETTER TALK MEANS BETTER TREATMENT.

12 million Americans are receiving treatment for COPD that is helping them to live longer and better with this serious lung disease. But, another 12 million have COPD and aren't yet diagnosed. Why? A recent survey points to a communications gap between health care providers and patients,

For tools to help start the conversation, visit COPD.nhlbi.nih.gov







Patient does not fully



Patient doesn't fully report



Patient has more











TOP

SYMPTOMS AREN'T TELLING THE DOCTOR



I didn't think of it.

I don't want another 'quit smokina' message.





problems will just go away in time.



I have had these problems for years.



Origin of the COPD National Action Plan

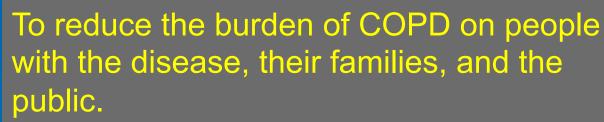






National Heart, Lung, and Blood Institute





- Serve as a guide to stakeholders to facilitate our working collaboratively and synergistically
- Clarify what actions need to be taken
- Create actionable pieces





COPD Town Hall Meeting

Set the foundation for the COPD National Action Plan

February 29 and March 1, 2016







More than **200** attendees – including patients, caregivers, healthcare providers, industry leaders, academic leaders and **14** federal partners

Attendees separated into six breakout groups based on the original Action Plan goals and developed 18 recommendations



COPD National Action Plan: Goals

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



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COPD National Action Plan: Implementation

All COPD stakeholders own the plan and need to have an active role in its implementation.

Patients and their Families

Industry Partners

Public Interest Organizations and Advocacy Groups



Government Agencies

Professional Societies

Scientific Investigators and Physicians

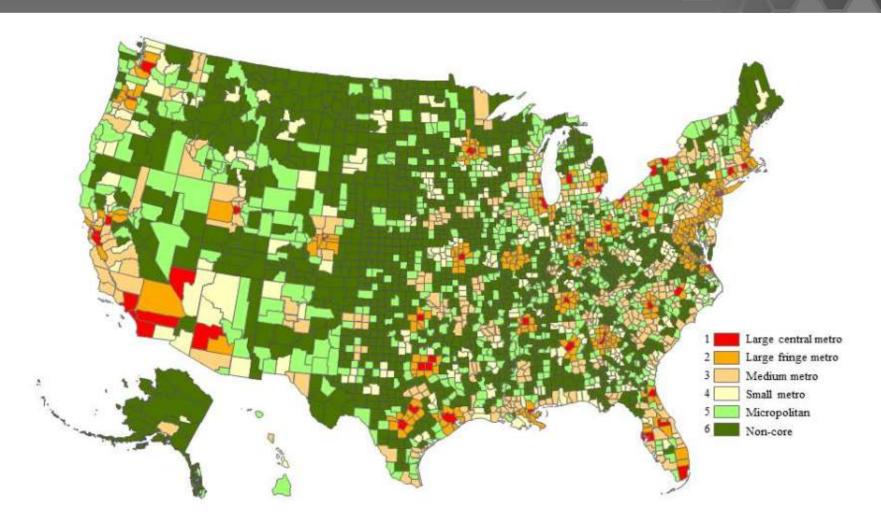


Path Forward for all Americans





National Center for Health Statistics 2013 Urban-Rural Classification Scheme for Counties



Source: <u>www.cdc.gov/nchs</u>. Vital Health Stat 2014;2(166)



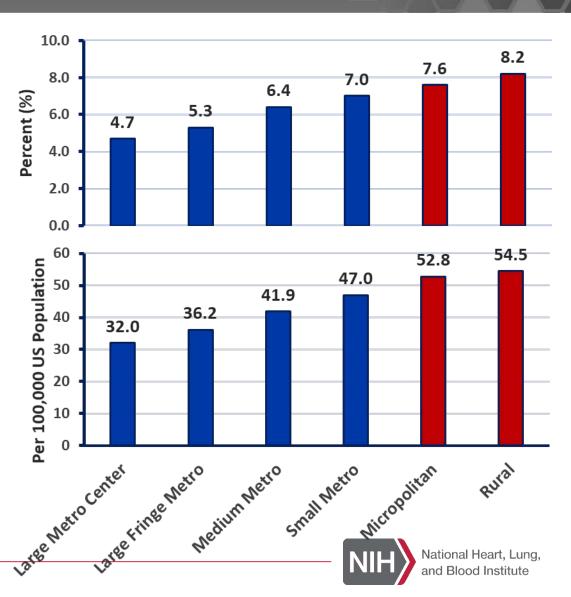
Urban-Rural difference in Diagnosis and Mortality 2015

Prevalence of doctordiagnosed COPD among adults is higher in rural settings

Source: CDC. MMWR 2018;67(7):205-211.

Death rates for COPD are higher in rural settings

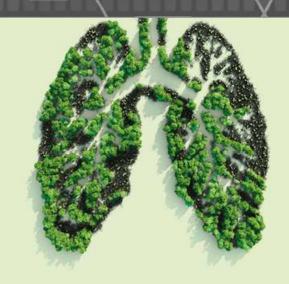
Source: CDC. MMWR 2018;67(7):205-211.



COPD & Rural Health:

A Dialogue on the National Action Plan.

Join the livestream to participate!



Date: **03.19.18**Time: **8:30 a.m. - 5:00 p.m.** EDT





LEARN MORE BREATHE BETTER

COPD Learn More Breathe Bettor* is a trademark of HHS

#COPDRuralHealth





Summary of Activities

2018

- Hosted COPD & Rural Health Meeting
- Awarded \$200K in subcontracts
- Released animated lungs video: Are your lungs trying to tell you something?

2017

- Released COPD National Action Plan (May 2017)
- DLD participation in COPD Documentary about Leonard Nimoy
- Released animated video component to radio PSA
- · COPD Journey video series

2016

- February/March: Held first COPD Town Hall
- · Launched HCP Toolkits
- Held public comment period for COPD National Action Plan

2015

- Spring: Issued \$148k in subcontracts
- Summer: Launched "Millions with COPD" radio PSA
- November: National COPD Awareness Month activities with Twitter chat, Thunderclap, RMT

2014

- Summer-Winter: Primary & secondary HCP research
- · November: National COPD Awareness Month Twitter Chat, Google Hangout, RMT

2013

- 80+ partners in all states
- Country Conquers COPD held 20th event
- Hosted second annual Twitter chat

2012

- 60+ partners in 30+ states, hosted first Twitter chat
- COPD prevalence data is released

2011

- January-August: 56 partners in 30 states
- Awarded \$400K in subcontracts
- CDC releases data on COPD across all 50 states via BRFSS

2010

- Partnership network grew to 40 partners in 20 states
- Campaign **supported summits in 9 states**; 5 state action plans were developed
- Launched "Places to Rest" PSA series

2009

- Held first partner meeting with 20 states (March) and began to formalize Breathe Better Network
- Launched Country Conquers COPD™, awarded \$450K in subcontracts

2008

· Winter: Grew to 16 partners by year's end

2007

- January: Campaign launched
- · Summer: "COPD: It has a name" PSA series

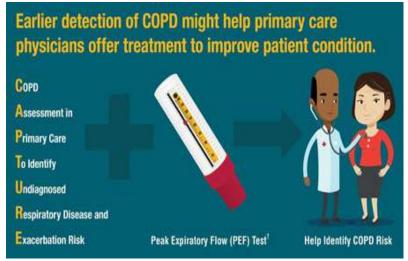






Finding Individuals with Undiagnosed COPD: CAPTURE - An NHLBI Funded Study

A simple questionnaire (5 questions) plus an easy test of pulmonary function (peak flow) may identify most people with undiagnosed COPD.



Martinez FJ et al, AJRCCM 2017; 195(6): 748-56

Please answer each question	No		Yes
Have you ever lived or worked in a place with dirty or polluted air, smoke, second-hand smoke, or dust?			
Does your breathing change with seasons, weather, or air quality?			
3. Does your breathing make it difficult to do things such as carry heavy loads, shovel dirt or snow, jog, play tennis, or swim?			
Compared to others your age, do you tire easily?			
	0	1	2 or more
5. In the past 12 months, how many times did you miss work, school, or other activities due to a cold, bronchitis, or pneumonia?			
For Clinic Use -			
Peak Expiratory Flow (PEF) (L/Min) - Best of Three (3) Tests			
(Recommended for scores ≥ 2)	No		Yes
Males: ≤ 350 L/M			
Female: ≤ 250 L/M			



Since March 2018: Moving the Needle for COPD in Rural Health

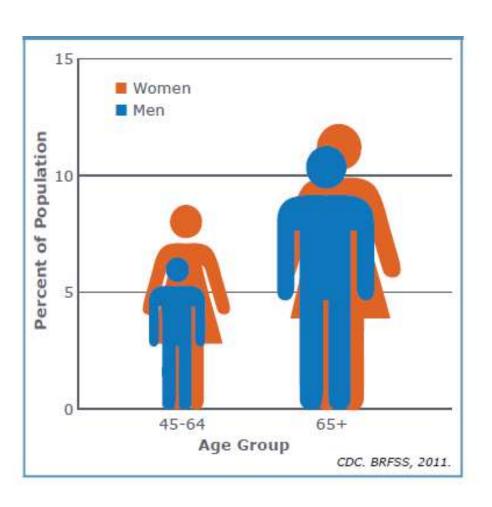
As a follow-up:

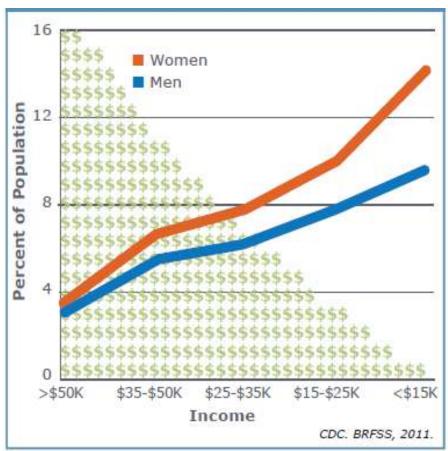
- •June 2018- the Federal Office of Rural Health Policy (FORHP) hosted another gathering to begin establishing actionable commitments to implementing the goals of the COPD National Action Plan.
- •September 2018 COPD was a focus area at the National Advisory Committee on Rural Health and Human Services

Activities around adapting the COPD National Action Plan to Rural USA

- Health Resources and Services Administration (HRSA- Federal agency)
 - Is compiling resources to help spread awareness of COPD
 - Working with health professional education accrediting bodies to expand COPD training in required curricula
- National Rural Health Association (NHRA)
 - Collaborate with HRSA-FORHP to ensure that there is an education session on COPD at NRHA's annual conference
- •NRHA communications team work with NHLBI to reach out to the 51 Rural Health Services Organizations
- •Grace Anne Dorney Koppel Foundation to help establish pulmonary rehab clinics in areas with high prevalence and little access

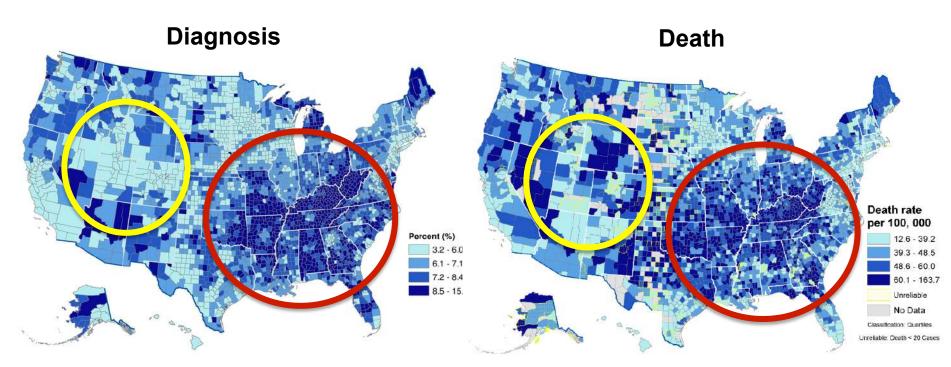
COPD is higher in women, the elderly, the poor







U.S. COPD Diagnoses and Deaths



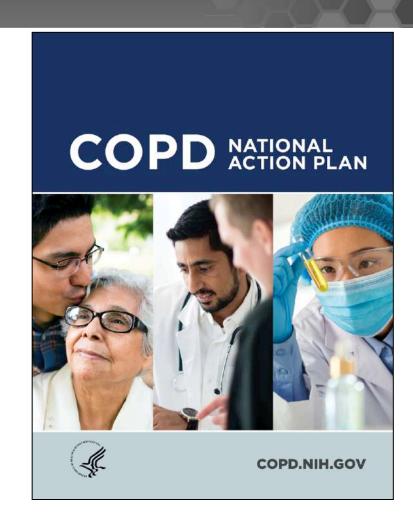
Discrepancy in some rural areas between provider-diagnosed COPD (low) and COPD death rates (high)

CDC. MMWR 2018;67(7):205-211 & CDC Unpublished death certificate data, 2010-2015.



The COPD National Action Plan

- Provides a comprehensive framework for action by those affected by the disease and those who care about reducing its burden.
- Developed with input from the broad COPD community.

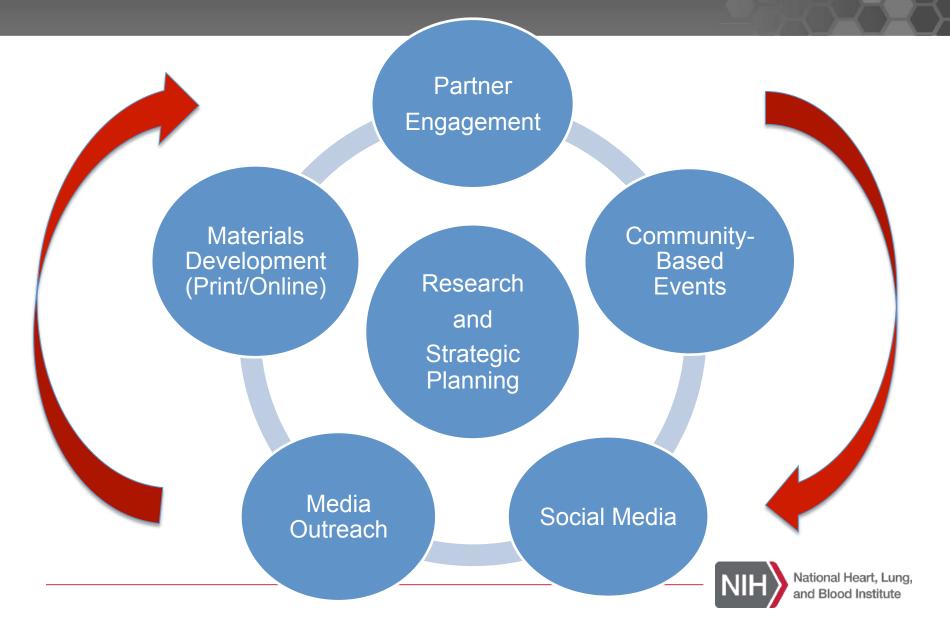


Downloadable for free at:

https://www.nhlbi.nih.gov/health-topics/education-and-awareness/COPD-national-action-plan



Summary- Campaign Components



A Congressional Charge

November 24, 2014

Congress of the United States Washington, DC 20515

Dr. Thomas R. Frieden, MD, MPH Director Centers for Disease Control and Prevention 1600 Clifton Road Atlanta, GA 30333 Dr. Francis S. Collins, MD, PhD Director National Institutes of Health 9000 Rockville Pike Bethesda, MD 20892

Dear Directors Frieden and Collins:

As members of the Congressional Chronic Obstructive Pulmonary Disease (COPD) caucus, we write to request that the NIH and the CDC create a national federal action plan for COPD in fiscal year 2015.

Beginning in the 111th Congress, Federal appropriations language directed the NIH and CDC for collaboration and coordination among federal and external stakeholders to create a COPD National Action Plan. This would be a huge step forward for the 15 million Americans living with this disease, and the 12-14 million still undiagnosed. It is our understanding that the CDC and the NIH have both convened expert stakeholder groups to address COPD, but this has not yielded a comprehensive plan. We hope a strategy will be realized as soon as possible.

John Lewis

Member of Congress

David P. Joyce

Member of Congress

Carol Shea-Porter

Member of Congress



With NIH & CDC support, NHLBI to convene a meeting to develop a National Action Plan

The Honorable John Lewis

Member of the Congressional Chronic

Obstructive Pulmonary Diseases Caucus

U.S. House of Representatives

Washington, D.C. 20515-3313

JAN 2 9 2015

visits for COPD) were specific goals that warrant coordinated federal action. In late 2015, the NHLBI will be convening a meeting involving federal and non-federal stakeholders, including patients, to develop a National Action Plan to coordinate activities targeting this disease, particularly those addressing these HP2020 objectives.

We share your commitment to helping the millions of people affected by COPD and we anticipate that achieving these HP2020 goals will make a significant difference in their lives. If you have further questions, please do not hesitate to contact us. Please note a similar letter is being sent to the cosigners of your letter.

Sincerely yours,

Francis S. Collins, M.D., Ph.D.

Director

National Institutes of Health

Jan Y. W.

Thomas R. Frieden, M.D., M.P.H.

homas deed

Director

Centers for Disease Control and Prevention



Community-based Events

- Established the Country Conquers COPD event series.
- Partner with local organizations







