

A woman with short dark hair, wearing a grey sweater, is shown in profile, coughing into her fist. Her other hand is pressed against her chest, suggesting respiratory distress. The background is a bright, indoor setting with a window and a plant.

LIVING WITH COPD

**Patient Experiences &
Health Policy Perspectives**

AUGUST 2025



INTRODUCTION

Chronic obstructive pulmonary disease, or COPD, affects millions of Americans. Many of them live with this condition without even knowing it.

COPD encompasses several lung conditions, including emphysema and chronic bronchitis, that make breathing difficult and can significantly impact quality of life.

The COPD Action Alliance conducted a national survey of 250 individuals diagnosed with COPD or suspecting they might have the condition. The survey explored patient experiences with access barriers to treatment and perspectives on health care policies affecting the COPD community. The results reveal important insights into the challenges patients face and highlight areas where policy improvements could make a meaningful difference.



PATIENT EXPERIENCE

Diagnosis & Duration

Among survey respondents, 58% had been formally diagnosed with COPD, while 42% suspected they might have COPD but had not yet received a diagnosis.

This finding emphasizes a key concern: **many people may be living with undiagnosed COPD, potentially missing opportunities for early intervention and treatment.**

For those who had been diagnosed or suspected of having COPD, the timeline varied significantly:

TIME SPENT WITH COPD SYMPTOMS OR DIAGNOSIS

0-6 MONTHS

12%

6 MOS-1 YEAR

26%

1-3 YEARS

25%

3 YEARS+

37%

How Patients Engage With Resources & Where Gaps Remain

The majority of patients surveyed have engaged with their health care providers about their conditions. Almost 50% visited a primary care doctor about their COPD, and 33% saw a lung specialist.

However, patient support and advocacy remain limited. Notably, 35% said none of these activities applied to them, suggesting significant room for improvement in connecting patients with available resources.



Risk Factors & Exposure

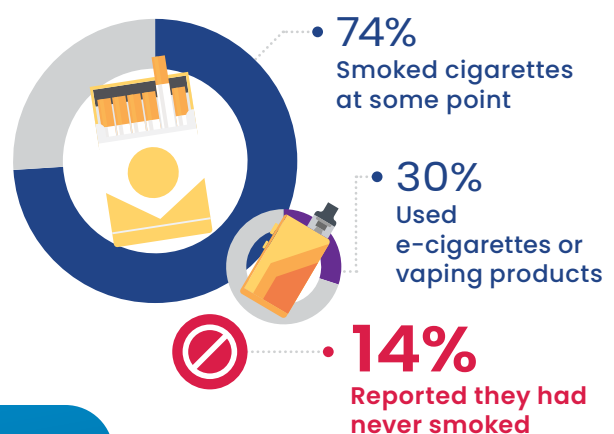
The survey revealed broad occupational and environmental exposure to a range of known COPD risk factors.

Respondents reported exposure to:



These findings highlight that environmental factors and occupational exposures are contributing factors to COPD, significantly raising the risk of disease.

Additionally, respondents noted they had:



(multiple responses allowed)



There's a stigma around COPD. Many people assume I have it because I smoked cigarettes, but I've never smoked. I grew up in a smoker's home and worked in jobs that contributed to my COPD.



PATIENT PERSPECTIVES ON POLICY, HEALTH CARE & IMPACT

Policy Priorities

Patients expressed strong support for a range of policy actions aimed at improving COPD care and outcomes, including:



- 65%
Strengthening health care coverage



- 55%
Ensuring access to treatment



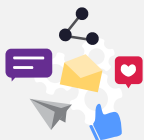
- 55%
Increasing research funding



- 50%
Expanding access to pulmonary rehabilitation



- 49%
Improving air quality standards



- 39%
Launching national awareness campaigns

The overwhelming majority of respondents believe that government intervention is needed to address COPD.

When asked whether current policies are making care better, **nearly half** said policies are not improving care, while only 21% said they are.

Almost 50% of respondents believe U.S. health care policies are not improving care for COPD patients.



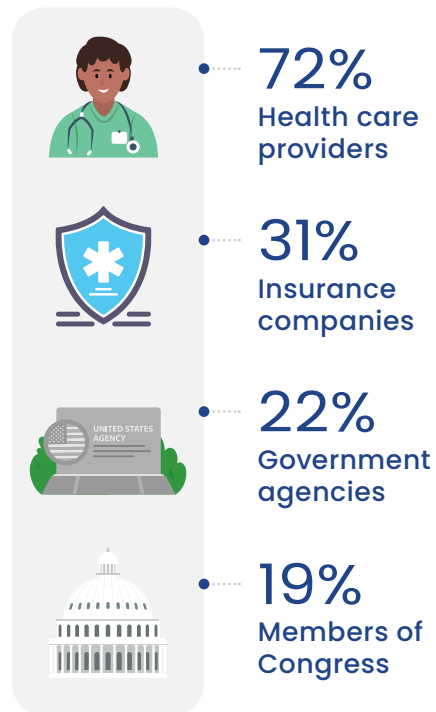
Health care policies should prioritize affordable access to inhalers, supplemental oxygen and pulmonary rehabilitation programs and ensure more comprehensive coverage for medications and treatments.

– U.S. veteran living with COPD



Health Care System

Patient confidence in the health care system varies significantly depending on who is making the decisions. Respondents noted their level of trust in the following:



(multiple responses allowed)

Furthermore, many patients find the health care system difficult to navigate, with 79% agreeing or strongly agreeing that navigating the system is challenging.

Access to care also presents major challenges.



ALMOST 1 IN 3

Reported facing barriers to getting COPD medications, treatments, or medical supplies because of insurance or health care policies.

The most common barriers to treatment include:

- Insurance coverage limitations and prior authorization requirements
- High out-of-pocket costs
- Challenges related to scheduling specialist appointments or obtaining equipment
- Supply chain disruptions affecting medication availability



I faced several barriers with insurance and health care policies while trying to access COPD treatment.

- COPD patient recalls experiencing prior authorization, step therapy and high out-of-pocket costs.



Personal Impact

The survey revealed important insights into the personal impact of COPD.

89%

Take COPD seriously

85%

Believe their doctors take COPD seriously

65%

Consider themselves knowledgeable about COPD

57%

Feel their family and friends understand their condition

31%

Feel or previously felt embarrassed to talk about COPD



81%

Say that a lack of awareness or education about COPD is a major challenge for patients.

Notably, only 40% of respondents correctly identified COPD as one of the leading causes of death in the United States, suggesting opportunities for improved patient education about the severity of the condition.



If I had been told years ago that I had COPD, I could have gotten the help I needed much sooner.



Most patients rely on sources within the health care system for information on COPD.



64%
Primary Care Physicians



41%
Health Care Websites



40%
Lung Specialists



16%
Government Websites

A photograph of a young Black female healthcare worker with a stethoscope around her neck, smiling and looking at a tablet. An elderly white male patient with glasses is looking at the same tablet. The image is overlaid with a semi-transparent purple filter.

CONCLUSION

The results of this survey highlight both the challenges and opportunities in COPD care and policy. While patients generally trust their health care providers and take their condition seriously, significant barriers remain in accessing care and navigating the health care system.

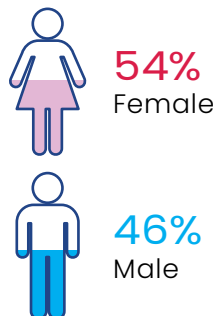
The high percentage of respondents who suspect they have COPD but remain undiagnosed underscores the critical need for improved education, awareness and screening efforts.

Patients face substantial barriers to treatment due to costs, insurance coverage limitations and access issues. There is doubt among respondents that insurance companies and policymakers will make decisions in patients' best interests. Still, patients strongly support policy interventions, particularly around strengthening health care coverage, ensuring treatment access and supporting expanded research.

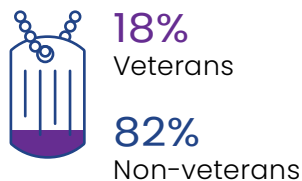
Moving forward, policymakers should consider comprehensive policy changes that increase coverage, improve access and raise awareness for COPD. By implementing these policies, decision makers can improve the lives of the 30 million Americans living with COPD.

DEMOGRAPHICS

Gender



Veteran Status



Age Range



Race/Ethnicity



 **COPD ACTION ALLIANCE**

COPDActionAlliance.org



copdaction



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