

# A Patient Charter for Chronic Obstructive Pulmonary Disease (COPD)

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## Foreword

**384 million people worldwide  
are affected by COPD.<sup>1</sup>**

The third leading cause of death among heart disease and stroke.<sup>1</sup> As global patient advocates, we believe it is essential to raise the level of awareness and understanding among patients, caregivers, healthcare professionals, policymakers and the public about the impact of COPD and opportunities to reform patient care. We believe patients should be empowered to live freely with COPD, without symptoms and exacerbations, reducing their interaction with hospitals and extending their life for as long as possible.



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P A T I E N T P L A T F O R M

# Introduction

**COPD is estimated to affect 384 million people worldwide.<sup>1</sup>**

Chronic Obstructive Pulmonary Disease (COPD) is a group of progressive lung conditions most commonly characterised by persistent respiratory symptoms (chronic cough, shortness of breath and sputum production) and lung function impairment due to airflow limitation and/or hyperinflation. The severity of symptoms, lung function impairment and experience of exacerbations (also known as flare ups) vary between patients.<sup>2</sup>

The global burden of COPD is growing. In 2015, 3.2 million people died from COPD worldwide, an increase of 11.6 per cent compared to 1990.<sup>3</sup> COPD also places significant burden on the global economy, with an estimated cost of greater than \$100 billion per year globally.<sup>2,4,5</sup>

Global strategy documents and guidelines exist, including those from the Global Initiative for Chronic Obstructive Lung Disease (GOLD) and the American Thoracic Society (ATS), which define best practices in COPD care based on the latest evidence. National guidelines also exist which vary in measures of disease severity, consideration of patient phenotype and treatment criteria,<sup>6</sup> demonstrating inconsistencies in how COPD patients are managed at a global and national level. In addition, almost 90 per cent of cases of COPD worldwide are not diagnosed<sup>7</sup> and adherence to therapy guidelines can be poor.<sup>8,9</sup>

Representatives of three national patient organisations along with seven clinicians discussed the value of establishing a Patient Charter as a potential starting point for discussions on how to reform care for patients with COPD. This Charter was subsequently initiated and funded by AstraZeneca and aims to set a standard for what people with COPD should expect from their ongoing care. These expectations are in line with the current best practice understanding from existing COPD services, to offer consensus on global standards of COPD care and drive timely, evidence-based treatment to maintain health status, minimise symptoms and prevent exacerbations. The purpose of this Charter is to mobilise governments, healthcare providers, policymakers, lung health industry partners and patients/caregivers to address the unmet need and burden in COPD, ultimately working together to deliver meaningful improvements in care, both now and in the future.

## Six principles of quality care for people with COPD

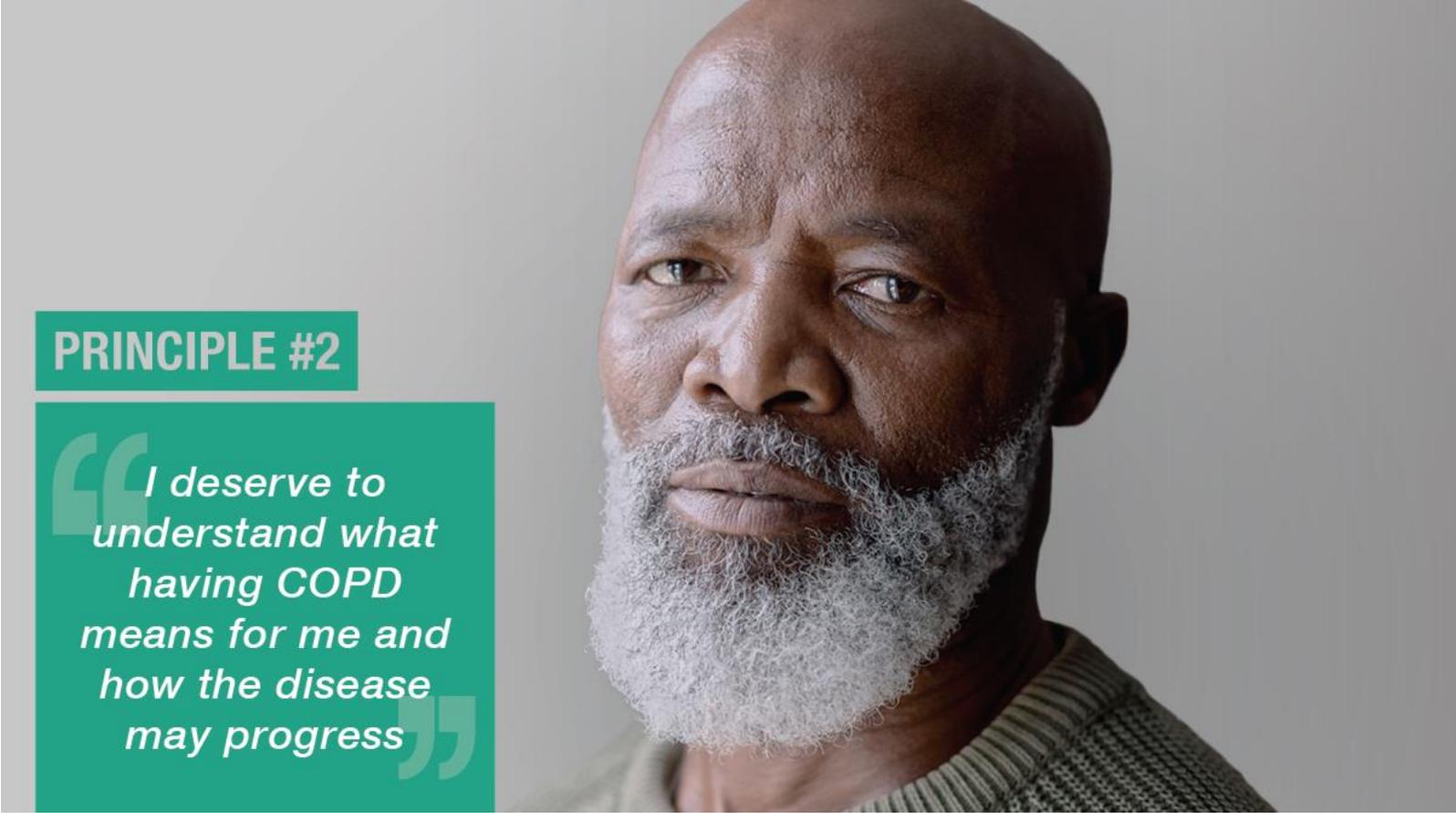
This Charter outlines six principles of quality care that patients should expect to receive, wherever they live. The principle concepts were developed by a working group of 20 clinicians and patient advocacy group representatives and refined by the committee of experts who authored the COPD Patient Charter.



## PRINCIPLE #1

*I deserve timely access for the diagnosis and assessment of my COPD*

- Symptoms in the early stages of COPD can be mild, meaning they are not always well recognised by patients, who often assume their symptoms are a result of ageing, or smoking<sup>10</sup>
- As such, COPD is frequently diagnosed late when the disease has already progressed. This is associated with higher rates of exacerbations increased multimorbidities and costs<sup>11</sup>
- Undiagnosed COPD also places significant burden on patients and the healthcare system. However, these patients are not recognised by healthcare professionals as having the disease and therefore not being properly managed and treated. Almost 90 per cent of cases of COPD may be undiagnosed worldwide<sup>7</sup> and they use healthcare services for their symptoms in the same way as diagnosed patients<sup>12</sup>
- Currently, there are no therapies that affect the rate of change once lung function has started to decline.<sup>13</sup> Controlling symptoms, preventing exacerbations and early death is therefore essential for people living with COPD
- Accurate diagnosis of COPD can only be made using spirometry, a physiological test to assess the reversibility of airflow limitation, which should be performed and interpreted by trained individuals.<sup>2</sup> However, this assessment alone is not recommended to inform treatment decisions<sup>2</sup> meaning that other diagnostic tools are also required
- Patients and healthcare professionals should have the tools to support them to recognise the initial symptoms of COPD and access to the right resources; including electronic medical records and diagnostic tests; to make an informed and accurate diagnosis



## PRINCIPLE #2

*I deserve to understand what having COPD means for me and how the disease may progress*

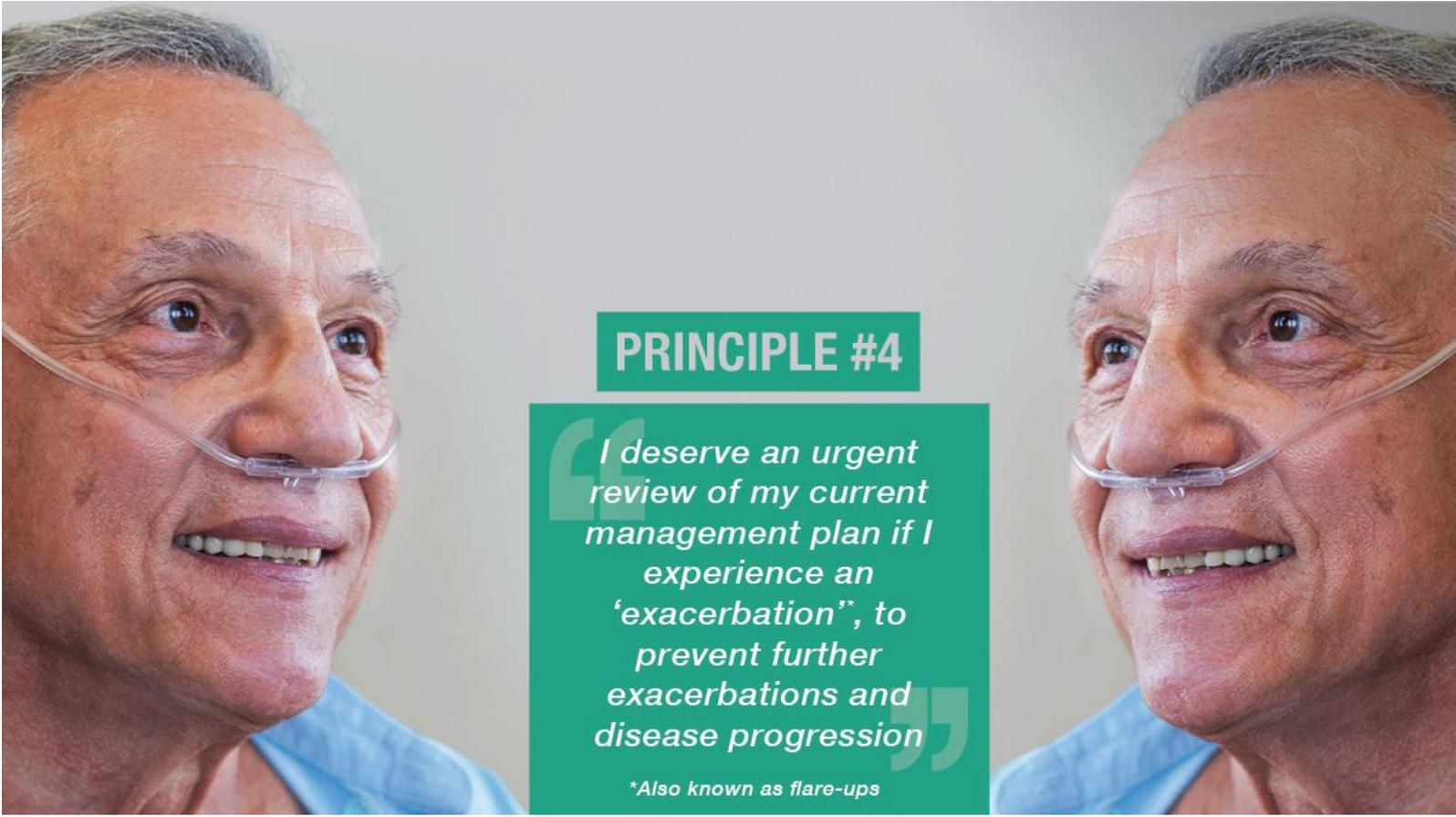
- COPD is a heterogeneous disease, which can be categorised based on symptom severity and history of exacerbations at initial diagnosis<sup>2</sup>
- However, as a progressive disease, symptoms may change or worsen over time and can lead to exacerbations. COPD is also associated with a number of multimorbidities, which further contribute to disease severity, reduced quality of life, and poor clinical outcomes.<sup>14,15</sup> These factors should drive a change in how the condition is managed (both the pharmacological and non-pharmacological management)
- With increasing demand for COPD services, it is becoming more important for patients to become active participants in their own care and respond to their symptoms with urgency to prevent further disease progression
- Self-management interventions in patients with COPD are associated with improved health-related quality of life, a reduction in hospital admissions, and improvement in symptoms<sup>16</sup>
- Patients should receive personalised education and training about their COPD and how it interacts with their other morbidities to enable them to actively participate in their own care, implementing long term changes and reporting changes in symptoms to their healthcare professional to prevent further disease progression



### PRINCIPLE #3

*I deserve access to the best available evidence-based, personalised treatment, to ensure I can live as well and as long as possible*

- Goals for the treatment of COPD are based on reducing symptoms and the risk of future exacerbations, preventing lung function decline and premature death.<sup>2</sup> Many therapies have been shown to be beneficial across these goals, including suggestions of reduced mortality<sup>17,18,19</sup>
- Many gaps exist in non-pharmacological (for example, pulmonary rehabilitation, including exercise training and education, and smoking cessation) and pharmacological management of COPD. Over two thirds of people are not prescribed maintenance therapy<sup>20</sup> and, of those receiving treatment, up to three quarters of people who experience two or more exacerbations continue to be undertreated according to GOLD recommendations<sup>21</sup>
- COPD is a heterogenous disease meaning that symptom severity, history of exacerbations, multimorbidities, impact on quality of life and biological markers will vary between and within patients and management of COPD should be personalised to the individual patient
- COPD patients should request an evidence-based and personalised management plan at both initial diagnosis and follow-up to enable a more proactive, timely prevention of disease progression rather than reacting to a worsening of health status



## PRINCIPLE #4

*I deserve an urgent review of my current management plan if I experience an ‘exacerbation’, to prevent further exacerbations and disease progression*

*\*Also known as flare-ups*

- Exacerbations have a detrimental impact on patients and society. Hospitalisations resulting from severe exacerbations account for approximately two thirds of all healthcare costs associated with COPD.<sup>22</sup> Frequent moderate (community treated) exacerbations or one severe (hospital) exacerbation increases a patient risk of death<sup>23</sup>
- Over 70 per cent of patients with COPD experience exacerbations within three years of diagnosis<sup>24,25,26</sup> and a history of exacerbations is the best predictor of future risk<sup>27</sup>
- Exacerbations are associated with an increased risk of cardiovascular complications, such as myocardial infarctions (MI) and strokes. The risk of MI doubles within 5 days of the start of an exacerbation, and then returns to baseline over time, and the risk of stroke increases by 40per cent<sup>a</sup> within ten days<sup>28</sup>
- Exacerbations also appear to have a significant impact on mental and emotional well-being, and this may be underestimated by clinicians<sup>29</sup>
- Despite this, COPD exacerbations are not responded to with urgency. The current global treatment paradigm is one of failure-driven escalation, whereby escalation in treatment is considered following a worsening of symptoms, such as exacerbations.<sup>2</sup> However, only 25 per cent patients received maintenance therapy, treatments offered to prevent or reduce symptoms, after an exacerbation<sup>30</sup> and over half of exacerbations go unreported<sup>31</sup>
- National policymakers and healthcare professionals should appreciate the significant burden associated with COPD and ensure exacerbations trigger a review of management and address the current global treatment paradigm of failure driven escalation, shifting to evidence-based treatment to maintain health status, minimise symptoms and prevent future exacerbations

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<sup>a</sup> Not statistically significant



## PRINCIPLE #5

*I deserve access to the right specialist care when needed (whether provided in hospital or in the community) to manage my COPD, irrespective of where I live*

- Specialist care refers to care provided by a healthcare professional who has the expert skills and understanding of COPD to provide appropriate care
- Staffing levels and the availability of specialist respiratory review is linked to reduced risk of death and quality of service in COPD.<sup>32,33</sup> People who received specialist review within 24 hours of admission to hospital for a severe exacerbation were 14per cent less likely to die as an inpatient compared to those who did not receive specialist review<sup>33</sup>
- Similarly, barriers exist in access to outpatient specialist COPD services and pulmonary rehabilitation. This is mainly attributed to limited resources, particularly within rural areas<sup>34</sup>
- However, with digital technologies, including remote consultations, COPD should become a benchmark of how such technologies can improve current services and enable the provision of tailored, specialist care, regardless of where a person lives

A close-up portrait of a woman with long, dark hair, looking slightly to the right with a neutral expression. The background is a plain, light grey.

## PRINCIPLE #6

*I deserve to live with COPD freely while maximising quality of life without stigma or guilt*

- Worldwide, the most common risk factor for COPD is tobacco smoking<sup>2</sup> and, as a result, there is a stigma associated with the condition
- As a result of this stigma, many patients experience self-blame, guilt and shame.<sup>35</sup> People with COPD also describe feeling stigmatised by healthcare professionals in some cases, which can lead to reluctance to access treatment<sup>36</sup>
- However, it is becoming clear COPD is not solely linked to tobacco smoking. There are a number of other risk factors linked with the condition, including indoor (household) and outdoor air pollution, genetic predispositions, abnormal lung developments and accelerated ageing<sup>2</sup>
- Healthcare professionals, patients and the general public should be educated about the numerous risk factors associated with COPD in order to reduce the associated stigma of the condition, ensuring that people are not discouraged from seeking help

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