COPD Uncovered represents the combined efforts of a multi-disciplinary committee of international experts, coming together to bring forward some of the most burning issues in COPD today. Their aim is to highlight the impact of COPD in an understudied and ignored patient segment between the ages of 40 and 65. The COPD Uncovered initiative is a compendium of research and analysis undertaken by experts in respiratory health. This initiative is sponsored by Novartis Pharma AG and is administered by a Secretariat from Chandler Chicco Companies (CCC). The studies underlying the COPD Uncovered Report were commissioned by Novartis Pharma AG.

COPD Uncovered aims to:

- Demonstrate the impact of inadequate COPD management on these individuals, their families and communities.
- Correct some key myths associated with COPD.
- Illustrate the pivotal role men and women between the ages of 40 and 65 play in society.
- Uncover the specific daily needs of this age group to create empathy and an urgency for better management of their COPD.
- Contribute evidence to the growing need for policymakers and healthcare providers to focus resources on improving the prevention, diagnosis and treatment of COPD.

This report is a first step in the initiative to illuminate the serious issues nations face with COPD sufferers in this age group. It sets the stage for the next phase in 2010 when COPD Uncovered will reveal results from the first international quantitative global survey of more than 2,000 COPD patients, aged 45–67, in six countries. This study will provide important insights into this critical population and provide additional evidence to push forward the agenda for better COPD management.

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Foreword

Society faces a major threat to its productivity, health and welfare as millions of people in their most productive years struggle against a disease that is often undiagnosed or poorly managed. Chronic obstructive pulmonary disease, or COPD, hits millions of people, particularly those at the peak of their earning power – between the ages of 40 and 65. In the prime of their lives, and a time when they are caring for children and aging parents, as well as contributing to their communities, people with COPD are struggling to sustain an active, productive life.

The size of this problem is considerable: 210 million people worldwide have COPD, yet it is likely that only about half of this group have been diagnosed. Of those diagnosed, more than half are under 65 years of age, indicating that this disease affects younger people in greater numbers than generally recognized. Moreover, the prevalence of COPD is rising, as are the many serious medical conditions often associated with it, including cardiovascular disease and depression. This contributes to a debilitating downward spiral.

Despite the magnitude of the problem, significant gaps exist in our understanding of the impact of COPD on the 40–65 year old patient population. More research and effort must be made to fill the gaps by clinicians, employers, policymakers and the public. The public is particularly important because COPD still carries a terrible stigma: seen as an old person’s disease caused by smoking, and therefore a disease brought on themselves.

Yet, most smokers with COPD acquired the habit before the health hazards were fully understood. Many started smoking at a time when it was acceptable, even seen as glamorous and cool. While this view has shifted in many countries, even if all smoking stopped today, the effect on COPD statistics would not be seen for up to 20 years. This is more evidence that urgent action is needed TODAY to address COPD, a leading and growing contributor to lost productivity and early death.

COPD Uncovered is the first initiative of its kind to investigate the economic, social, physical and emotional impact of COPD in the 40–65 years age group. It examines the growing costs of a condition that is rapidly becoming one of the world’s most serious health problems.

We ask the readers of this report to join us on the journey to reveal and counter misconceptions about the people struggling with COPD today, and to demonstrate the consequences to these patients, their families, healthcare providers and society if COPD is not addressed NOW.

It is hoped that COPD Uncovered can inform much-needed discussion and policymaking to ensure that appropriate resources are provided for the management of COPD, and bring to light the compelling reasons why we must invest in a generation of people who are essential to future sustainable and healthy global prosperity.

Christine Jenkins
Professor Christine Jenkins
GOLD Executive Committee Member
Clinical Professor, Concord Clinical School
NSW, Australia

Monica Fletcher
Chief Executive, Education for Health, United Kingdom
National Respiratory Training Center, United States
Chapter I
Two transformative generations drive the global economy today

Every day, about 1.7 billion people between the ages of 40 and 65 get up, go to work, look after their children or grandchildren, care for aging parents and contribute their part to daily life. This group makes up one-quarter of the world population. They include the post-war Baby Boomer generation. They also include the children of the Baby Boomers, those in their early 40s who are part of Generation X, or the Baby Bust.

These generations enjoyed much good fortune, unprecedented educational and economic opportunities and growing gender and racial equality. And, in their younger years, were sold a positive image of smoking. Advertising and popular culture taught these generations that cigarettes symbolized confidence, success and glamour – and many were seduced. This influence continued with the “sex, drugs and rock and roll” culture of the 1960s and 1970s. With virtually no restrictions on smoking in public venues, they grew up in smoke-filled homes and offices and airplanes with ashtrays in the armrests.

Today, these generations power the economic engines of developed nations worldwide – and they are among the hardest hit by COPD.

Most are at the peak of their earning and spending power. For example, of all the income earned by workers in the United States and United Kingdom, two-thirds is brought home by those between the ages of 40–65. This equates to as much as six trillion dollars a year, more than the total GDP of Japan. Commensurate with their income, they pay the highest tax rates – and so, the bulk of costs for national health, education and other services.

Women, who are both wage earners and the central care givers in families around the world, are particularly hard hit. As more women have become smokers, their risk of COPD has increased substantially. More women than men are now diagnosed with COPD.

COPD tends to occur at a younger age in women and at a lower threshold of exposure to cigarette smoke so prevalence is higher at the younger end of this age group. Women with COPD also report more accompanying symptoms of ill-health and poorer quality of life than men.

50% of U.S. people aged 54–64 years are still employed full-time and less than one in five are fully retired.
To understand the impact of a disease that strikes this ‘sandwich generation’, those caring for children and aging parents, look to the U.S. Nearly 50% of 45–55 year old women have both living parents and children under 21, and more than 50% of women are providing their children with high levels of financial support.11

In many [industrialized economies] an increasing female (especially maternal) labor supply is seen as being important to maintaining growth and ensuring sustainable pension and social protection systems more generally.12

Babies and Bosses, Organization for Economic Cooperation and Development (OECD).

And we need these generations to continue earning... Six out of ten have given substantial financial assistance to their children and grandchildren over the previous five years.8 And surveys show that they expect to work beyond the official retirement date so they can continue to support both themselves and their family.11 Only 38% felt they were on track or had achieved their goals for saving for retirement.8

Additionally, societies are aging. People are living longer and fewer children are born. With the younger group too small to counterbalance the growing number of older people, those between 40–65 years of age will increase and be even more depended upon to care for families and contribute to society.

COPD is a leading threat to continued productivity. Patients aged 40–65 make up more than half of all diagnosed COPD patients worldwide.3 A great many of those in this age group already feel the impact of COPD on their ability to lead active, productive lives. Chapters 2 and 3 explore the changing face of COPD and its impact on individuals, families and societies in more detail.
In the next decade, COPD – a disease that has been largely unknown and misunderstood until recent years – will become the third leading cause of death. It is a chronic, progressive disease of the airways that affects 210 million people worldwide, leading to three million deaths every year\(^1\). And there is no cure.

**Chapter 2**

The growing pace and changing face of COPD

*COPD is a severely debilitating disease.* People with COPD experience progressive lung deterioration that leads to chronic shortness of breath, cough and other airway-related symptoms\(^15\). These symptoms cause profound disability, limiting work and other daily activities such as shopping, performing household chores, or caring for others. For COPD sufferers this means nearly 28,000 years of lost productivity annually worldwide as measured by disability-adjusted life years (DALYs)\(^16\). DALYs are a measure of years of productive life lost due to disabilities and early deaths.

Currently, COPD ranks tenth among disorders that cause the greatest worldwide burden in terms of DALYs, far exceeding more widely known diseases such as diabetes and asthma\(^16\). This ranking is projected to rise in coming decades, further highlighting the urgent need to address COPD as a serious threat to public health.

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**What is COPD?**

Chronic obstructive pulmonary disease (COPD) is a debilitating, life-threatening and progressive lung disease that interferes with normal breathing. COPD refers to emphysema and chronic bronchitis – two commonly co-existing diseases of the lung. COPD is not curable, but it can be treated. Due to lung deterioration, people with COPD experience symptoms like chronic shortness of breath and cough\(^15\) that impact the ability to lead an active and productive life.

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**Disability-Adjusted Life Years (DALYs) Attributable to Disorders Causing the Greatest Burden Worldwide**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Disorder</th>
<th>Number of DALYs (x10(^3))</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lower respiratory infections</td>
<td>91.3</td>
</tr>
<tr>
<td>2</td>
<td>HIV/AIDS</td>
<td>84.4</td>
</tr>
<tr>
<td>3</td>
<td>Unipolar depressive disorders</td>
<td>67.2</td>
</tr>
<tr>
<td>4</td>
<td>Diarrhoeal diseases</td>
<td>61.9</td>
</tr>
<tr>
<td>5</td>
<td>Ischaemic heart diseases</td>
<td>58.6</td>
</tr>
<tr>
<td>6</td>
<td>Cerebrovascular disease</td>
<td>49.2</td>
</tr>
<tr>
<td>7</td>
<td>Malaria</td>
<td>46.5</td>
</tr>
<tr>
<td>8</td>
<td>Road traffic accidents</td>
<td>38.7</td>
</tr>
<tr>
<td>9</td>
<td>Tuberculosis</td>
<td>34.7</td>
</tr>
<tr>
<td>10</td>
<td>Chronic obstructive pulmonary disease</td>
<td><strong>27.7</strong></td>
</tr>
<tr>
<td>11</td>
<td>Congenital abnormalities</td>
<td>27.3</td>
</tr>
<tr>
<td>12</td>
<td>Hearing loss – adult onset</td>
<td>26.0</td>
</tr>
<tr>
<td>13</td>
<td>Cataracts</td>
<td>25.2</td>
</tr>
<tr>
<td>14</td>
<td>Measles</td>
<td>22.4</td>
</tr>
<tr>
<td>15</td>
<td>Violence</td>
<td>21.4</td>
</tr>
<tr>
<td>16</td>
<td>Self-inflicted injuries</td>
<td>20.7</td>
</tr>
<tr>
<td>17</td>
<td>Alcohol use disorders</td>
<td>20.3</td>
</tr>
<tr>
<td>18</td>
<td>Protein energy malnutrition</td>
<td>16.9</td>
</tr>
<tr>
<td>19</td>
<td>Falls</td>
<td>16.2</td>
</tr>
<tr>
<td>20</td>
<td>Diabetes mellitus</td>
<td>15.4</td>
</tr>
<tr>
<td>21</td>
<td>Schizophrenia</td>
<td>16.1</td>
</tr>
<tr>
<td>22</td>
<td>Asthma</td>
<td>15.3</td>
</tr>
<tr>
<td>23</td>
<td>Osteoarthritis</td>
<td>14.8</td>
</tr>
<tr>
<td>24</td>
<td>Vision loss, age-related and other</td>
<td>14.1</td>
</tr>
<tr>
<td>25</td>
<td>Cirrhosis of the liver</td>
<td>13.9</td>
</tr>
</tbody>
</table>

Source: Global surveillance, prevention and control of chronic respiratory diseases: a comprehensive approach. Jean Bousquet and Nikolai Khaltaev, editors. World Health Organization 2007\(^16\).
Despite the disability associated with COPD, approximately half of people remain undiagnosed and therefore inadequately managed. COPD is diagnosed by assessing symptoms, checking medical history – including the number of years a patient has spent smoking (pack years) – and measuring airway limitation by a simple spirometry test that determines lung function\(^{15}\).

Even though spirometry is an important health measurement and commonly used for diagnosis, patients remain undiagnosed for several reasons. COPD progresses slowly over time, and sufferers may mistake their symptoms as lack of fitness or signs of aging. Current or former smokers may be less likely to talk about symptoms they feel are a result of their smoking. Additionally, as sufferers of COPD present with symptoms that obstruct their lungs, doctors may diagnose the cause as asthma – especially if spirometry is not performed. There is also the factor that COPD has varying definitions, and until recent years, has not been widely known.

Management of COPD varies greatly, leading to suboptimal outcomes for patients. COPD cannot be cured, so treatments aim to slow the decline in lung function by relieving symptoms and avoiding exacerbations – episodes when symptoms become severe enough to require resource-intensive and expensive emergency care. Bronchodilators, for example, have been shown to improve lung function and also reduce the number of exacerbations\(^{17}\).

Healthcare professionals have an increasing armory of medication and processes for the management of COPD which includes bronchodilators to widen the airways and make breathing easier, anti-inflammatory corticosteroids to treat and prevent exacerbations, and nicotine replacement therapy to help patients give up cigarettes\(^{15}\). Due to the highly addictive nature of smoking, cessation therapy is successful in 12–35% of cases, and long-term success rates can be lower\(^{18}\). And depending on the severity, healthcare professionals may use oxygen therapy and rehabilitation, including dietary review, during hospitalization for treatment of exacerbations\(^{15}\).

There are a number of powerful factors contributing to an increase in COPD. The primary cause of COPD is cigarette smoke\(^{15}\). Today, 1.3 billion people smoke, a number that includes an increase among women and individuals in developing countries. Preventative measures such as smoking cessation are increasingly important, especially because of the slow, progressive onset of COPD.

However, it does not mean smoking cessation should precede medical management. Many former smokers develop symptoms and are diagnosed a decade or two after they stop. And the reality is that people still smoke. It is highly addictive and achieving an entirely smoke-free society may be impossible. Even if everyone stopped smoking today, the rates of COPD would still continue to increase for the next 20 years\(^{4}\).
COPD is often associated with serious accompanying medical conditions, adding significantly to the overall burden of disease. A number of other health issues are commonly associated with COPD, including cardiovascular and metabolic diseases, osteoporosis and depression. These contribute to the disease having a deeper impact on both the individual patient and on society. Why comorbidities are so common remains unclear and needs to be better defined.

When comparing COPD with a well known disease, diabetes, the prevalence and burden to society of COPD are much higher. In fact, as seen in the chart below, COPD has nearly double the burden of diabetes globally. And COPD is more prevalent than diabetes and causes more deaths. Yet, diabetes has been driven to the top of healthcare agendas.

<table>
<thead>
<tr>
<th></th>
<th>Diabetes</th>
<th>COPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence</td>
<td>180m</td>
<td>210m</td>
</tr>
<tr>
<td>Mortality</td>
<td>1.1m</td>
<td>3m</td>
</tr>
<tr>
<td>Disability (DALYs x10^3)</td>
<td>15.4</td>
<td>27.7</td>
</tr>
</tbody>
</table>

COPD is a serious and growing burden, that affects many more people than the preconceived notion it is commonly associated with: an old male smoker. It is becoming increasingly evident that more needs to be done to help the growing number of younger and female patients with COPD, an age group that makes up more than half of those working today. The costs of COPD – both financial and emotional – on these individuals, their families and societies are discussed further in the next chapter.

About 40% of people with COPD suffer from heart disease\textsuperscript{20} and 10% from diabetes\textsuperscript{21}.

17–42% of people with COPD suffer from high blood pressure\textsuperscript{22,23}.

2–19% of people with COPD have osteoporosis – twice as common as those without COPD\textsuperscript{21,22}.

18–22% of people with COPD suffer from depression – three times as common as those without\textsuperscript{22}.

COPD is complex. The multiple consequences of COPD include breathlessness, exercise limitation, muscle wasting, fatigue, and exacerbations. As COPD progresses, patients fail to exercise, feel depressed, and experience low self-esteem. Impaired health status... [has] an impact upon patient behavior.

Professor Paul Jones, St Georges Hospital, London\textsuperscript{24}.
COPD is a major economic burden for countries throughout the world and the projected rise in disease prevalence is extremely rapid.

*Dr Khaltaev, WHO, Non-communicable diseases program*.

**The costs of COPD are a major economic burden.** Everyone pays the price of COPD – patients in middle age feel old beyond their years, their families and communities struggle to support them, and the governments pay thousands of dollars per patient and billions each year in direct and indirect costs. Although COPD is incurable, with proper diagnosis and management, the costs don’t have to be so high. Identifying COPD early and treating it appropriately can keep people productive longer, contributing to the financial well-being of their families, economic growth of nations and a better quality of life for those suffering from the disease.

The challenge is to understand the real costs as they now stand so that policymakers can focus on providing the right level of resources needed for the effective care of this critical population in their most productive years. More work is needed to define the true economic costs of COPD. So far, we have only a fragmented picture.

A look at the U.S. provides a glimpse of costs. In 2007, the most recent year for which figures are available, the total national cost of COPD was estimated at $42.6 billion (€28.4 billion): $26.7 billion in direct medical costs, and $15.9 billion in lost income due to disability and premature death. Of the direct costs, 40–65 year old American COPD patients represent 67% of physician office visits and 43% of hospitalizations. And these costs only reflect patients who have been diagnosed. The actual costs may be much larger.
A Swedish study found that 40% of total COPD healthcare costs were related to patients with undiagnosed, and therefore untreated, COPD[27]. Even before all cases of COPD are identified, disability payments by some nations to their incapacitated workers average nearly 1% of national gross domestic product[28].

In Canada, France, Germany, Italy, Spain, the UK and the U.S., the cost of COPD averages €3,767 ($5,646) per patient each year[28].

In China the smoking-attributable healthcare expenditure for respiratory diseases in 2000 was over 7 million Yuan, 4.5 million Yuan for those aged 35–64[29].

A 2009 survey in Chinese urban areas found the average direct medical cost of COPD per patient to be 11,744 Yuan annually, and the direct non-medical cost to be 1570 Yuan[30].

Indirect lost productivity attributable to COPD particularly impacts the economies of France, The Netherlands and the UK, accounting for 67%, 50% and 41% of overall costs, respectively[31].

So what is driving these costs?
Hospitalizations, due to exacerbations of COPD, and productivity. With exacerbations accounting for the majority of direct healthcare costs, prevention remains a critical component of COPD management. In five out of seven countries analyzed, the majority (52–84%) of direct costs associated with COPD were due to inpatient hospitalizations[31].

From an indirect standpoint, an extremely high proportion of total COPD costs can be attributed to loss of productivity, although the exact figure is not known. Only the U.S. has explicit, respiratory-specific criteria for those seeking disability payment for COPD. If all the disabled COPD patients meeting the U.S. eligibility criteria in eight industrialized nations were compensated, the total cost would range from €3.3–16.6 billion ($5–25 billion) per year[28]. Similarly, COPD likely accounts for extremely high disability costs in disability payments to those who can no longer work.

Patients with COPD are not the only ones whose productivity suffers because of the disease. COPD is also responsible for a significant loss of productivity among family members and others who provide informal care. Although these costs do not directly impact government spending, they do significantly reduce home income – a serious issue for low-income families who also have the highest incidence of COPD[32]. The impact on home income puts particular pressure on the economies of developing countries where the threat of COPD is especially high, in part because of smoking but also because of unregulated or poorly regulated pollution.

The total cost burden of chronic illness in the workplace – especially lost productivity – from respiratory conditions, most importantly COPD, exceeds that of any other major disease category.

Sean Sullivan, JD. President & CEO, Institute for Health and Productivity Management.
Chapter 3 – Counting the costs of COPD in 40–65 year olds

Direct and Indirect Costs for a COPD Patient More Than 40 Years of Age

<table>
<thead>
<tr>
<th>Country</th>
<th>Direct Cost</th>
<th>Indirect Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>CA$3,195</td>
<td>$3,020</td>
</tr>
<tr>
<td></td>
<td>(€2,044)</td>
<td></td>
</tr>
<tr>
<td>U.S.</td>
<td>$5,646</td>
<td>€3,798</td>
</tr>
<tr>
<td></td>
<td>($3,020)</td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td>€3,538</td>
<td>$5,296</td>
</tr>
<tr>
<td></td>
<td>($5,296)</td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td>€1,308</td>
<td>$1,958</td>
</tr>
<tr>
<td></td>
<td>($1,958)</td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>£1,639</td>
<td>€1,826</td>
</tr>
<tr>
<td></td>
<td>($2,729)</td>
<td></td>
</tr>
<tr>
<td>The Netherlands</td>
<td>€1,608</td>
<td>$2,407</td>
</tr>
<tr>
<td></td>
<td>($2,407)</td>
<td></td>
</tr>
<tr>
<td>France</td>
<td>€1,608</td>
<td>$2,407</td>
</tr>
<tr>
<td></td>
<td>($2,407)</td>
<td></td>
</tr>
</tbody>
</table>

The costs of COPD are more than just financial. The COPD Uncovered team analyzed data from a 2007 KantarHealth National Health and Wellness Survey – the world’s largest, international, self-reported patient database – and found that COPD patients aged 40–65 with responsibilities at work or at home reported significant deterioration in quality of life, absenteeism and loss of productivity.

They reported trouble breathing both during days and nights, anxiety and depression, and frequent admissions to hospital with acute exacerbations. Respondents reported having missed, on average, well over one working day in a week due to poor health. And even those who could work had trouble performing. Of those who managed to get to work, nearly half of U.S. respondents and more than a third of EU respondents reported high levels of lost productivity.

Patients and families share the physical and emotional impact. Over the last decade, more than 100 studies have documented the adverse effects of COPD on the families of COPD patients. What has been established is COPD patients suffer a deteriorating quality of life as acute exacerbations become more frequent with age. There has been little research, however, focused specifically on the experience of people aged 40–65 years with COPD. While the image of the Baby Boomers and Generation X may be one of vibrant good health and active living, COPD patients find themselves feeling older than their years and sicker than expected.

In qualitative research carried out for COPD Uncovered in the U.S., France, Germany, Spain and the UK, 85 COPD patients aged 45–68, 41 partners and 10 children were interviewed about the physical and emotional burden of the disease and their thoughts on the future. Through semi-structured interviews and projective exercises in focus groups, researchers collected their descriptions, opinions and feelings about life with COPD.

One theme that came through loud and clear from the interviews was the frustration COPD patients feel in not being able to perform on a daily basis to their own expectations.

Some of the other common themes that emerged from the interviews included feeling old beyond their years, the unpredictability of symptoms and the emotional burden on the family.

Half of U.S. respondents were often or always breathless.

Two-fifths of U.S. respondents reported feeling anxious or depressed.

Over one-third of EU respondents and nearly half of U.S. respondents cited difficulties carrying out everyday activities.

Nearly 10 hours of work was lost in the week prior to the survey.

Around 1 in 6 respondents had visited the ER or hospital in the 6 months prior to the survey.
I feel like I am old. I feel like I am really old, and I am 51.

UK patient
Chapter 3  Counting the costs of COPD in 40–65 year olds

The most important thing I’ve lost is probably getting together with my dad and playing outdoors.

UK son

I hate not being able to do something and that my wife has to help me. It is infuriating. I have never depended on anyone.

Spanish patient

I’m totally disgusted with my life.

U.S. patient
I worry that his condition could get worse. That at some point he will not be able to walk anymore but has to sit in a wheelchair and needs to take oxygen. That it will come to the point that my dad is not taking care of me anymore but that I have to take care of my dad.

*German son*

She is throwing her life away and she is throwing my life away.

*U.S. spouse*

We had a very big group of friends and relatives, but since my wife got ill, only 2 or 3 people are left.

*U.S. spouse*

Seeing my husband with breathlessness gives me feelings of helplessness and rage, because I can’t do anything about it.

*UK spouse*
The cost of treatment is high and increasing, yet it is the cost of not treating the disease that is far higher. If nations do not invest in prevention, early diagnosis and treatment, the costs will rise dramatically in coming decades. Sufferers who are not diagnosed early and treated properly are much more likely to have serious exacerbations and complications of the disease, including co-morbidities, and are thus more expensive to treat than those at the early stage of the disease. Understudied and ignored COPD sufferers in this critical age group – 40–65 – means increased disability and loss of productivity. It means that at the peak of their earning and spending power, they cannot meet the demands of their daily responsibilities and their quality of life declines, affecting friends, family and society.

National governments must work to gather the data necessary to understand the full scope and cost of COPD, while international health organizations must pool the data to create a picture of COPD internationally. By understanding the costs, we can begin to plan for how to address the proper diagnosis and treatment of COPD to reduce the unnecessary economic burdens that exist today.
Uncovering the threat

Recognizing COPD as a growing threat to the health, well-being and productivity of people aged 40–65 is only a first step towards slowing the progress of this disease. The investigations undertaken as part of the COPD Uncovered initiative illustrate that:

• COPD is significantly affecting a younger population than previously thought and it is doing so at a time when society is increasingly reliant on their productivity and spending power to drive future economic growth.

• COPD symptoms are already debilitating patients aged 40–65 and reducing their ability to work and participate in family and social activities. Their disability will progress if their need for treatment isn’t recognized and met.

• Until COPD is more effectively managed in this age group, the burden on national economies and health systems will continue to grow. The direct costs of hospital treatment for acute exacerbations and the indirect costs of disability compensation and lost productivity will rise.

• Even with potentially better techniques to aid smoking cessation, the long-term effects of COPD among current and former smokers will persist for decades, requiring more intensive medical management.

Improving management

To maintain and improve the health of 40–65 year old COPD patients will require a joint effort by all stakeholders – politicians, health professionals, employers, unions, patients and the public. Urgent action must focus on:

• More research and analysis to better understand the needs of the COPD patient.

• Promoting early identification and diagnosis of people in the 40–65 age group with mild COPD symptoms who can benefit from early, tailored intervention such as pulmonary rehabilitation and smoking cessation.

• Initiating and sustaining cost-effective management of COPD patients to better control symptoms, minimize disease progression and optimize their ability to continue participating in and contributing to society.

• Helping patients avoid exacerbations, providing social and economic benefits.
There remain many unanswered questions and there is more we need to uncover if we are to make understanding and meeting the needs of understudied and ignored COPD sufferers between the ages of 40 and 65 the number one COPD issue today.

**Questions**

How can we best diagnose and assess the impact of COPD in active 40–65 year olds?

What is the true global cost of COPD in those aged 40–65?

How should clinical services be organized to help patients 40–65 meet their specific daily needs?

Given the varied ways in which patients 40–65 are affected by COPD, how do we take a broader view of COPD to better manage the whole patient?

Following the release of this report, the COPD Uncovered experts are conducting further quantitative research into the direct and indirect costs of the disease among this age group. In 2010, they expect to release the results of the study that will look at the specific impact of COPD on the daily lives of more than 2,000 COPD patients aged 45–67 from the U.S., the UK, Germany, Brazil, China and Turkey. The research is intended to inform decision-making by health providers, economic and health policymakers and industry, as well as to point the way to the sort of policies that may be needed.

The forthcoming global patient survey is being conducted by research specialist Education for Health (lead investigator Monica Fletcher), via an educational grant from Novartis. The survey is being overseen by a Steering Committee made up of:

- Professor Neil Barnes (UK), Consultant Physician, Barts and The London NHS Trust Medical and Emergency Directorate, The London Chest Hospital.
- Professor Sonia Buist (U.S.), Professor of Medicine, Physiology & Pharmacology, Oregon Health & Sciences University.
- Professor John Hutton (UK), York Health Economics Consortium, University of York.
- Professor Christine Jenkins (Australia), Clinical Professor, Concord Clinical School, Thoracic Physician Concord Hospital; GOLD Executive Committee member.
- Professor Paul Jones (UK), Professor of Respiratory Medicine, St Georges Hospital, London.
- Dr Marianella Salapatas (Greece), President, European Federation of Allergy and Airways Diseases Patients’ Associations.
- Professor Thys van der Molen (The Netherlands), Department of General Practice, University of Groningen.
- John Walsh (U.S.), President and CEO, COPD Foundation.
The Initiative
The COPD Uncovered initiative is a compendium of research and analysis undertaken by experts in respiratory health. This initiative is sponsored by Novartis Pharma AG and is administered by a Secretariat from Chandler Chicco Companies (CCC). The studies underlying the COPD Uncovered Report were commissioned by Novartis Pharma AG.

COPD Uncovered aims to:

- Demonstrate the impact of inadequate COPD management on these individuals, their families and communities.
- Correct some key myths associated with COPD.
- Illustrate the pivotal role men and women between the ages of 40 and 65 play in society.
- Uncover the specific daily needs of this age group to create empathy and an urgency for better management of their COPD.
- Contribute evidence to the growing need for policymakers and healthcare providers to focus resources on improving the prevention, diagnosis and treatment of COPD.

The Report
This COPD Uncovered Report, issued on World COPD Day 2009, is authored by the following individuals, supported by Novartis, with editorial assistance from medical education specialists from CCC:

- Monica Fletcher, principle lead for COPD Uncovered and Chief Executive, Education for Health, National Respiratory Training Center.
- Dr Marianella Salapatas, President, European Federation of Allergy and Airways Diseases Patients’ Associations.
- Professor Thys van der Molen, Department of General Practice, University of Groningen.
- John Walsh, President and CEO, COPD Foundation.

Novartis
The Novartis Pharma AG respiratory franchise is committed to discovering, developing, and delivering innovative medicines to enhance quality of care, ease suffering, and prevent and cure a broad range of respiratory diseases.
Appendix  Data sources and analysis

The information included in this report was sourced from three investigations, the results of which we also hope to publish separately:

- An extensive review of epidemiological, quality of life and health economic COPD studies published between January 1999 to March 2009 was undertaken by medical education specialists from CCC, commissioned by Novartis. Studies were limited to human studies and in English language and included only clinical trials, meta-analyses, reviews and single cases.

- Analysis of the National Health and Wellness Survey (NHWS) database – the largest self-reported patient database of its kind, providing demographic, attitudinal, quality of life, resource utilization and treatment information – was undertaken by KantarHealth and health economic specialists from CCC, commissioned by Novartis. Data in the database are collected via a self-reported online questionnaire, and the database currently holds data from over 63,000 U.S. adults and 53,000 EU adults. For the current analysis, data was retrieved from the U.S. (n=1,573), UK (n=237), France (n=314), Germany (n=615), Italy (n=139) and Spain (n=58) on the following group of patients:

  - Those aged 40–65 years, diagnosed with COPD by a physician.
  - Who were also employed full time, part time, self-employed, homemaker, or a caregiver (i.e. those who are or need to be active and productive).

- Qualitative research was conducted by the market research company, Brintnall & Nicolini, commissioned by Novartis. Patients aged between 45–68 years, their partners and children were recruited through physician referral, COPD patient registries and patient associations in the UK, Germany, France, Spain and the U.S. A total of 85 COPD patients (U.S.=28, France=14, Germany=16, Spain=14, UK=13) participated in the study together with 41 partners and 10 children. The emotional and social challenges faced by COPD patients, their partners and/or children were explored during semi-structured (formal projective exercises plus open discussion) focus group, triad and diad interviews. Projective exercises involved non-comparative rating scale exercises, picture-based stimuli and sentence completion tasks.
References


3 Data on file, Novartis Pharma AG: MattsonJack COPD Est. 2008 US + EUS; Global COPD Chart Pull (Quant)


24 Jones PW. Health status and the spiral of decline. COPD 2009;6:59–63


30 He QY, Zhou X, Xie CM et al. [Impact of chronic obstructive pulmonary disease on quality of life and economic burden in Chinese urban areas]. Zhonghua jie He He Xi Za Zhi 2009;32(4):253–7


32 Sullivan SD, Ramsey SD, Lee TA. The economic burden of COPD. Chest 2000;117(2,Suppl.):S5–95


