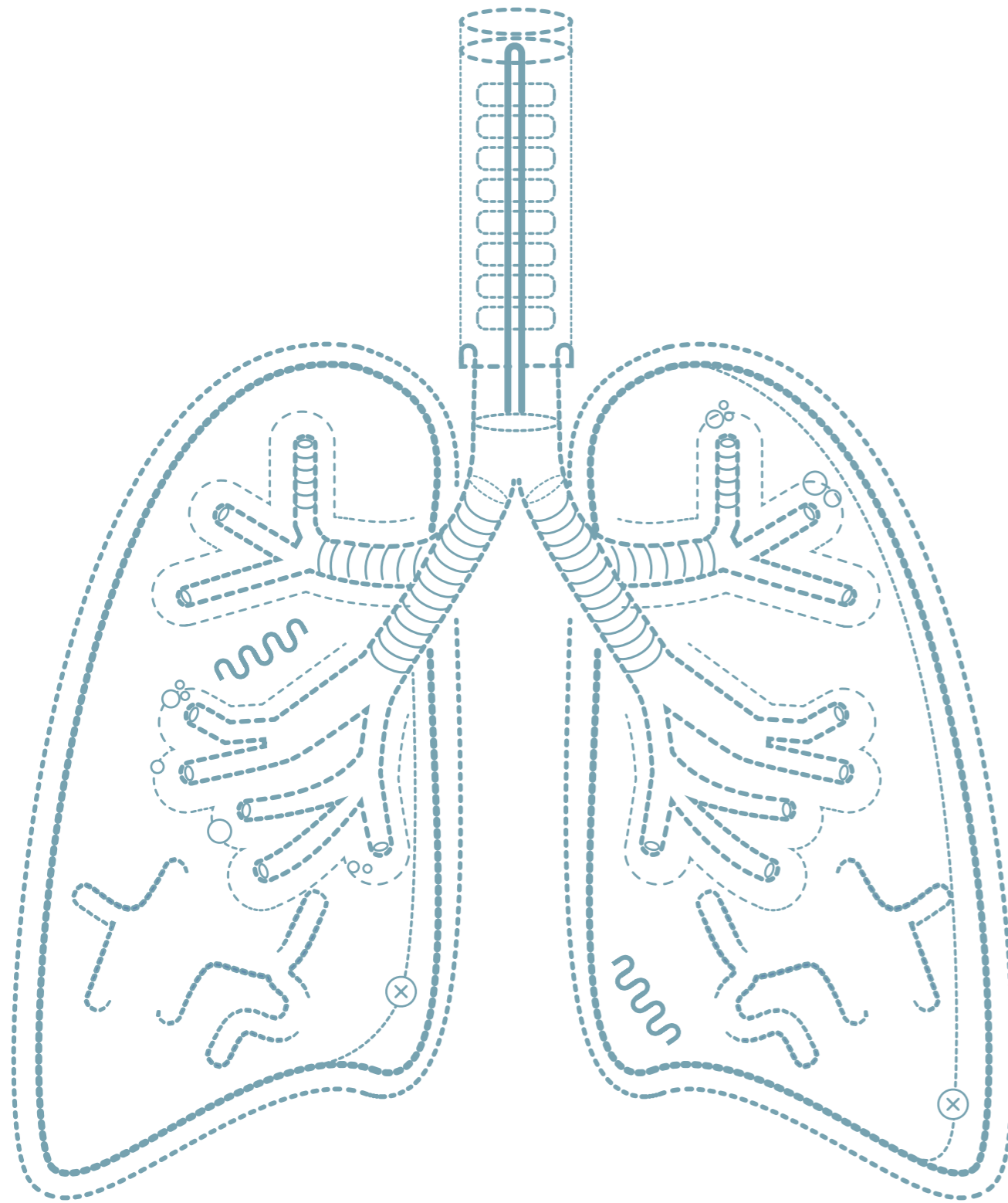


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**UNCOVERING ASTHMA:  
BREATHING A FRESH  
PERSPECTIVE INTO MANAGING  
SEVERE ASTHMA IN EUROPE**

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## SEVERE ASTHMA EUROPE'S HIDDEN CHRONIC HEALTH ISSUE



### FOREWORD

**Severe asthma**, although difficult to define, is becoming an increasing problem to manage for people and their families, as well as the obvious impact on healthcare systems in Europe. There are various definitions of this chronic condition, but a widely accepted definition of severe asthma which is supported by the European Respiratory Society (ERS) and American Thoracic Society (ATS) has described severe asthma as “asthma which requires treatment with high dose inhaled corticosteroids (ICS) plus a second controller (and/or systemic corticosteroids) to prevent it from becoming ‘uncontrolled’ or which remains ‘uncontrolled’ despite this therapy.”<sup>1</sup>

Although the diagnosis of asthma according to established guidelines should be relatively straightforward, people often face a **lengthy journey** of being correctly diagnosed especially with regard to severe asthma. The severity of acute asthma exacerbations is often underestimated by patients, their relatives, and healthcare professionals. Despite a range of treatments available, there is a clear **unmet need** in providing adequate treatment for this sizeable population of asthma sufferers.

The Uncovering Asthma Report helps to highlight the real life **challenges** of managing severe asthma. It is important to hear real life experiences, beyond the clinical presentation of this lifelong condition, and we hope this report addresses the many real challenges faced by these people, their families and loved ones, as well as healthcare professionals who help manage this potentially life-threatening condition on a daily basis.

A majority of people living with asthma can have their condition effectively managed by regular medication and live relatively normal lives. However, a sizeable proportion, around **1.5 million people in Europe, are living with a severe form of asthma**, which may not respond to currently available pharmacological treatments.<sup>2</sup>

It was with this in mind that this report was commissioned to uncover the true burden of severe asthma in Europe and breathe a new perspective into how we approach managing this condition. It is our hope that this report not only **raises awareness** of the impact of severe asthma, but also serves as a call to

action, encouraging people living with severe asthma to reappraise the impact asthma has on their lives and readdress how best to manage it in consultation with their healthcare professional.

With a collective effort based on a foundation of understanding the real life impact and challenging the norms of currently available treatment, together, we can provide severe asthma sufferers with the care and management they deserve.

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1.5 million people are living with severe asthma in Europe<sup>1</sup>



Severe asthma affects five percent of asthma sufferers - some estimates put this as high as 10–20%<sup>3</sup>



Asthma can be deadly: annual worldwide deaths from asthma have been estimated at 250,000<sup>4</sup>

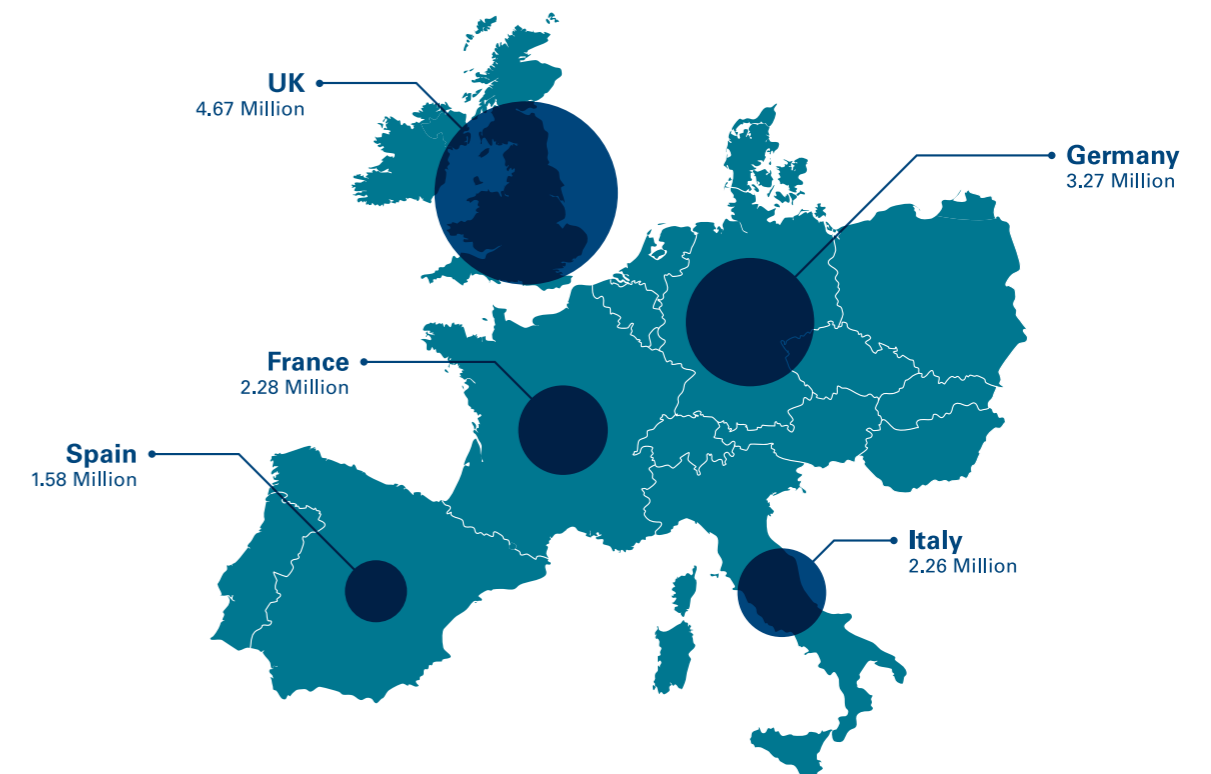


Severe asthma often does not respond to available medication



The total cost of asthma in Europe has been estimated at €19.3 billion<sup>5</sup> per year

### PREVALENCE OF ASTHMA IN EUROPE<sup>6</sup>





## EXECUTIVE SUMMARY



The Uncovering Asthma Report aims to highlight the stark reality faced by people who live with the chronic and life threatening condition that is **severe asthma, which is estimated to affect up to 1.5 million people across Europe.**<sup>1</sup> In order to assess the impact severe asthma has on people, their lives and their families and loved ones, an online survey in five European countries was conducted during April 2015. **The report surveyed 869 severe asthma sufferers** aged 18 and above, who were all screened to ensure they suffered from severe asthma.

### THE STRUGGLE OF LIVING WITH SEVERE ASTHMA ON A DAILY BASIS

The everyday struggles of living with severe asthma can have a devastating effect on peoples' lives. **A staggering 71% of people surveyed said that their severe asthma affected them on a weekly basis,** with one in four people being affected daily by their asthma symptoms. The survey found severe asthma prevents people from undertaking everyday activities that are often taken for granted such as playing sport, household chores and gardening.

What is evident from the report findings is that **severe asthma affects every aspect of a person's life,** beyond their immediate health and wellbeing needs. Severe asthma puts a strain on healthcare systems, impacts on wider society and also affects every aspect of their personal life. **The effects can be truly devastating, and in some circumstances, life threatening.**

Moreover, people living with severe asthma experienced anxiety, depression and anger on a regular basis. Many people living with severe asthma felt that if they were able to better control their asthma symptoms, this would allow them to live more active and positive lives. **71% of people said the biggest impact their severe asthma had on their physical activities was being unable to play sport.**

### SOCIETY IS SUFFERING AS A RESULT OF SEVERE ASTHMA

The impact of severe asthma has far-reaching effects on wider society, and often leaves people unable to fully contribute economically to society. **The survey found that a significant proportion (30%) have taken time off work, university or their studies** in the past 12 months due to hospitalisation or visiting a hospital emergency department. **On average, people with severe asthma have taken 5.7 days off as a direct result of their severe asthma.** The cost of chronic diseases on the economy has been estimated to account for 75% of all healthcare related costs.<sup>7</sup>

Employers are often faced with having to contend with productivity losses, which can be substantial to the economy.

Among those people who are in work or education, nearly half (46%) stated they had had to reduce their working hours or take days off due to their severe asthma. Almost a quarter have had to change role or leave a job due to their asthma. **Astonishingly, one in five people surveyed reported their asthma symptoms mean they are unable to work or study at all.**

### THE IMPACT ON HEALTHCARE SYSTEMS

Healthcare systems across Europe are under increasing amounts of strain to deliver care for long term chronic conditions. **The cost of asthma care in Europe is currently estimated at €19.3 billion,** and is likely to continue to rise. The cost of asthma goes beyond primary healthcare related to the cost of asthma treatment, especially in those people with severe asthma; loss of productivity in the workplace also impacts on the economy.<sup>5</sup>

The survey found that **almost a third of people who live with severe asthma had been hospitalised in the past 12 months** as a direct result of their severe asthma symptoms.

Among those who have been hospitalised, over half have visited at least twice, with seven in 10 (72%) admitted as inpatients. The management of severe asthma is usually controlled by medication; the survey found that nearly three quarters of people living with severe asthma are currently being prescribed at least three types of medication.

**This report calls for urgent action on how people living with severe asthma in Europe are cared for by healthcare systems.** A more structured approach is needed to ensure every patient with this severe form of asthma is offered the best possible care for their condition.

## INTRODUCTION

In Europe, at least **1.5 million people suffer with severe asthma** which can be difficult to manage using currently available medication and in extreme circumstances can be fatal.

The burden of severe asthma goes beyond the strains it has healthcare costs, but also on lost productivity and a significant impact on people's lives.<sup>4</sup> One study estimates that **€9.8 billion is lost in work productivity in Europe due to asthma**.<sup>8</sup>

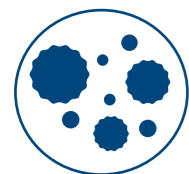
## CAUSES OF SEVERE ASTHMA

Asthma is most commonly diagnosed in early childhood. There has been a sharp rise in the number of people being diagnosed with asthma in Europe, which suggests environmental factors as well as a

genetic predisposition to developing asthma is the cause of this rise. It is still unclear what the definitive causes of this are, but a 'Western' environment is most likely to due to the urbanisation of developed nations.<sup>1</sup>

## TRIGGERS OF A SEVERE ASTHMA ATTACK

Various factors can trigger a severe asthma attack. Some of the most common causes of asthma attacks include:<sup>9,10</sup>



DUST



POLLEN



POLLUTION



MILD/MODERATE PHYSICAL EXERCISE



WEATHER



STRESS



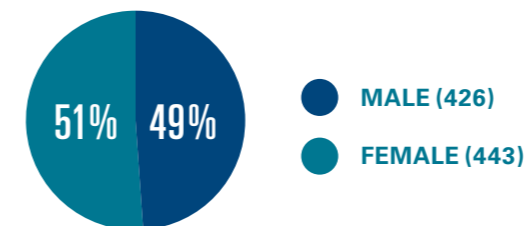
PETS

FOR MANY PEOPLE LIVING WITH SEVERE ASTHMA, BEING ABLE TO CONTROL THEIR SYMPTOMS BETTER WOULD ALLOW THEM TO LIVE MORE ACTIVE, FREER AND POSITIVE LIVES.

## UNCOVERING ASTHMA: METHODOLOGY



The Uncovering Asthma Report findings are based from a survey of 869 severe asthma sufferers aged 18+ from five European countries.



Severe asthma sufferers were defined as those who say that they suffer from asthma and who have had more than two prescriptions for steroid tablets from their doctor for asthma in the past two years. The research was conducted in accordance with ISO 20252 and ISO 27001, the international standards for market research and information security management.

To ensure the survey was scientifically robust and valid, the questions were reviewed and ratified by a number of renowned respiratory physicians from across Europe. We have also worked with key third party stakeholders to support the initiative and endorse the call to action, which can be found in full at the end of this report. This survey and report has been sponsored and commissioned by Boston Scientific.

| COUNTRY        | SAMPLE SIZE |
|----------------|-------------|
| United Kingdom | 200         |
| Germany        | 157         |
| France         | 198         |
| Spain          | 144         |
| Italy          | 170         |

| AGE RANGE | OVERALL % |
|-----------|-----------|
| 18-25     | 10        |
| 26-35     | 17        |
| 36-45     | 19        |
| 46-55     | 17        |
| 56-65     | 24        |
| 65+       | 12        |

## THE PERSONAL IMPACT OF SEVERE ASTHMA

When people were asked how often their severe asthma affects their lives, the survey found that over a quarter of people are affected by their severe

asthma symptoms on a **daily basis**. A staggering **71% of people** surveyed said that their asthma affects them weekly.

### A. THE WORRYING PSYCHOLOGICAL AND EMOTIONAL BURDEN OF SEVERE ASTHMA

What is clear from the Uncovering Asthma Report is the profound emotional burden and in some cases, the psychological impact living with severe asthma has on people. Worryingly, **nearly a third of people**

**living with severe asthma said that their condition made them feel depressed** in the last month. **Feelings of anxiety were cited by nearly 40% of people surveyed.**<sup>12</sup>

### B. THE BURDEN OF THERAPY

An estimated **3.7% of all people with asthma do not respond to standard asthma treatment** and they are therefore at higher risk of a life-threatening asthma attack.<sup>11</sup> One in every two people living with severe asthma surveyed said they were being prescribed two or more medicines to treat their severe asthma.

**Nearly half of women surveyed said they were concerned about weight gain and/or obesity due to taking steroid tablets to manage their severe asthma.** Over a quarter of men (27%) surveyed said they were concerned about high blood pressure due to their steroid treatment.

More than half of people living with severe asthma currently have two inhalers to control their severe asthma. **As people get older, they are more likely to have three inhalers to control their severe asthma; a quarter of people over the age of 65 had three inhalers.** Most patients regularly use either a reliever inhaler or a preventer inhaler to treat their severe asthma.<sup>12</sup>

*“It was like a vicious cycle, I had to take the steroids to control my severe asthma, but at the same time I couldn’t participate in physical exercise as that could trigger my asthma, even with the medication I was stuck between a rock and a hard place.”*

– Reah Yarworth, 24, United Kingdom

The potential side effects from currently prescribed asthma treatments are a real cause for concern for people living with severe asthma.

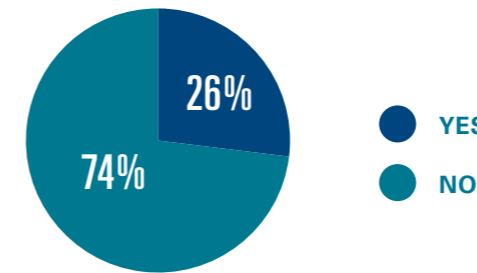
### C. THE DAILY STRUGGLE OF LIVING WITH SEVERE ASTHMA

One of the most significant findings from the Uncovering Asthma Report is daily impact this chronic disease has on people. **71% of people surveyed said that their severe asthma affected their lives on a weekly basis.** Over a quarter of people said that they are affected by their severe asthma on a daily basis (Figure 1).<sup>12</sup>

*“I was hospitalised four times during my two pregnancies, because I had trouble breathing. I was in hospital at least seven to eight days, and once I was back home I still needed time to fully recover.”*

– Magalie Becart, 30, France

**Figure 1:** Over a quarter of people said that they are affected by their severe asthma on a daily basis.

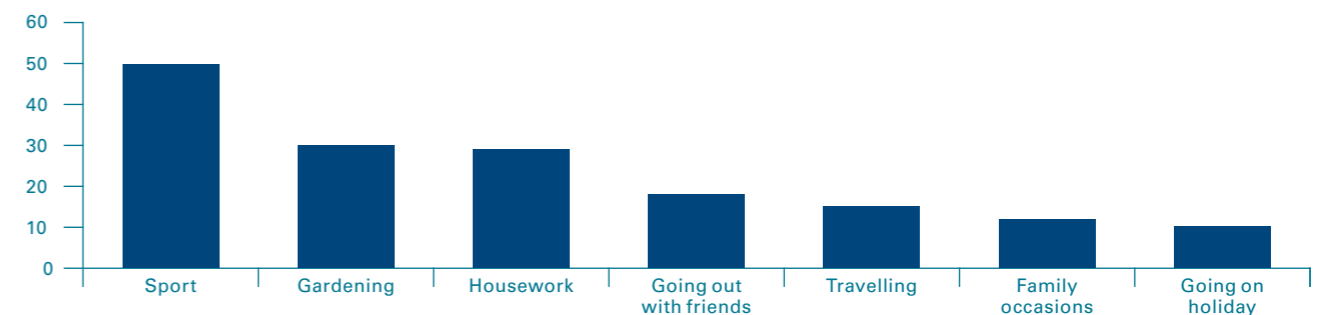


**FOR NEARLY HALF OF PEOPLE SURVEYED THEIR SEVERE ASTHMA SYMPTOMS PREVENTED THEM FROM SEEING THEIR FAMILY OR FRIENDS ON A WEEKLY BASIS.**

The survey also found that the impact of severe asthma affects peoples’ family and friends more than previously thought. 27% of people surveyed said their severe asthma symptoms prevent them from seeing family or friends. **For those who noted this impact on seeing family and friends, nearly half said their severe asthma symptoms prevented them from seeing their loved ones on a weekly basis.**<sup>12</sup>

Participating in sport and recreational activities was also heavily impacted on by severe asthma. **50% of people surveyed, said they were unable to participate in sport or physical exercise due to their severe asthma.**

**Figure 2:** Sport, gardening and housework are the main recreational activities severe asthma sufferers are prevented from undertaking



**A QUARTER OF PEOPLE SAY THEIR PERSONAL RELATIONSHIPS OR SEX LIFE HAS BEEN RESTRICTED BY THEIR ASTHMA.**

However, simple household chores such as gardening and cleaning are also affected, and for some people are not possible as they could cause an attack. (Figure 2). One in five people surveyed said even walking would trigger an asthma attack.

In terms of how this translated across men and women, men are significantly more likely than women (29% vs 18%) to report that their sex life is adversely reported by their asthma either a great deal or fair amount.

## THE SOCIETAL BURDEN OF SEVERE ASTHMA

One of the most revealing things the survey discovered is people who live with severe asthma often face daily disruptions to their routine. People with severe asthma often have to take time off work or education due to their condition, and in extreme cases the career and educational choices we all take for granted are often dictated by their condition.<sup>12</sup>

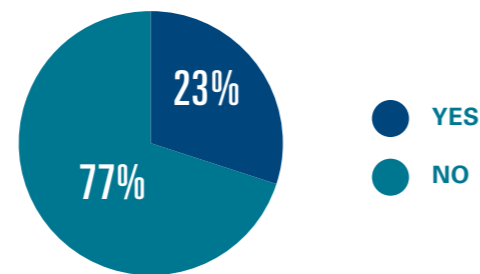
**Overall, nearly a quarter of people in work or education have had to change role or leave a job due to their severe asthma symptoms** (Figure 3 and 4). One in five people surveyed said that as a result of severe asthma, they were unable to work or study at all.

A quarter of people surveyed think their career has been negatively affected due to their severe asthma. **30% of people living with severe asthma who were in employment said that they had been late for work due to their symptoms.**<sup>12</sup>

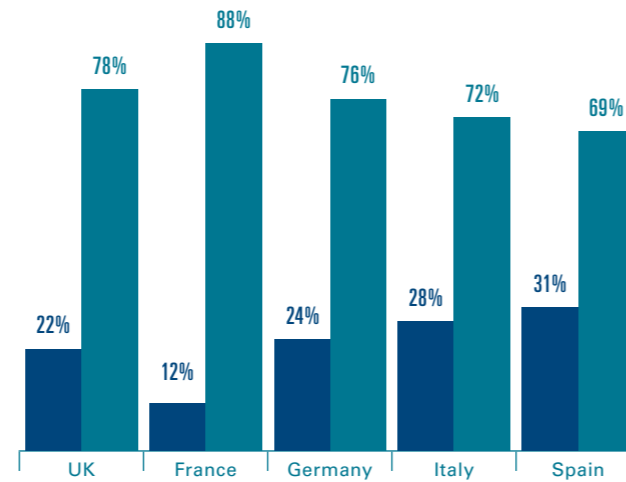
*“As a result of my severe asthma, I was taking eight or nine days off a month from work. My severe asthma meant my sleep was disrupted which meant I was always exhausted. Even though I was taking my medication regularly, I still suffered from regular asthma attacks. When I was younger, I dreamed of being a jockey, but being around horses and being outside in the countryside would trigger severe asthma attacks. My asthma prevented me from pursuing the career choice of my dreams, which was heart-breaking for me.”*

– Michael Keenan, 53, United Kingdom

**Figure 3:** Percentage of people who have had to change their job role due to severe asthma.



**Figure 4:** A quarter of those in work or education have had to change role or leave a job due to their asthma symptoms.



*“Mowing the lawn was simply impossible. Being outside in the garden was one of the main triggers for an asthma attack. If I was to go outside in the garden, a severe asthma attack was almost certain and would leave me gasping for breath.”*

– Michael Keenan, 53, United Kingdom

The Uncovering Asthma survey found that in the past 12 months, 30% of people surveyed across Europe had been hospitalised due to their severe asthma (Figure 5).<sup>12</sup>

**ONE IN FIVE SUFFERERS IN WORK OR EDUCATION CLAIM THEIR ASTHMA SYMPTOMS MEAN THEY ARE UNABLE TO WORK OR STUDY.**

Men were significantly more likely to be hospitalised due to their severe asthma compared with women:

- 34% of men surveyed had been hospitalised due to their severe asthma in the past year
- In contrast 26% of women had been hospitalised due to their severe asthma in the past year<sup>12</sup>

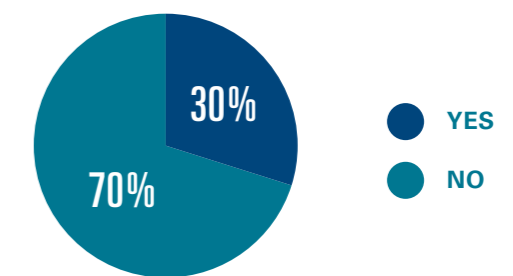
Nearly half of 18–25 people surveyed, were more likely to seek medical care in hospital due to their severe asthma.<sup>12</sup> (Figure 6)

*“People who end up in emergency services suffering from a severe asthma attack should be considered treatment failure, they produce a huge burden of care, frequently ending in high dependency unit or being admitted to hospital for several days. Severe asthma sufferers including those who get multiple hospital attendances for emergency care should be seen by a specialist team with multidisciplinary members.”*

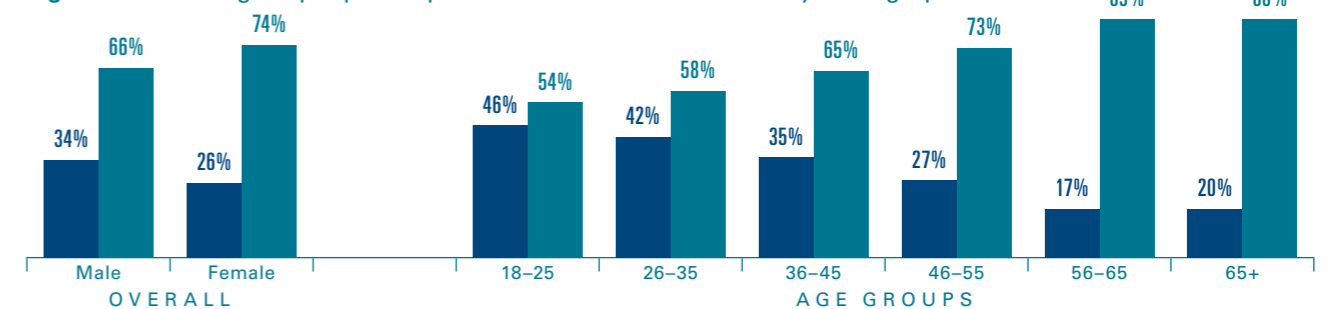
– Dr Rob Niven, Senior Lecturer in Respiratory Medicine, University Hospital of South Manchester NHS Foundation Trust, Manchester, United Kingdom

**30% OF PEOPLE SURVEYED ACROSS EUROPE HAD BEEN HOSPITALISED DUE TO THEIR SEVERE ASTHMA.**

**Figure 5:** Percentage of people hospitalised due to severe asthma.



**Figure 6:** Percentage of people hospitalised due to severe asthma by demographic.



*“When I was at primary school, I would be in hospital around six times a year due to my severe asthma attacks. I was usually there for three days at a time, and often in the high dependency unit for treatment. It was a worrying time for me and my family.”*

– Reah Yarworth, 24, United Kingdom

**ON AVERAGE PEOPLE SUFFERING FROM SEVERE ASTHMA SPENT THREE DAYS IN HOSPITAL PER VISIT.**



## BETTER UNDERSTANDING OF OTHER TREATMENT OPTIONS IS URGENTLY NEEDED

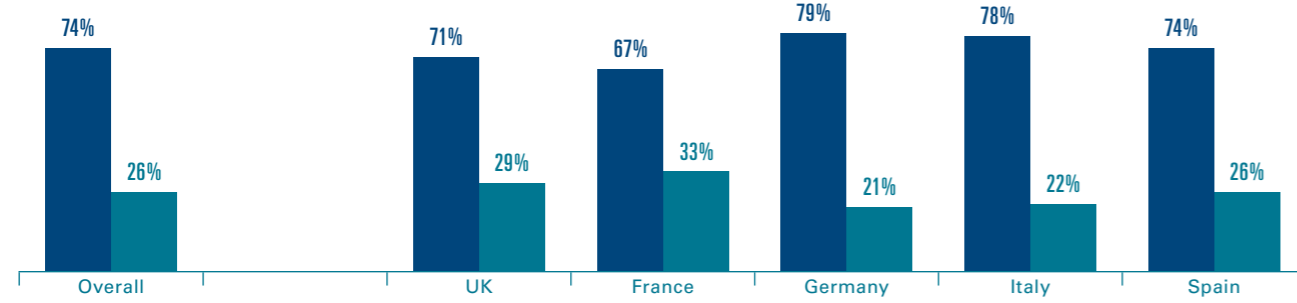
### A ONCE IN A LIFETIME NON-DRUG TREATMENT OPTION – BRONCHIAL THERMOPLASTY

One of the most profound findings from the report was that people suffering from severe asthma overwhelmingly would like to know about non drug based therapies to treat their severe asthma. **75% of people surveyed said they would like to understand more about non-drug based procedures for their severe asthma** (Figure 7).

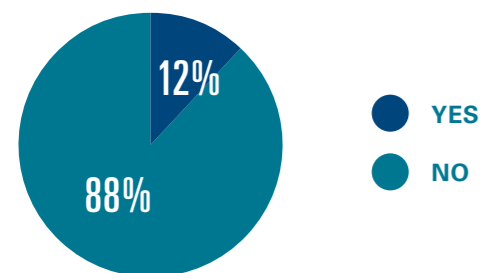
Despite being prescribed multiple medications for their severe asthma, the likelihood of suffering a potentially life threatening asthma attack still exists.

Despite bronchial thermoplasty being approved for use in Europe since 2011, only 12% of people surveyed had heard of it as treatment option for severe asthma (Figure 8 and 9).<sup>12</sup>

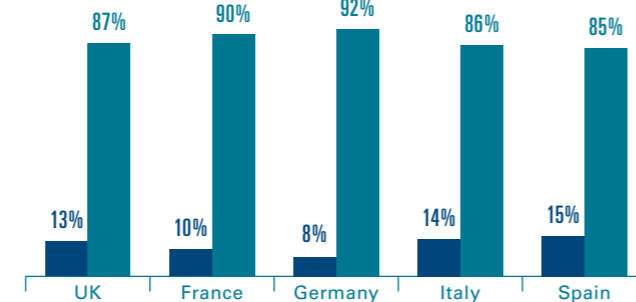
**Figure 7:** Three quarters say they would be interested in finding out about a non-drug based procedure if they were suitable for it.



**Figure 8:** Awareness of bronchial thermoplasty in Europe.



**Figure 9:** Awareness of bronchial thermoplasty per country.



**88% OF PEOPLE SURVEYED HAD NOT HEARD OF BRONCHIAL THERMOPLASTY AS A TREATMENT OPTION FOR SEVERE ASTHMA.**

Bronchial thermoplasty, if used in accordance with the Global Initiative for Asthma (GINA) 2015 Global Strategy Report for Asthma Management and Prevention guidelines, is recommended for adult patients whose asthma remains uncontrolled despite application of recommended therapeutic regimens and referral to an asthma specialty centre (Step 5).<sup>13</sup>

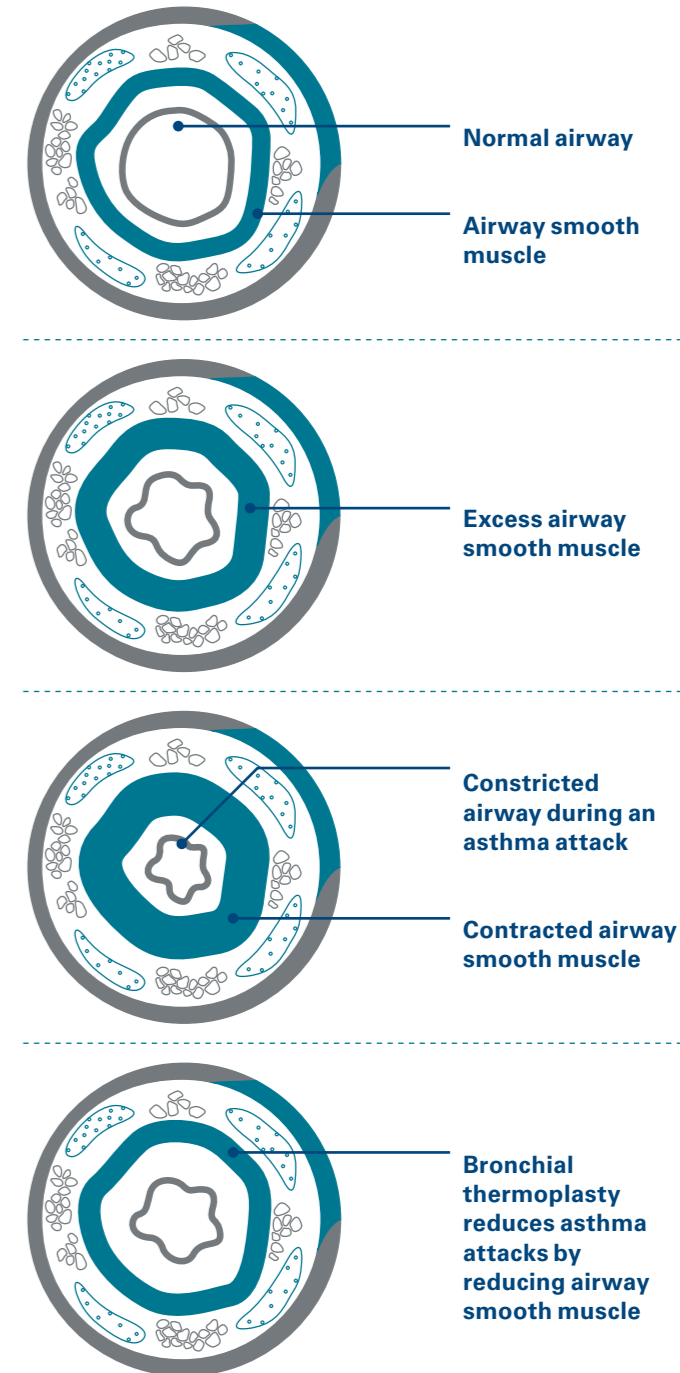
The GINA guidelines mirror those of The European Respiratory Society (ERS)/American Thoracic Society (ATS) Task Force on severe asthma which issued updated guidelines on the definition, evaluation and treatment of severe asthma in 2014.<sup>2</sup> These guidelines state a strong recommendation that bronchial thermoplasty is performed in adults with severe asthma only in the context of an Institutional Review Board-approved independent systematic registry or a clinical study.<sup>2</sup>

*“Bronchial thermoplasty is one of the most novel therapies we have when it comes to treating people who suffer from severe asthma. There is no other treatment that I have used for my severe asthma patients that can give the long term benefits bronchial thermoplasty has to offer.”*

— Professor Michel Aubier, Professor of Pulmonology at the University Denis Diderot - Paris VII, Head of Pulmonology Department of Bichat Hospital Paris, France

*“Bronchial thermoplasty has changed my life. I am now able to enjoy my life so much more. I can do things that I never dreamed of, such as cutting the lawn or taking bags down the stairs, which when you have a young family like I do to take care of is so important.”*

— Michael Keenan, 53, United Kingdom





# SPECIALISED SEVERE ASTHMA CARE PROVISIONS NEEDED ACROSS EUROPE

Poorly controlled severe asthma still remains a significant social and economic burden and leads to increased healthcare use, with negative effects on a person's quality of life. Bronchial thermoplasty, as an innovative non drug based therapy for people with severe and persistent asthma is a proven, safe and effective treatment option for this subset of patients.<sup>14,15</sup> The report revealed a startling lack of awareness among patients who suffer from severe asthma of this effective and safe therapy.<sup>12</sup>

In order to ensure people with severe asthma are given the correct treatment provisions, and those that are recommended by the Global Initiative for Asthma (GINA) and The European Respiratory Society (ERS)/ American Thoracic Society (ATS) Task Force, we propose the following actions:

## A REVIEW OF THE CURRENT PROVISIONS IN PLACE FOR SEVERE ASTHMA SUFFERERS IN EUROPE

## COMPREHENSIVE INFORMATION ON ALL AVAILABLE TREATMENT OPTIONS FOR PEOPLE WITH SEVERE ASTHMA

## FASTER ACCESS TO SPECIALISED SEVERE ASTHMA CLINICS

## GREATER POWER TO HEALTHCARE PROFESSIONALS TO RECOMMEND NOVEL TREATMENT OPTIONS FOR PATIENTS WHO QUALIFY FOR BRONCHIAL THERMOPLASTY

## ENHANCED TRAINING FOR HEALTHCARE PROFESSIONALS ON THE CLINICAL BENEFITS OF BRONCHIAL THERMOPLASTY

## BETTER SUPPORT FOR ASTHMA CHARITIES TO PROVIDE IMPARTIAL INFORMATION ON ALL TREATMENT OPTIONS

## LONG TERM STUDIES ON THE COST SAVING BENEFIT FOR NON-DRUG BASED THERAPIES FOR SEVERE ASTHMA

## PUTTING PATIENTS AT THE HEART OF ALL DECISIONS MADE ON TREATMENT

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## ACKNOWLEDGMENTS



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Professor Aubier specialises in the management of patients with airway obstruction (asthma and COPD). His main research interest is the cellular and molecular mechanisms of airway remodelling in asthma of COPD and the impact on environment on respiratory health. Professor Aubier is author of 300 publications in peer reviewed journals and serves on various grant review committees including Wellcome Trust, MRC, NIH and Inserm.



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Dr Rob Niven, Senior Lecturer in Respiratory Medicine, University Hospital of South Manchester NHS Foundation Trust, Manchester, United Kingdom

Dr Rob Niven is a Senior Lecturer and Consultant Respiratory Physician at the University of Manchester and University Hospital of South Manchester. As a clinician he runs a supra-regional service for severe asthma. He has assessed over 1,000 severe asthma patients, with around 50% of these referrals being for patients on maintenance oral steroids. He is a core member of the UK National Severe Asthma Network, with nearly 1,000 patients entered onto a national database from multiple centres, with Manchester a core contributor.

As a researcher he has published over 100 peer reviewed papers and authored five book chapters. Areas of interest have included occupational lung disease, environmental epidemiology and more recently clinical practice in severe asthma. He has innovated research into clinical practice in the fields of hypertonic saline for bronchiectasis as a therapy, awareness and diagnosis of dysfunctional breathing patterns, the role of antifungal therapy in severe asthma with fungal sensitisation and has been PI and CI on trials of Bronchial Thermoplasty and new biologics. In recent years he has published widely on studies of omalizumab. In addition he is a keen educator and leads the final year exams for the south Manchester site as well as being active in all aspects of education at undergraduate level.



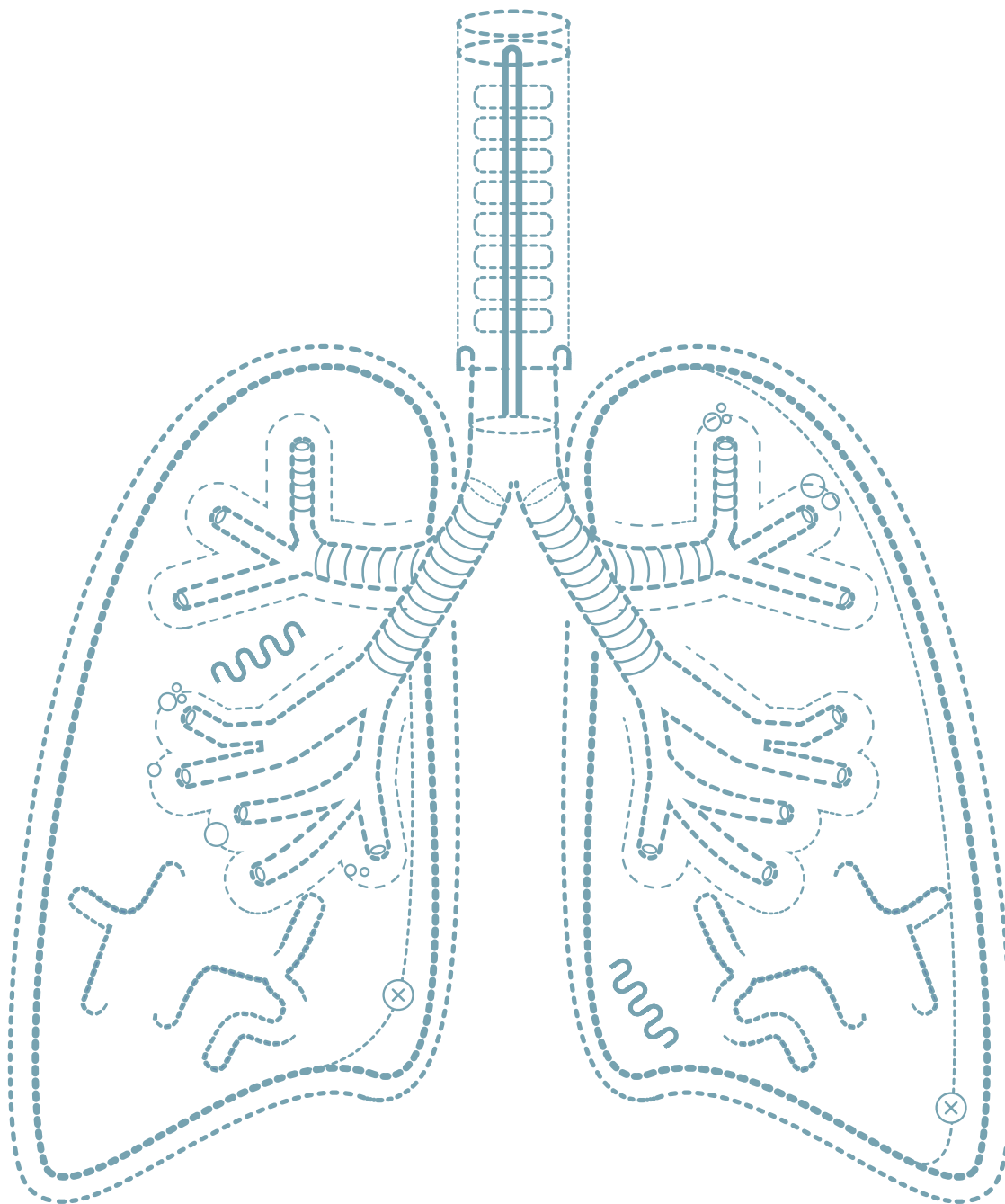
### INTERASMA

INTERASMA is an International Health Organization completely focused on all aspects of asthma which bridges the gap between Academia and the world of clinical practice.



### CHRISTINE ROLLAND

Director of Association Asthme & Allergies (France) President, (EFA) European Federation of Allergy and Airways Diseases Patients' Associations.



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