



# REPORT

ACTIVE PATIENTS

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October 2019

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We acknowledge and graciously thank the many individuals and organisations for their contributions and guidance:

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**We sincerely thank our sustainable funding partners AstraZeneca, Chiesi and GSK for their unrestricted grants in making this report possible.**





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## INTRODUCTION TO ACTIVE ASTHMA AND COPD PATIENTS ACCESS CARE REPORT

10 percent of the European population has chronic obstructive pulmonary disease (COPD) and 30 million children and adults less than 45 years old have asthma in Europe.<sup>1</sup> Both conditions debilitate one's ability to breathe, an act that is essential to every facet of life. People's ability to take charge of their own health care should be guaranteed everywhere and to everyone. In Europe, we have registered significant improvements in health in general in the last decades. However, unequal access to healthcare remains a problem, both between as well as within countries and population groups.<sup>2</sup> Therefore, it is important to measure the current limitations of access to healthcare and to inform accordingly policy makers, healthcare professionals and patients so that specific initiatives can be undertaken to fill existing and persisting gaps.



This is especially important for people with chronic diseases, whose access to appropriate diagnostic tools and optimal treatments can serve to slow down the progression of the condition, ensure better control over the treatment modalities, and thus improve Quality of Life (QoL) and provide for full participation in society. If active and informed patients have improved opportunities to access the best care, the majority of patients need to be empowered in order to be aware of available options and solutions and to take control over their condition through guided self-management with their healthcare professionals. Similarly, public institutions need to be informed about all factors that impact the health of people with chronic diseases and put in place preventative measures that can make Europeans a healthier population.

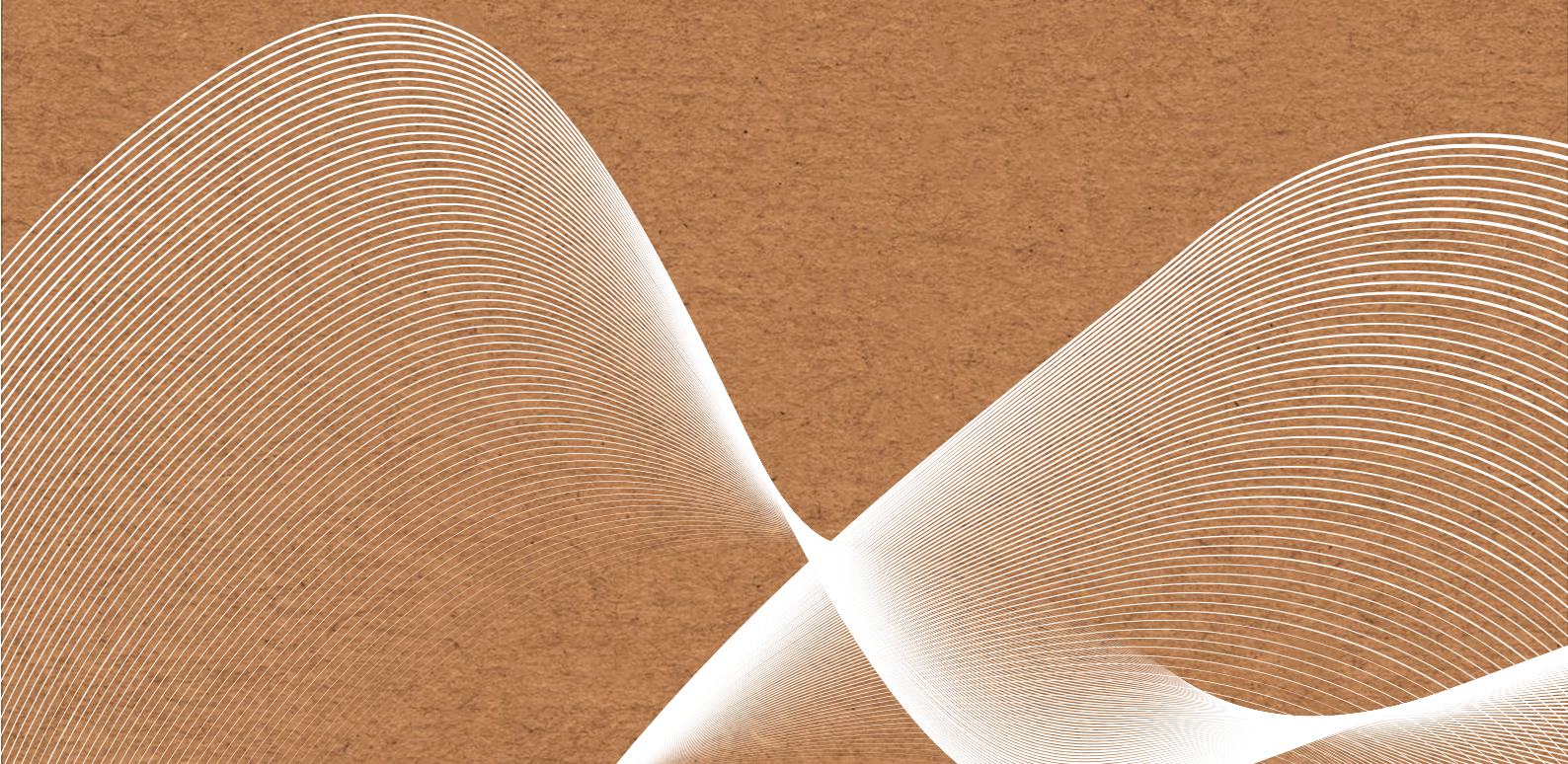
With the Active Patients Access Care study, the European Federation of Allergy and Airways Diseases Patients' Associations provides an overview of patient-reported levels of access to prevention, diagnosis, care and empowerment by people with asthma and COPD in Europe. Additionally, EFA provides recommendations for stakeholders to overcome identified gaps.

774 patients with asthma and COPD from Finland, France, Germany, Italy, Poland, Spain and the UK took part and were interviewed via phone between November 2018 and January 2019. In most of countries, patients were recruited via physicians to guarantee that all participants had a clear diagnosis of either asthma or COPD, and to ensure a balanced representation of severity for each disease among people with mild (15 per country per condition), moderate (20 per country per condition) and severe (20 per country per condition) stages of illness. Only in Finland were patients recruited via social media groups, support groups and patients' referral identified by our Finnish member association because of Finland's unique healthcare system. Adult patients of different ages participated from Germany, UK, Finland, France, Italy and Spain. Polish patients were on average older.

This report brings aggregated results from all countries surveyed on access to diagnosis and care for asthma and for COPD in Europe as reported by patients. The results on prevention and patient empowerment are both for asthma and COPD patients combined as we saw more similarities than differences. You will find country-by-country asthma and COPD access fact sheets at the end of the report. These country fact sheets provide summaries and highlight specific figures and deviations from overall results. We hope you will not only find the report enlightening but also a vital tool to help patients solve gaps in asthma and COPD access to care, prevention and patient empowerment by working to implement the action points provided at the end of the report.



# ASTHMA



## ACCESS TO ASTHMA DIAGNOSIS

Asthma is a non-communicable chronic inflammatory disease that does not transmit to others. Asthma causes inflammation of the smaller airways deep in the lungs (bronchioles) that narrows the airways. It often starts in childhood and affects one in five school children (20%) in Europe. Some outgrow childhood asthma for reasons that are still not clear; many do not or get asthma later in life. Today, there are 30,000,000 children and adults under 45 years of age who live with asthma in Europe. Approximately 10% of adults with asthma suffer from severe and life-threatening symptoms.<sup>3</sup> Receiving an asthma diagnosis as early as possible is crucial in the life of patients.

“

*I'd hoped it was something different so it struck me when I got the diagnosis.*

UK

”

### Three-year average wait for first diagnosis of asthma

“

*I did not recognize that the disease already started when I was 15 years old.*

Germany

”

Patients who participated in our survey waited on average three years to get a first diagnosis after they perceived the first symptoms of asthma. This is far too long time. The average age for noticing their first symptoms was 21, and for diagnosis 24 years old, with variation between one year and 71 years of age for an initial diagnosis of asthma. The three-year average waiting time to get an asthma diagnosis varies greatly across countries. In Finland and Poland, asthma patients perceived, on average, their first symptoms at an older age (26 and 29 years, respectively), and it took them longer to receive a diagnosis (seven years later on average). Taking into account country differences on asthma care, this leads to the perception that the older the patients are when they perceive their first symptoms, the longer they have to wait to have them properly diagnosed.

Not having access to an early diagnosis has a dramatic impact on the lives of people with asthma. Overall, two in five asthma patients believe that they would be in better health condition now had they received a proper diagnosis earlier. In fact, of those patients who received the diagnosis ten years or more after noticing the first symptoms, 46% had severe asthma, 35% had moderate asthma and 19% lived with mild asthma. Delayed diagnosis and treatment may therefore lead to a worsening of asthma severity.

The level of education of people with asthma correlates to the time gap between the perception of the first symptoms and the first diagnosis: patients with a higher level of education wait one and a half years less to receive a first diagnosis compared to those with a lower level of education. This leads to the perception that there is inequity on the basis of patient educational status in the access to a proper asthma diagnosis, resulting in delayed treatment and a potential increase in the severity of the condition.



## Asthma is mostly diagnosed in primary care

“

*If the doctor at the clinic had done suitable tests, asthma might not have developed – there were some symptoms for three years, but they were not taken into account.*

Poland

”

In most cases, people with asthma receive their first diagnosis through a non-specialist general practitioner or community doctor (41%), followed by pulmonologists (33%), paediatricians (14%), allergologists (9%) and healthcare professionals in the emergency room (4%).

Only about two in five patients (42%) receive a first diagnosis of asthma from a specialist (pulmonologist or allergologist). Approximately three in four of the asthma patients that did not receive the first diagnosis by a specialist were later referred to a pulmonologist. **However, the average waiting time to see a specialist is as long as five months.**

Worryingly, 12% of patients were never referred to a specialist regardless of the severity of their asthma. The patients who reported never being referred to a specialist were initially diagnosed by a general practitioner (70%), a paediatrician (26%) or a healthcare professional in the emergency room (4%).

Given the variance among health systems in the European Union, there are numerous national guidelines on when to refer asthma patients from a generalist to a specialist<sup>4</sup> doctor. The majority of the existing guidelines recommend referring a patient to a specialist when the diagnosis of asthma is uncertain. In general, these national guidelines are used in parallel with the Global Initiative for Asthma (GINA) asthma management guidelines.<sup>5</sup>

Almost half (44%) of the asthma patients in our survey who were diagnosed in their childhood had problems in their transition from paediatric to adult care.

## Asthma is not simple and misdiagnosis is still common

“

*They did not know whether it was asthma or COPD.*

Finland

”

“

*I think there was not a proper diagnosis when I was young.*

Spain

”

Asthma symptoms, and especially difficulty in breathing, are not only specific to asthma. Mistakenly, they can be confused with other respiratory diseases, like COPD, or cardiovascular diseases especially later in life.<sup>6</sup> Yet asthma is one of the most common chronic respiratory diseases and one of the top non-communicable conditions in Europe. It is therefore surprising that 16% of all respondents to our survey initially received a wrong diagnosis for their asthma.



Our survey highlights two important variables for incorrect diagnosis. First, the chances of getting a wrong diagnosis depend on the country: 36% in Poland, 27% in Spain and 21% in Finland. Secondly, the more severe the asthma, the higher the risk for an incorrect diagnosis: asthma patients who initially received an incorrect diagnosis currently have severe (48%) or moderate (33%) asthma.

Taking into account the impact asthma has in respiratory health and quality of life, misdiagnosis can be devastating for patients: the patients in our survey only received a corrected diagnosis of asthma 4.5 years afterwards.

Considering that general practitioners and pulmonologists are at the forefront of asthma diagnosis (74% combined), it is more likely that they provide a wrong diagnosis: 38% of misdiagnosis were provided by pulmonologists and 33% by general practitioners. Additionally, allergologists (16%) and paediatricians (7%) also confuse asthma with other pathologies. Only in a few cases did patients receive a wrong diagnosis by a healthcare professional in the emergency room (5%) or during their stay at hospital (2%), which is easily explained if their admission to hospital was due to respiratory distress.

Unfortunately, we cannot as yet determine if the wrong diagnosis rate among pulmonologists and general practitioners is due to the quantity of cases they treat, to their interpretation of diagnostic results or due to other issues concerning the patient, such as the timing and accuracy in reporting their symptoms. In any case, **having one in six people with asthma misdiagnosed is a burden that the patient community cannot accept.**

Despite the fact that the overall rate of wrong diagnosis is relatively high (16%) and that the need to have better diagnostic tests is listed as top research priority by the asthma patients in this survey, nine in ten of them are satisfied with the diagnostic process. In Finland and Poland, patients reported higher levels of dissatisfaction with the diagnostic process (18%).

“

*The illness was diagnosed by a specialist. But there were communication problems between the paediatrician and the specialist.*

France

”

## **Patients have access to the recommended diagnostic tests, but feel it is a top research priority**

A positive sign in clinical practice is that the patients in our survey went through diagnostic tests recommended in the most recent Global Initiative for Asthma (GINA) Guidelines, which is lung function or spirometry testing to document variable expiratory airflow limitation, including the use of relief spray when needed.<sup>7</sup> In this context, the spirometry test is recognized as more reliable than the peak flow meter test.

The five diagnostic tests mostly used in the seven European countries surveyed are physical exams (87%), consultation that includes a review of the patient's medical history (84%), spirometry test (74%), allergy testing (55%) and spirometry test including taking a relief spray (37%).

Although consultations and physical exams are not diagnostic tests by themselves, consultations allow healthcare professionals to perform all the required tests for a diagnosis, including physical exams to identify the external signs of reduced lung capacity and not least to have a dialogue with patients.



In light of the high percentage of misdiagnosis (16% of all respondents), further research is needed to better understand the underlying reasons for misdiagnosis and to identify the best practices to reduce the occurrence of misdiagnosis.

Despite all the available diagnostic tests, 60% of the asthma patients in our survey estimate that many asthma cases are unreported. We do not know if their perception is based on unreported symptoms (due to limited patient education and self-awareness) or on lack of diagnosis (deficient healthcare systems and poor patient-doctor communication).



## ACCESS TO ASTHMA CARE

Asthma patients who report not having their disease in control experience fatigue and breathlessness when engaged in daily life activities and sports, in addition to night-time symptoms. Having an asthma exacerbation results in breathlessness and wheezing. Yet with proper care and treatment, people with asthma can live and work normal lives.

### **Asthma patients have to rely on healthcare professionals more than expected**

While the majority of people with asthma can usually be managed in primary care, some clinical situations require a referral for expert advice for diagnosis and/or management of the disease.

Practice is aligned with the recommendations from guidelines. A vast majority of patients (81%) rely on their general practitioners for the management of their asthma. However, pulmonologists are also involved in the treatment of three out of four patients. On average, only 20% of the patients reported assistance by an allergologist, although in countries like Poland and Spain, allergologists appear to be more systematically involved (55% and 38% respectively). Surprisingly, nurses are not involved in the management of asthma (only 1%), despite having a specific role in some countries. For example, the United Kingdom has nurses specialised in asthma, while in Finland nurses perform asthma controls on regular basis.

While it is clear that patients with severe asthma visit the pulmonologist often (85%) because of their needs, **it is interesting that two in three of the patients with mild asthma also see a pulmonologist.** It might be needed in some cases but, when looking at the GINA<sup>8</sup>, asthma can be managed in primary care up to a mild state and a referral for expert advice is needed in case of:

- Persistent uncontrolled asthma or frequent exacerbations
- Risk factors for asthma-related death
- Evidence of, or risk of, significant treatment side-effects
- Symptoms suggesting complications or sub-types of asthma

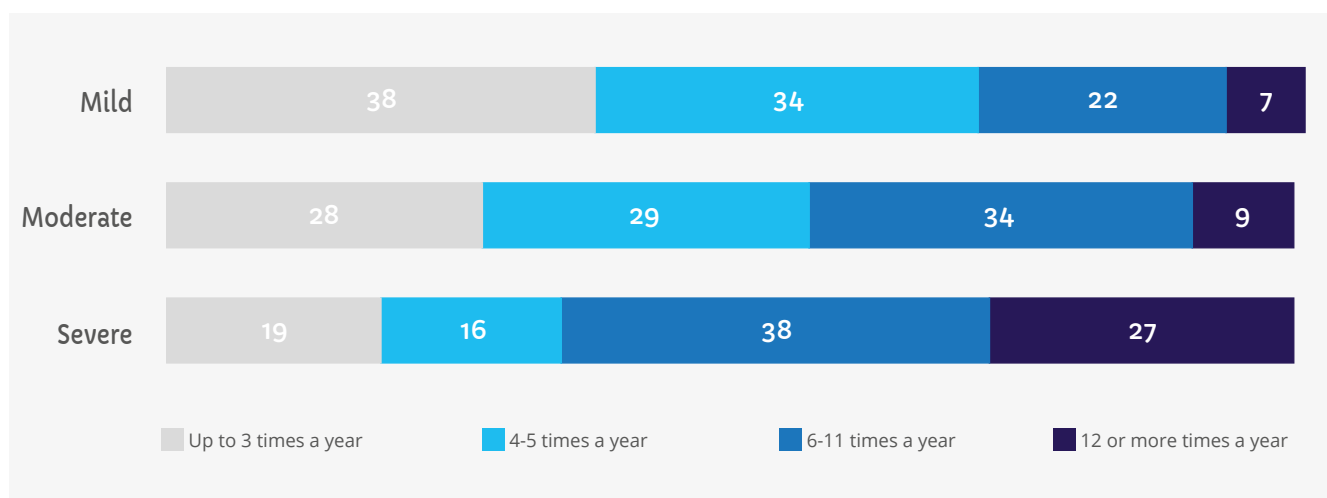
This suggests that a majority of patients have problems in managing their asthma. Asthma patients who reported not visiting a specialist provided the following rationale: there was no need to see a specialist – perhaps because their asthma was under control (37%); they never discussed that possibility with their general practitioner (30%); or, they trust their primary care physician to provide adequate care (17%).

In general, asthma patients see their doctor often: the majority (52%) of patients have up to five visits per year, one in three patients see their doctor from six to eleven times per year, which is considerable, while the remaining 15% of people with asthma visit their doctor at least once a month (12 times a year or more). As expected, the frequency of visiting healthcare professionals increases with the disease severity (Figure 1).

Overall, we notice half of asthma patients visit their doctor often, especially their general practitioner, at least quarterly, which is the maximum recommended. In the GINA guidelines, asthma patients should be seen within the one-to-three months after starting a new treatment and every three-to-twelve months thereafter. After an exacerbation, they should have a review visit within one week.

According to the EFA member associations in the seven countries surveyed, people with asthma visit their doctor because of difficulties controlling symptoms, low effectiveness of their treatment which can lead to more exacerbations or, in some countries, to have a closer follow up with their physician partly motivated by the free or very high reimbursement of consultations with them. **Asthma is still clearly managed at the clinic, in contrast to the current emphasis on empowering patients** in guided self-care with the use of digitally enabled follow-up, monitoring and adjustment.

**Figure 1. Frequency of asthma patient visits to healthcare professionals (%)**



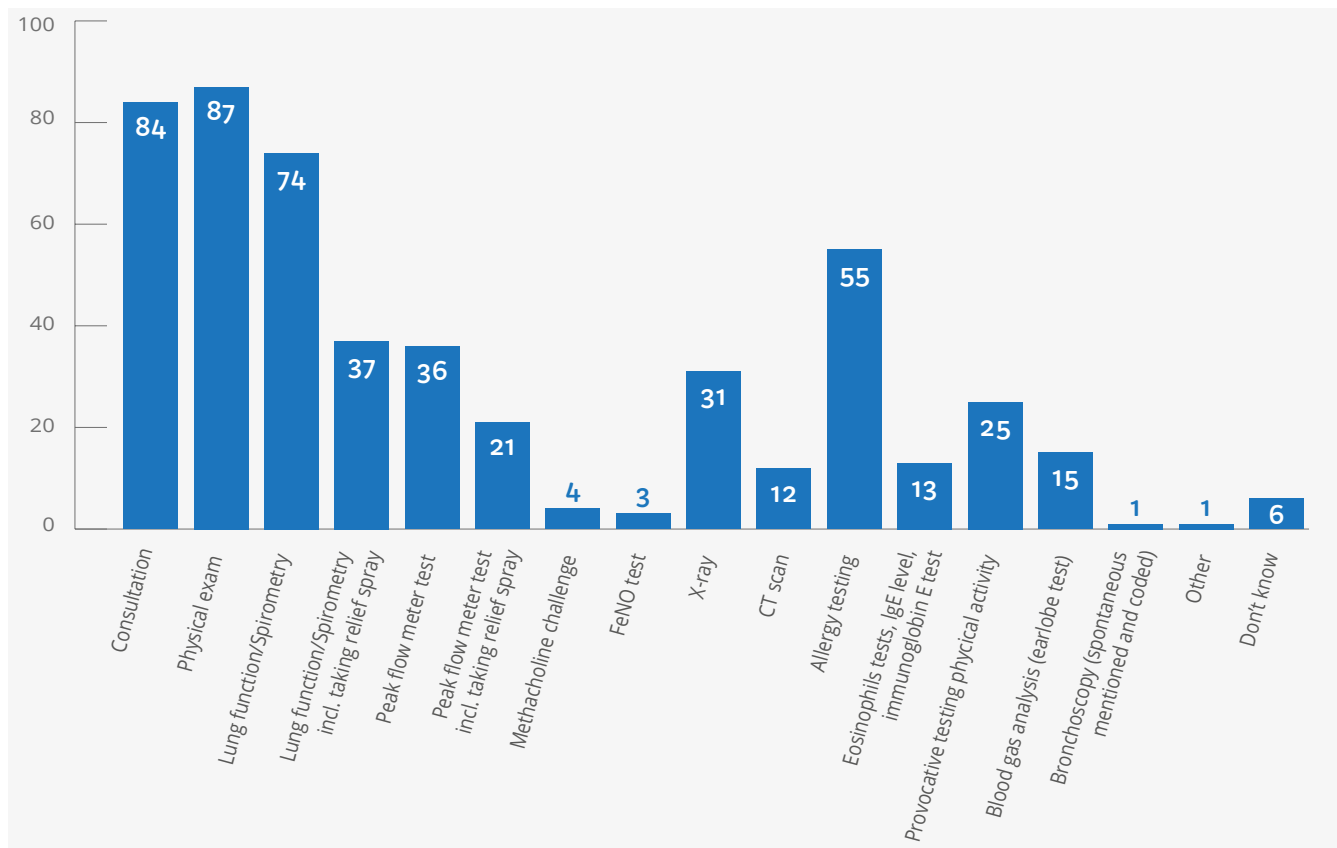
Asthma patients reported that travel distance to their main specialist is on average 24 kilometres. Patients living in rural areas have to travel 10 kilometres more (34 km) on average to reach their specialist.

Consultation with the doctor lasts 21 minutes on average, which is higher than expected. One reason could be that consultations with specialists take longer than those with general practitioners: the latter normally range from 8-18 minutes in the countries surveyed according to a recent review and information provided by local patient organisation Members of EFA.<sup>9</sup>








### Diagnostic tests are used less in follow-up

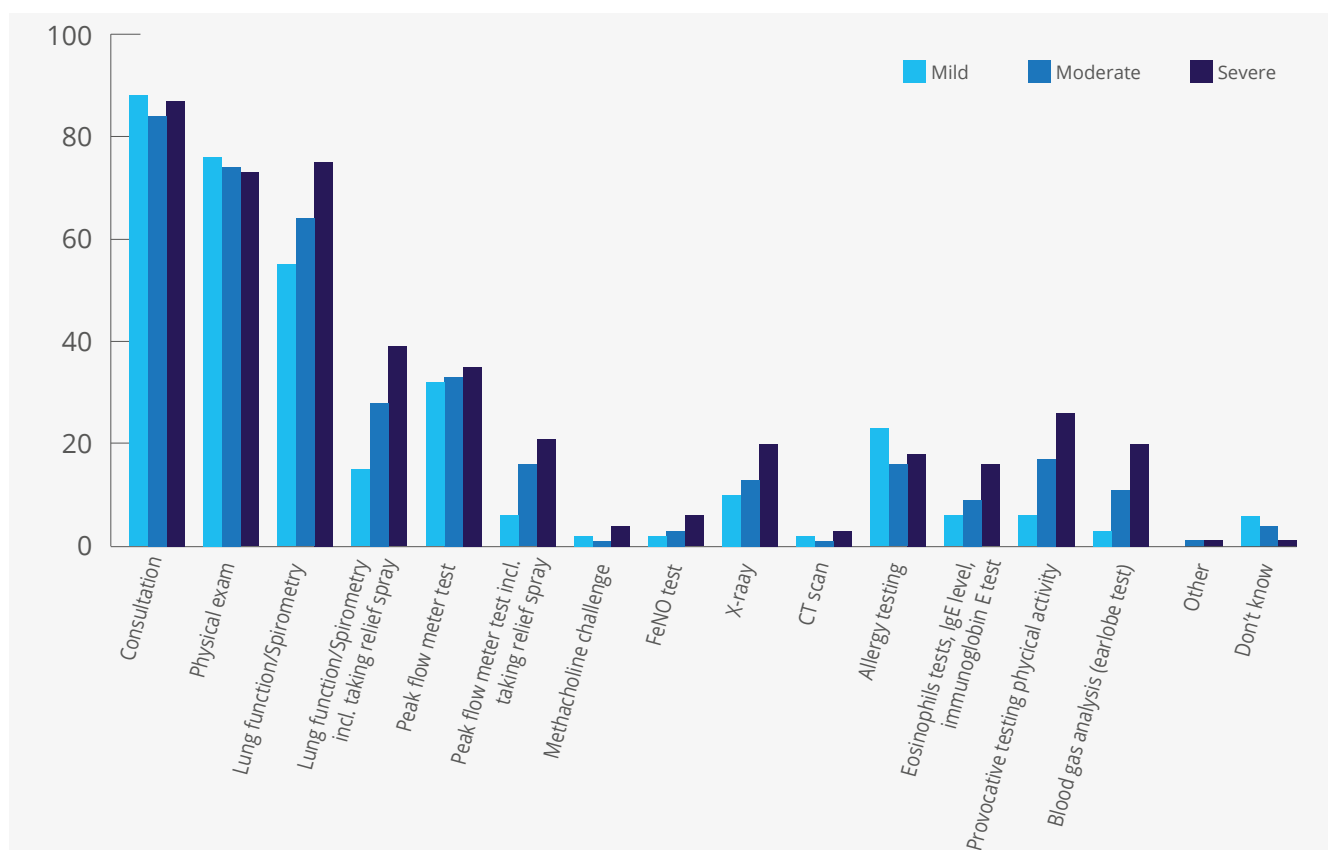
The tests that patients go through on a regular basis to check up on and monitor their asthma are the same as the tests used in the diagnosis phase (most commonly consultation, physical exams, spirometry and peak flow tests). The number of tests used in follow-up consultations decreases once the diagnosis is provided. Our survey results show disparities in the use of diagnostic tools: allergy tests are repeated less often compared to the diagnosis phase, patients with mild asthma receive spirometry testing less often and also less provocative testing, in Poland and Spain peak flow is hardly used. (Figure 2).

**Figure 2. Tests used for the first diagnosis of asthma (%)**



**Figure 3. Satisfaction with diagnostic process asthma (%)**

							
Very satisfied	13	18	22	20	21	18	5
Satisfied	50	65	58	62	43	55	67
Neutral	5	11	9	15	13	18	18
Dissatisfied	14	2	4	0	13	4	2
Very dissatisfied	4	0	0	0	5	4	0
No answer/don't know	14	4	7	4	5	2	7

**Figure 4. Tests conducted on asthma patients on a regular basis (%)**








### Patients are treating asthma symptoms instead of inflammation

Asthma is a chronic inflammatory disease that requires regular medication in order to be properly controlled. Given that the disease affects the lungs, contingency medications are also needed when symptoms worsen due to respiratory infection, environmental factors or other health issues that impact the lungs.

Patients reported that their asthma is most commonly treated with inhaled corticosteroids (72%) and emergency relief (62%) medication. These results confirm the persistent reliance on emergency relief/SABA overuse.<sup>10</sup>

Other common treatments that patients report using to treat their asthma are LABA reliever<sup>11</sup> (34%) and LABA and cortisone combined (37%), while about 1/3 of the patients currently use antihistamines, most likely to treat the most common co-morbidity in asthma, allergic rhinitis (Table A).

**Table A. Treatments currently used by patients for their asthma, by country (%)**

	Average							
Inhaled corticosteroids/Cortisone controller or preventer	72	46	58	75	73	79	84	87
Leukotriene modifiers	19	41	4	11	22	32	11	15
Long-acting beta agonists/LABA reliever	34	7	42	42	40	45	25	38
Combination inhalers LABA and cortisone combined	37	64	25	42	27	39	27	33
Theophylline/Theophyllins	10	2	15	11	13	11	15	5
Short-acting beta agonists/SABA/ emergency relief spray	62	79	60	84	45	54	60	51
Ipratropium	7	0	2	2	5	36	4	0
Tiotropium/LAMA	7	16	5	5	11	0	4	9
Oral corticosteroids/Cortisone (pills)	21	18	15	20	15	27	40	11
Intravenous corticosteroids/Cortisone (IV)	5	0	4	4	5	2	13	5
Antihistamines/Antiallergics	30	21	20	16	27	66	38	22
Desensitization/immunotherapy	7	2	4	9	5	11	15	4
Biologics	4	2	7	9	2	9	2	0
Pulmonary rehabilitation programme	8	0	7	13	13	11	4	7
Other	2	0	2	2	0	5	2	0
None	0	2	0	0	0	0	0	0

**Table B. Treatments currently used by patients for their asthma (%)**

	Average	Mild	Moderate	Severe
Inhaled corticosteroids/Cortisone controller or preventer	72	61	74	77
Leukotriene modifiers	19	19	24	16
Long-acting beta agonists/LABA reliever	34	29	28	44
Combination inhalers LABA and cortisone combined	37	15	43	48
Theophylline/Theophyllins	10	4	15	10
Short-acting beta agonists/SABA/ emergency relief spray	62	60	57	67
Ipratropium	7	1	6	12
Tiotropium/LAMA	7	1	9	11
Oral corticosteroids/cortisone (pills)	21	8	10	40
Intravenous corticosteroids/Cortisone (IV)	5	2	4	8
Antihistamines/Antiallergics	30	22	29	38
Desensitization/immunotherapy	7	4	6	10
Biologics	4	0	4	9
Pulmonary rehabilitation programme	8	1	7	13
Other	2	0	1	3
None	0	1	0	0

In addition to inhaled corticosteroids and emergency relief, patients with severe asthma more frequently use LABA (44%), or a combination of LABA and cortisone (48%) and oral corticosteroids (40%) (Table B). This is worrisome given that some traditional asthma controller medications are less effective in the treatment of severe asthma.<sup>12</sup> **Patients are treating only their asthma symptoms and not the underlying inflammation.** They report using emergency relief for the treatment of mild (60%) and moderate (57%) severity of asthma (Table B). This is entirely against the international guidelines which consider the reduction of reliever medications as both an important goal in asthma management and a measure of the success of asthma treatment.<sup>13</sup> The self-management of and education on asthma is not in control, and we report on this in the final chapter.

## **Asthma patients rely too often on the emergency room**

Asthma and allergy are the most common chronic diseases in children and are the leading cause of school absences, emergency visits and hospitalisations in Europe.

Very distressing data arising from our survey is that one in four asthma patients ended up in the emergency room at least once in the previous year. This is even higher for patients with severe asthma: one in two severe patients have been to the emergency at least once and 6% of them even more than three times per year (Figure 5). This is extremely worrisome and may mean that either the treatment or the adherence to the treatment, or both in varying combinations, are failing to prevent asthma attacks and exacerbation. **While new research with targeted therapy and personalised medicine present new hope for people with asthma, it is far from a reality.**

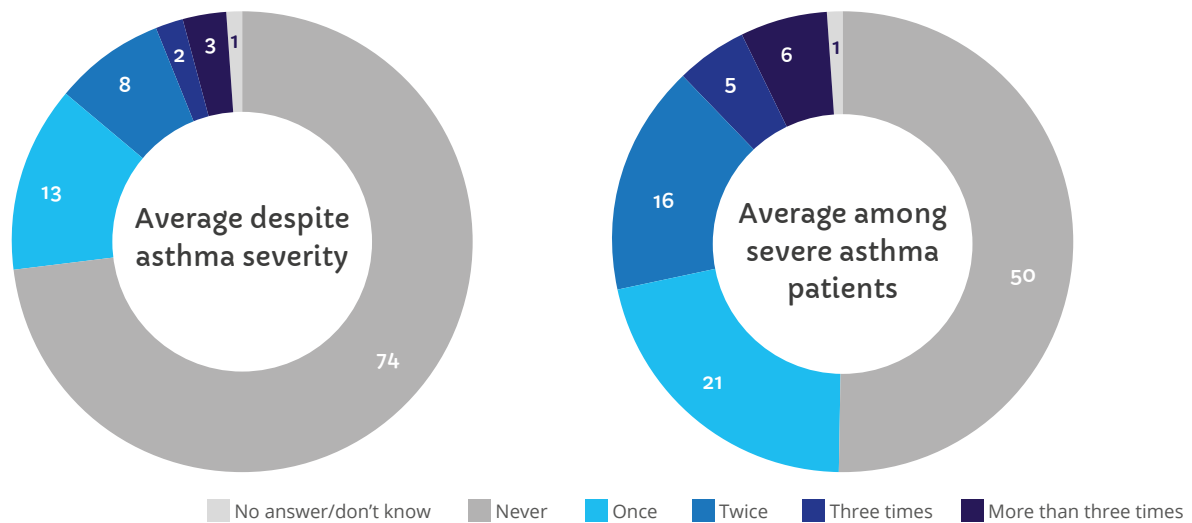
This is so despite the fact that the EU quickly embraced the personalised approach as an emerging movement. Indeed, in an effort to follow progress in biological treatments, the EU has recognised the benefits of personalised medicine for patients, healthcare providers and health systems alike, but also the need for further scientific advance.<sup>14</sup> Moreover, in recent years the EU has funded several projects in the field. These include the U BIOPRED project, which looked at the biological characteristics of severe asthma patients. Additionally, the European Commission Directorate General for Research and Development has organised two major conferences on personalised medicines (2011 and 2016).

## **Asthma and allergies go hand in hand**

Many people with asthma also have allergies that serve as a trigger factor for asthma. The therapies prescribed for one in three asthma patients in our survey are intended to treat other asthma comorbidities, such as allergies.

As expected, allergies are by far the most common other chronic disease among asthma patients: the prevalence of allergy to pollen (37%) is specifically high, but also allergy to animals (29%) and dust mites (28%). Cardiac diseases are another comorbidity for one in four asthma patients. These further complicate the treatment regime at home.

**Figure 5. Frequency of being in the emergency room during the last 12 months for asthma patients (%)**



### Out-of-pocket payments for services are common

We also asked patients about reimbursement for services they use in the management of asthma. At least half of the patients usually benefit from consultations, prescriptions, spirometry, laboratory tests, medical aids (i.e. inhalers, medical devices), X-rays or CT-scans. Overall, asthma patients pay (whether partially or fully) for 1/3 of these services out of their pocket. The top out-of-pocket expenses are for antibiotics, prescriptions and medical devices.

This perception might be influenced by the patients' misperception of what they are actually paying fully or partially, since they might not be aware of the real cost of the service and a portion of it might be paid already by the insurance.

### Patients have many concerns over efficacy and side-effects

While asthma patients seem to be able to access doctors and specialists in the countries surveyed, 56% of participants feel that asthma does not get enough attention compared to other chronic diseases and their perception on the overall burden of asthma is worrisome: the patients in this survey report that their lives are significantly and negatively impacted, especially in relation to productivity (50%), social interactions (43%) and finances (46%).

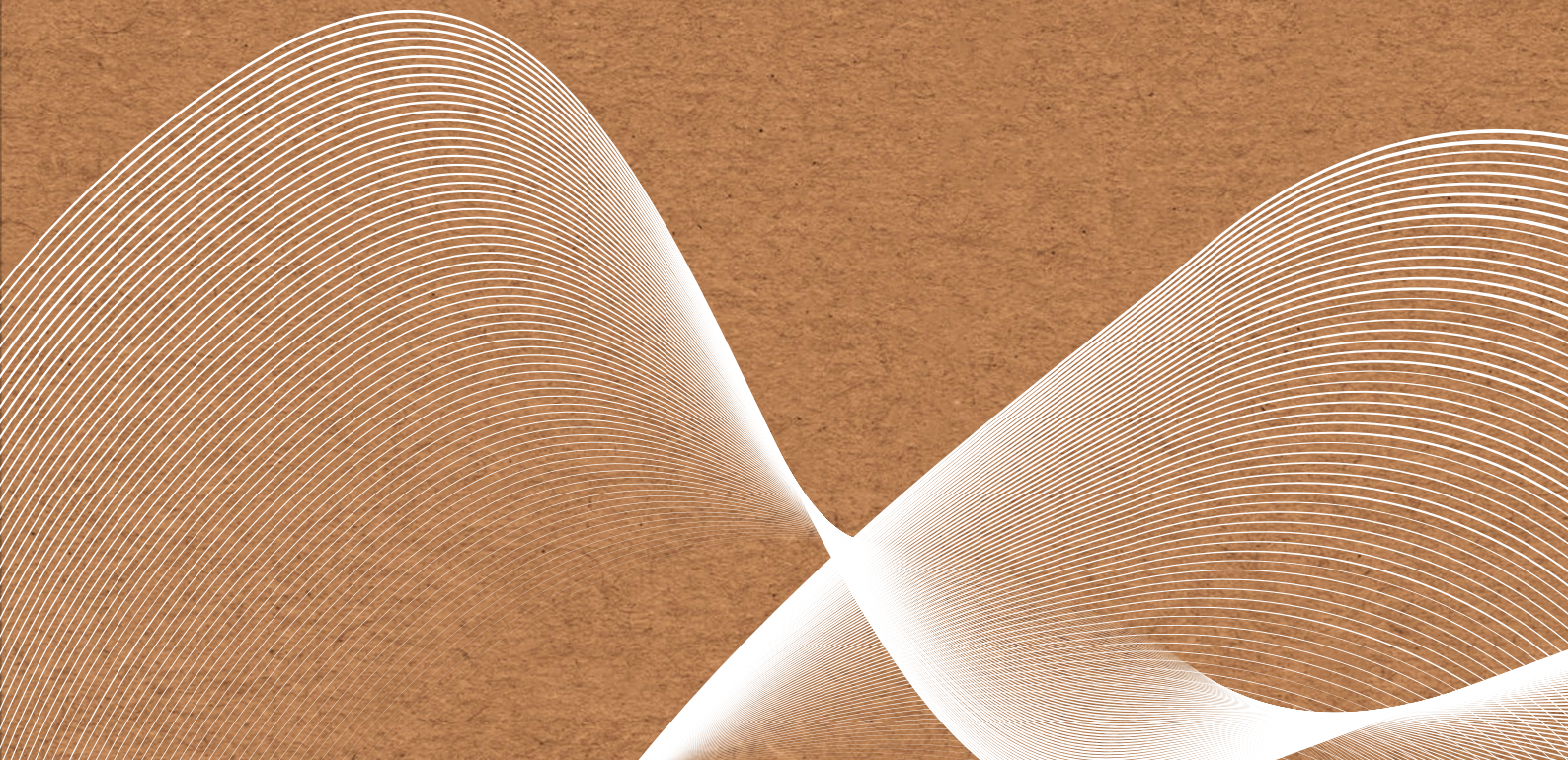
Half of asthma patients are concerned about the side effects of cortisone, which is the most common and the basis treatment of asthma. Although the side-effects of cortisone are well-documented, cortisone continues to play an important role in the management of both asthma and COPD, while personalised medicine will additionally help to provide targeted treatments for severe asthma. Not surprisingly, **asthma patients list as a top research priority, in addition to better diagnostic tests, the development of more efficient and effective therapies that are faster acting and pose fewer side-effects.**

Despite this apprehension, 70% of patients agree that asthma is being well-researched and there is a wide consensus that asthma therapy and treatment have considerably improved within the past years.





COPD



## ACCESS TO COPD DIAGNOSIS

“

*My symptoms were not taken seriously and it took a long time.*

Finland

”

Chronic obstructive pulmonary disease (COPD) is an umbrella term that describes chronic limitations in the lung airflow. It is a progressive and irreversible disease that causes inflammation in the lungs, damages lung tissue permanently and narrows the airways - making breathing progressively worse. COPD mainly affects people over the age of 40. COPD becomes more common with increasing age. COPD is currently more common in men than in women. In Europe, COPD is primarily caused by smoking and exposure to tobacco smoke, while in developing countries cooking stoves can also cause COPD.

Early detection and correct diagnosis is fundamental to guarantee a timely, effective, correct treatment and preventive plan that can help patients to properly manage the disease and cope with unexpected situations.

### First diagnosis of COPD is mostly given by specialists

“

*I trust my doctor and do not want to embarrass him.*

UK

”

COPD starts frequently in middle-aged people - a fact confirmed by our survey, wherein almost half of the patients noticed the first symptoms of COPD just before their 50<sup>th</sup> year. On average, their symptoms started at the age of 48.3 years and they received the first diagnosis on average at 51.7 years old, more than three years after their first symptoms.

The majority, almost three in five COPD patients, received their first diagnosis from a pulmonologist (59%), while the rest received it from general practitioners (37%) or at hospital or the emergency room (2%). **Worryingly, it took the COPD patients seven months on average to have a consultation with a specialist for that initial diagnosis.** Taking into account the progressive nature of COPD, this is a very long waiting time to get the correct advice and care to help patients cope with the disease.

Of the COPD patients who were never referred to a specialist after the diagnosis, almost one in five patients (19%) was diagnosed by a general practitioner. While most of the non-referred cases were diagnosed with mild COPD (52%), half of them are today at advanced COPD stages: 24% have moderate COPD and 24% have severe COPD.

## COPD is dramatically underdiagnosed

A recent research review points out that despite accessible diagnostic tests, under-diagnosis of COPD in Europe is very high, ranging from 66% in Norway to 95% in Austria.<sup>15</sup>

The patients in our survey believe that to be the case as well: 70% of them assume there is a high number of unreported COPD cases. Recent national estimations in Spain and France highlight that eight in ten people with COPD have not been diagnosed.<sup>16 17</sup>

According to EFA member associations in the survey countries, the high rate of under-diagnosis of COPD can be linked to patients' own perceptions of their respiratory symptoms, as they can easily be associated with ageing problems or tobacco side-effects and, therefore, not discussed with the doctor. It is therefore crucial to inform smokers and those who are regularly exposed to second-hand smoke about the long-term consequences of consumption and exposure to tobacco smoke and the need to seek for diagnosis and care without delay, as one in two lifelong smokers will develop COPD.<sup>18</sup>

## Misdiagnosis of COPD takes a long time to be corrected

Despite being very common, COPD can be confused with other respiratory conditions that share similar symptoms, such as asthma.<sup>19</sup> The European Respiratory Society and the American Thoracic Society have set the diagnosis criteria of COPD on the forced expiratory volume that one person can exhale in the first second (FEV1) through a spirometry test. In COPD, it is precisely the reduced efficiency in exhaling, clearing the lungs off carbon dioxide, that leads one to suspect a diagnosis of COPD.

Although the measurements to diagnose COPD are clearly set, still 16% of COPD patients in our survey initially received a wrong diagnosis. Unfortunately, diagnosis and care vary across Europe, impacting the patients' chances to slow down and take charge of the disease. According to the survey, there is a higher probability to get a wrong diagnosis for people in Spain, Poland (27-29%) and Finland (20%).








Misdiagnosis can have a dramatic effect on people's lives. **COPD patients who initially received a wrong diagnosis have to wait 5 years to receive the right one.** Such a long period might have increased the severity of COPD for three in four patients, as those who reported being initially misdiagnosed live today with mild (25%), moderate (38%) and severe (37%) stages of COPD.

It is therefore no surprise that one in two patients assume they would be in a better health condition now had they received an earlier diagnosis.

Incorrect diagnoses (16%) were mostly provided by pulmonologists (52%), general practitioners (43%), healthcare professionals at hospital (3%), and at the emergency room (2%).

Despite waiting times and misdiagnosis, COPD patients are overall satisfied with the healthcare system. In general, nine in ten COPD patients report that they are satisfied with the diagnostic process and only 7% report they are dissatisfied. Only the Finnish patients were highly dissatisfied with the diagnostic process (28%) (Figure 6).

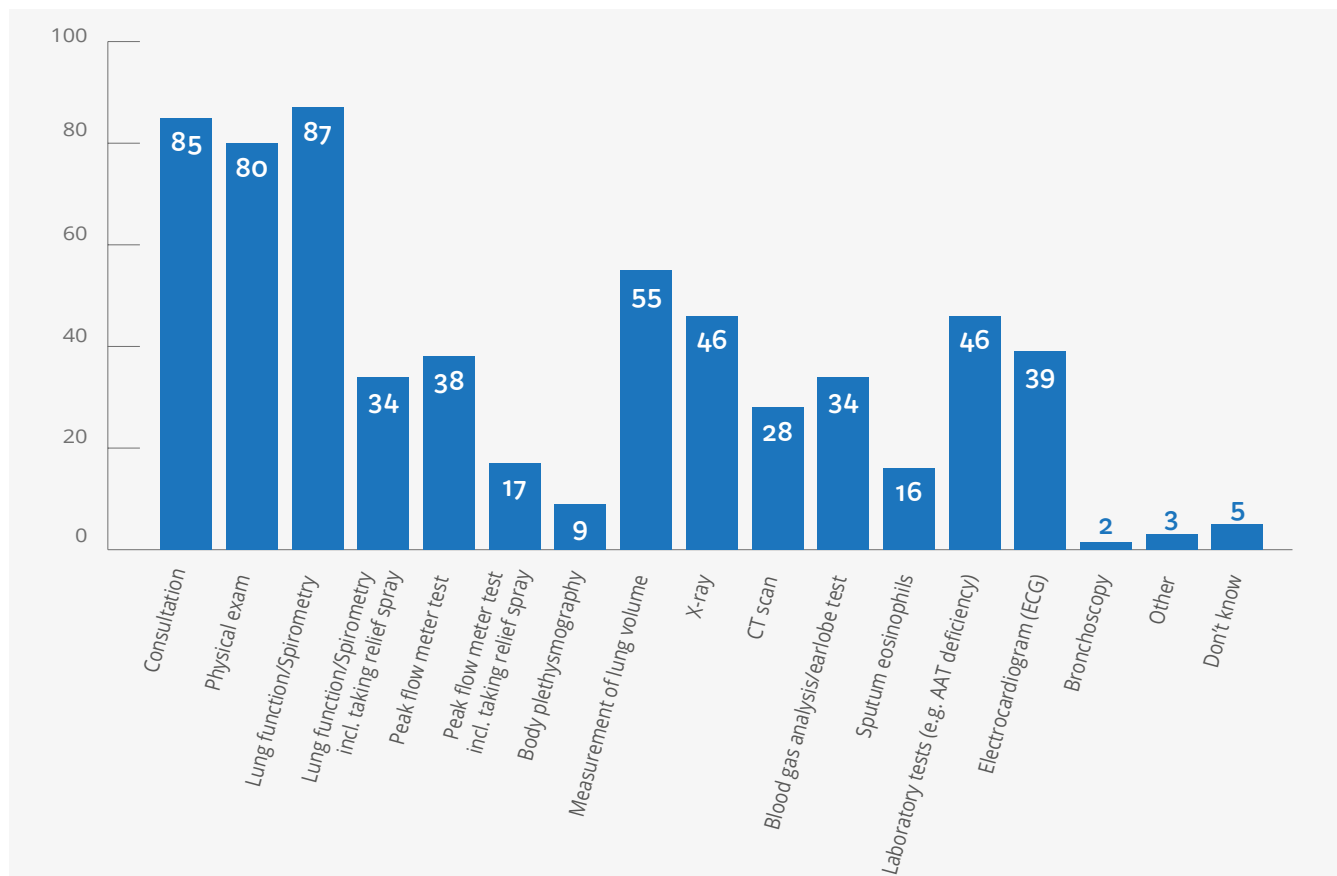
**Figure 6. Satisfaction with diagnostic process COPD (%)**

							
Very satisfied	18	4	13	13	36	16	4
Satisfied	45	80	71	73	46	60	75
Neutral	9	15	11	11	13	20	16
Dissatisfied	24	2	5	2	2	2	5
Very dissatisfied	4	0	0	2	0	2	0
No answer/don't know	0	0	0	0	4	0	0

**Diagnostic tests for COPD are in line with guidelines**

Our survey shows that according to patients in the seven countries, the tests for diagnosis are in-line with the recommendations by the Global Initiative for Chronic Obstructive Lung Diseases (GOLD) 2019 guidelines.<sup>20</sup> Most COPD patients remember having a spirometry test (87%), a medical consultation (85%) and a physical exam (80%) in order to receive their first diagnosis.

**Figure 7. Tests used for the first diagnosis of COPD (%)**



More than half of COPD patients also did a measurement of the lung volume, except in Finland, where this test is less used and is substituted by spirometry with relief spray (64%) and the use of peak flow tests (36%). However, the international guidelines do not recommend the peak flow test as the only diagnostic test because of its weak specificity to COPD.

Healthcare professionals also tend to require X-rays to diagnose COPD (46%), a practice interpreted by local patient organisations that are members of EFA as a way to discard other respiratory diseases (Figure 7). In light of the high percentage of misdiagnosis (16% of all respondents) in which half of the cases are performed by a specialist, diagnostic test performance and interpretation must be prioritised for both research and education.

## ACCESS TO COPD CARE

COPD is a serious disease and its consequences go beyond the lungs. Difficult breathing is permanent and progressive. Shortness of breath whilst doing daily routines such as having a shower, climbing the stairs, or exercising can isolate patients at home, especially if they do not have access to multidisciplinary support and feel that they cannot do anything other than slow down.

The lack of oxygen that defines COPD impacts all bodily organs dramatically. However, COPD-related mortality is underestimated because often comorbidities, such as cardiovascular diseases and lung cancer, but also respiratory failure, are considered the patients' final cause of death.<sup>21</sup> COPD is also linked to diabetes and obesity, further complicating life and care.

Given that COPD is a progressive but relatively slow disease, **patients need the right care to continue productive and meaningful lives**. Crucially, it is important to prevent disability and dropping out of working life prematurely. Access to preventative therapies such as smoking-cessation programmes, pulmonary rehabilitation and help in continuing or start exercising are fundamental to limit and slow down COPD progression. Treatments to prevent respiratory infections and to tackle chronic inflammation serve to stabilise the lungs and allow people to enjoy their lives and remain in the workforce.

### **COPD patients have easy access to their doctors**

People with COPD report that they are primarily assisted by pulmonologists and general practitioners in the management of their disease. Other healthcare professionals are rarely involved.

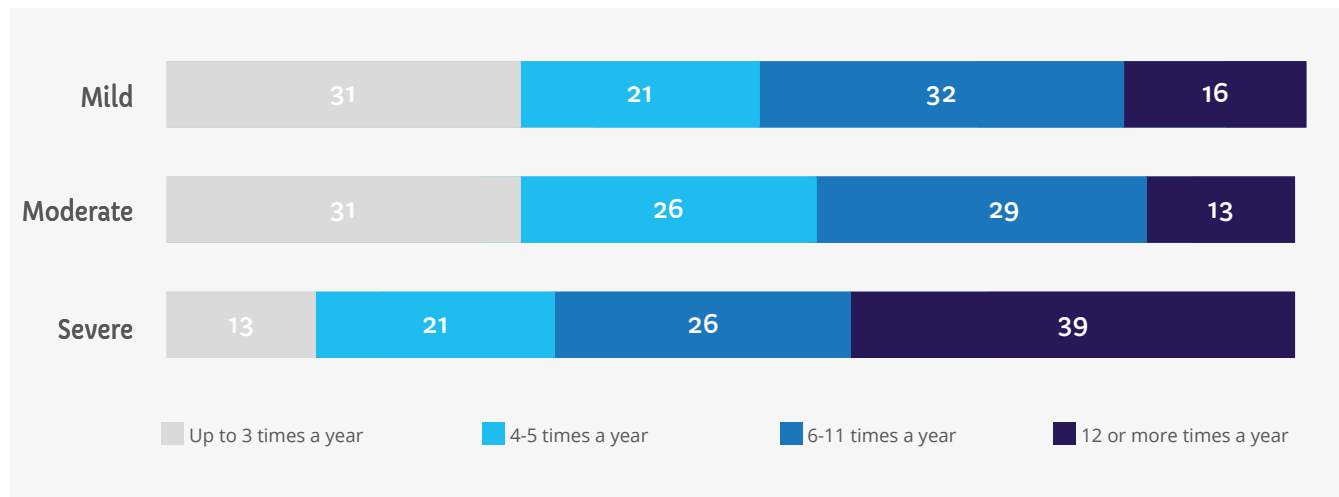
Pulmonologists are the first-line of care for COPD, especially for severe COPD (81% on average and 88% among patients with severe COPD), followed by general physicians (79%).

Surprisingly, nurses seem to be rarely involved in the care of the COPD patients in our survey, despite some countries giving them a very important role. In Finland, for example, nurses are consulted before referring a patient to a general practitioner or a specialist.

However, 15% of patients do not have specialists involved in their COPD care. Patients who do not consult a pulmonologist do not see the need to visit a specialist (41%), or it was never discussed with or suggested by the general practitioner (29%). Some patients (8%) find specialists to be too expensive.

Half of patients (52%) see their doctor more than six times per year, and one in four patients visit the doctor at least once a month (Figure 8). This finding is similar in asthma. The frequency of visiting healthcare professionals significantly increases with the disease severity: one in three patients with severe COPD consult their doctor at least once every month. Similar to the findings for asthma, it seems that COPD is very much managed and followed up at the clinic.

**Figure 8. Frequency of COPD patient visits to HC professionals (%)**



Overall, COPD patients visit their general practitioners the most (55% of patients visit their GP at least four times a year) and go to the pulmonologists twice a year (71% of patients).

COPD patients travel 21 km on average to meet their main specialist. This access overall is good, especially taking into account that the average distance to a specialist for a patient living in a rural area is increased by only 8 km.

The average duration of a consultation with a healthcare professional is 24 minutes, and over 30 minutes for one in three patients. The duration can differ significantly depending on the type of healthcare professional the patient is visiting. According to the information provided by EFA member associations in the survey countries, consultations with general practitioners usually last 10 to 15 minutes.

### **COPD severity does not change the types of diagnostic tests used for follow-up**

When they visit a physician for a routine check-up, patients are mostly going through consultations (79%), physical exams (77%), and spirometry tests (70%), while other tests are only proposed to one in three patients. One explanation is that some testing measures that are frequently used during the diagnosis phase are not used for follow-up.

The severity of COPD does not impact the number of device-based testing used for patients. For example, patients with severe COPD report doing less spirometry (65%) than those with moderate disease (75%), but they go more often through physical exams compared to the rest of patients.

### **The most efficient COPD therapies remain underutilised**

Looking at the therapies used to tackle COPD, **the results of our study confirm that smoking cessation plays a key role in treating COPD and preventing it from progressing.** In the words of the European Medicines Agency (EMA), smoking cessation is the sole treatment that appears to best modify the rate of decline in lung function and to improve overall survival.<sup>22</sup> However, it is striking that only 53% of patients in all countries surveyed utilise smoking cessation treatment.








In-line with international COPD guidelines<sup>23</sup>, common pharmacological treatments such as emergency relief spray (SABA) and reliever (LABA) are the most used treatment options. Only one in three patients combine inhalers with steroids (LAMA) as well as inhaled steroids.

Unfortunately, only 13% of COPD patients benefit from pulmonary rehabilitation programmes. Pulmonary rehabilitation is proven to be the most effective therapeutic strategy to improve shortness of breath, health status and exercise tolerance.<sup>24</sup> It is worrisome that only one patient in ten has access to it. Pulmonary rehabilitation should especially be recommended to recover lung capacity after exacerbations or respiratory infections, which can lead to a permanent worsening of COPD.

One explanation for this restricted access to therapy is that respiratory physiotherapists are often non-specialised.<sup>25</sup> However, the good news is that in many European countries there is an increased number of healthcare professionals specialising in respiratory physiotherapy and rehabilitation, as this is encouraged at the European level.<sup>26</sup> So far this has not improved access.

In general, the more severe the COPD is, the more treatments patients use. This is clearly the case with medical oxygen therapy, used by almost half of patients with severe COPD, but only by 7% of mild and 9% of moderate cases. COPD severity also increases the use of LAMA-Corticosteroids, used by more than half of the patients with severe COPD (54%), compared to all COPD patients (36%) (Table D).

**Table C. Treatments currently used by patients for their COPD (%)**

	Average							
Smoking cessation	53	51	45	56	49	46	65	55
Short-acting bronchodilators/SABA/emergency relief spray	64	78	49	75	55	77	71	42
Long-acting bronchodilators/LABA reliever	53	31	45	69	60	48	75	45
Inhaled steroids/cortisone (controller and preventer)	33	24	40	38	27	43	35	25
Combination inhalers with steroids/LAMA corticosteroids	36	44	29	38	42	25	24	51
Combination inhalers without steroids/LAMA/LABA	14	13	11	11	13	11	31	11
Triple therapy LAMA, LABA and cortisone	8	11	9	9	7	2	13	5
Oral steroids/oral corticosteroids/Cortisone (pills)	16	11	16	16	15	9	25	18
Phosphodiesterase -4 inhibitors/PDE4-inhibitors	8	5	5	9	9	4	11	13
Theophylline/Theophyllins	12	11	5	11	18	9	15	18
Antibiotics	15	9	5	11	20	16	42	4
Oxygen therapy	21	5	24	25	31	13	27	24
Pulmonary rehabilitation programme	13	0	2	18	20	13	24	16
Other	3	0	2	2	0	18	0	2
None	1	4	0	2	0	0	2	2

**Table D. Treatments currently used by patients for their COPD (%)**

	Average	Mild	Moderate	Severe
Short-acting bronchodilators/ SABA/ emergency relief spray	64	56	60	74
Long-acting bronchodilators/LABA reliver	53	43	52	63
Smoking cessation	53	63	51	46
Combination inhalers with steroids/ LAMA corticosteroids	36	18	33	54
Inhaled steroids/cortisone (controller and preventer)	33	25	27	46
Oxygen therapy	21	7	9	45
Oral steroids/oral corticosteroids/ Cortisone (pills)	16	7	11	28
Antibiotics	15	10	13	21
Combination inhalers without steroids/ LAMA/LABA	14	10	17	15
Pulmonary rehabilitation programme	13	9	11	18
Theophylline/Theophyllins	12	14	11	13
Triple therapy LAMA, LABA and cortisone	8	2	7	14
Phosphodiesterase -4 inhibitors/ PDE4-inhibitors	8	9	3	12
Other	3	3	4	3
None	1	4	1	0

### Co-morbidities further worsen the health of COPD patients

People with COPD live frequently with co-morbidities, especially cardiovascular diseases (39%), osteoporosis (21%), allergy to pollen (19%) and obesity (16%) -- diseases that are often intimately linked to COPD.

A significant number of patients (28%) believe that comorbidities directly influence their COPD through worsening of breathing (24%), interactions between treatments (21%) and through a general impact on their health condition (19%).

In addition to treatment, therapies and follow-up by healthcare professionals, the management of COPD includes laboratory tests, medical aids like measuring devices, and seasonal vaccination. Vaccination against influenza (the flu) is necessary for COPD patients because it reduces serious illness and death. Just over half (53%) of patients report being vaccinated against flu regularly, which is far too low. In addition, only 37% of patients receive pneumococcus vaccination, which reduces the incidence of pneumonia (which can be caused by the flu), a condition that is devastating for anyone, but especially serious for people with a chronic respiratory disease like COPD.

### COPD patients end up in the emergency room far too often

Despite treatment and frequent follow-up consultations, one in three COPD patients in our survey ended up in the emergency room within the last 12 months. What is worse, this situation dramatically increased with severity: over half of patients with severe COPD (56%) rely on emergency services at least once a year (Figure 9).

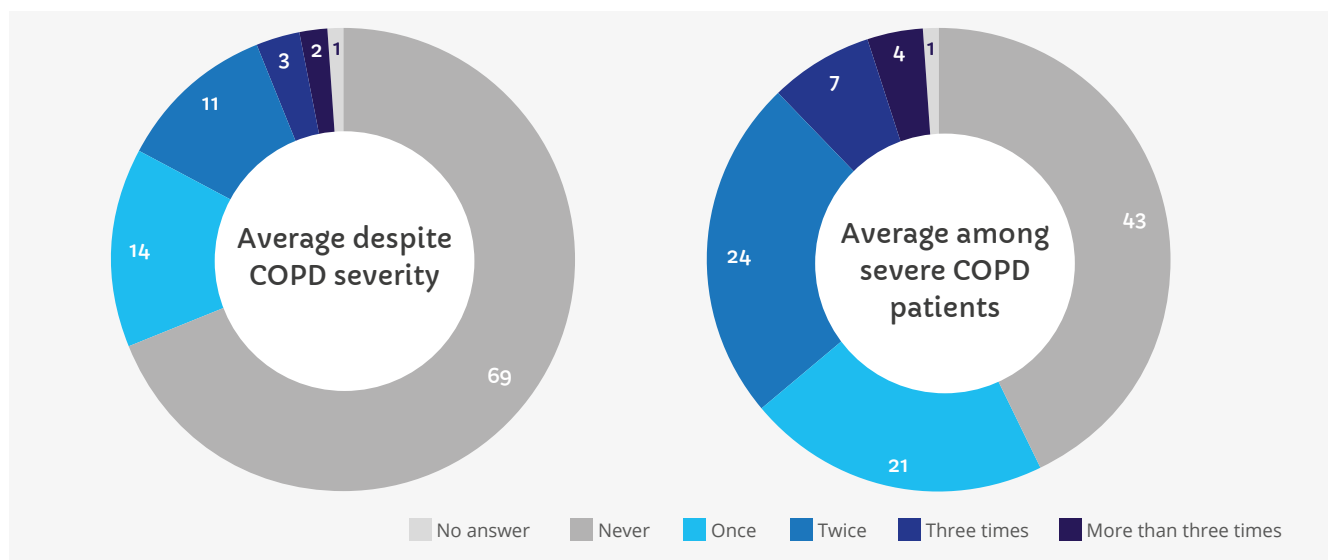
This completely collides with the European Respiratory Society/American Thoracic Society guidelines that recommend home-based management programmes, also known as "hospital-at-home", as an alternative to hospitalisation in patients presenting to the emergency room with COPD exacerbation.<sup>27</sup> The programme



involves nurses and other healthcare professionals such as physicians, social workers and physical therapists. What is more, **regular hospitalisation is not an appropriate management strategy for COPD**, in addition to being costly and stressful.

It is an alert for healthcare professionals and health systems that something in the access to care for COPD patients is not working effectively to properly manage the disease.

**Figure 9. Frequency of being in the emergency room during the last 12 months for COPD patients (%)**



### Out-of-pocket payments for services are common

Patients report paying for services such as prescriptions (65% fully or partial payment), antibiotics (60%), medical aids (59%) and transportation (53%). In most cases, these are out-of-pocket co-payments that are partially reimbursed by health insurance. Luckily, on average patients have to pay fully for only 7% of the services. This includes transportation (15%), flu vaccination (14%), pneumococcus vaccination (13%) and medical aids (12%). However, if added all up, including cost for co-morbidities, this can be difficult to bear given modest financial means.

### COPD patients have many concerns over efficacy and side-effects

Overall, and despite worrying data about overuse of the emergency room, people with COPD are quite satisfied with their access to doctors and specialists, treatments and services. A majority (60%) also believe that therapies and treatments for COPD have considerably improved in the past years. However, more than half of COPD patients (55%) believe that COPD does not get enough attention compared to other diseases.

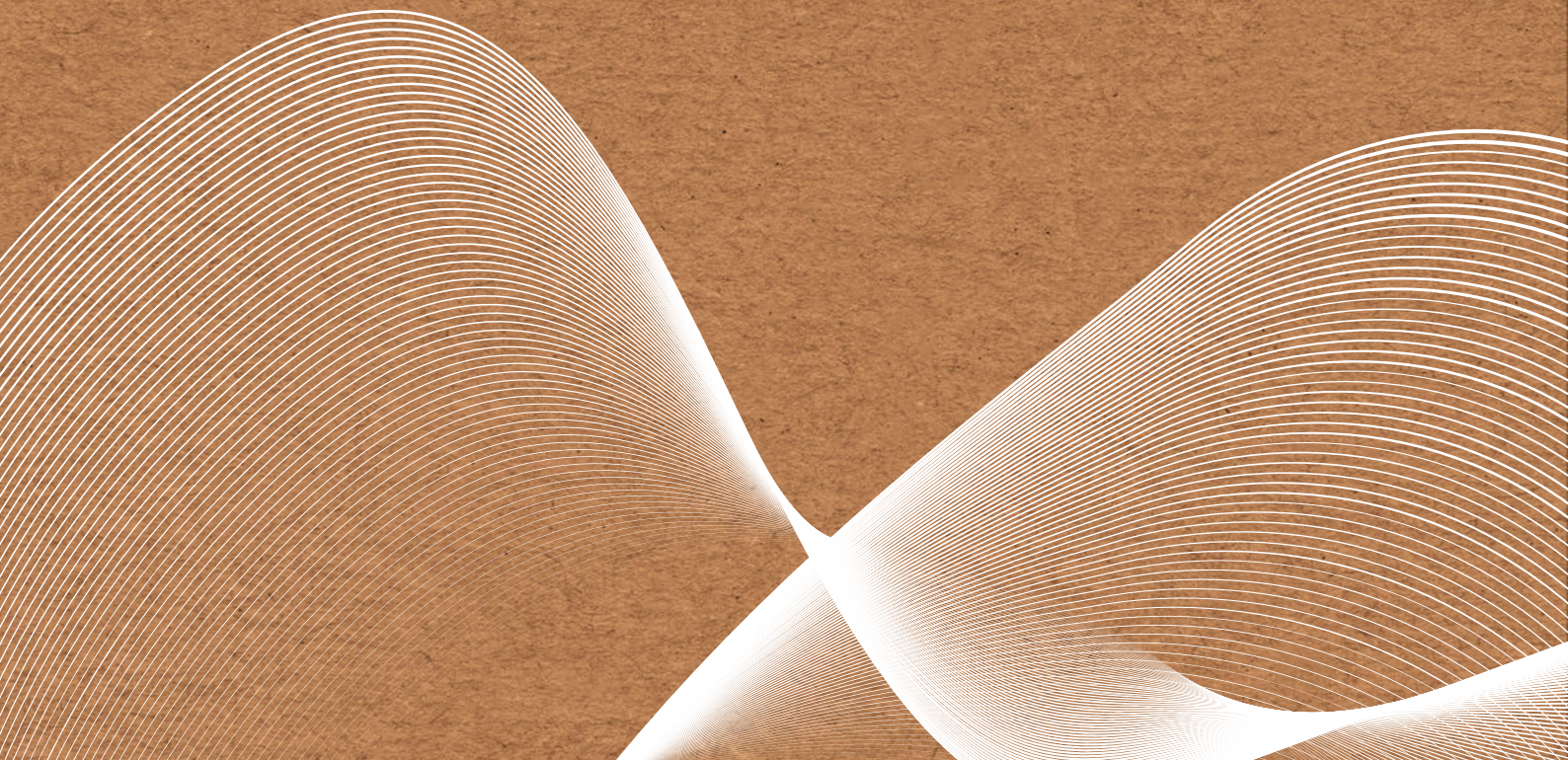
Coupled with the frequent emergency room visits, patients seem to accept their situation regarding care and management.

Similar to the asthma patients in this survey, almost half of COPD patients are concerned about the effectiveness of their treatment and the side-effects of cortisone (49%). Side-effects are also of concern for the European Union as stated in a 2016 EMA review of the risk of pneumonia for COPD patients under inhaled corticosteroid; however, EMA concluded that the medicine's benefits continue to outweigh the risks.<sup>28</sup>

COPD patients hope for further research on more efficient and faster treatment options. There is a clear call to improve care and treatment to relieve the burden of COPD.



# PREVENTION



## ACCESS TO PREVENTION OF ASTHMA AND COPD

Asthma and COPD patients need to include healthy life habits in their lifestyle, like being alert to air -quality both in outdoor and indoor environments, quitting smoking, eating nutritious, healthy food and regular exercise. The urgency of the need for a healthy lifestyle also depends on severity of the disease.

Exercise, a healthy diet and a supportive way of thinking can significantly help ease asthma and COPD symptoms and improve quality of life. For patients living with a severe respiratory condition, taking good care becomes fundamental.

### Patients are conscious of the risk factors affecting their asthma and COPD

People living with asthma and COPD are very vulnerable to polluted air of all sorts as they experience difficulty breathing right after exposure, and worse, can have an exacerbation of their disease. Asthma and COPD patients report that they are aware of what triggers their health condition, especially when it comes about individual risk factors like stress or obesity, and outdoor and indoor pollutants. However, only 34% are satisfied or highly satisfied with the national measures to tackle these risk factors, and two in three asthma and COPD patients think that authorities are doing too little to protect them from polluted air.

Overall, 23% of patients are dissatisfied with government efforts to protect against risk factors. However, in Finland, almost half of the patients are dissatisfied with the government's efforts, whereas in Poland and Spain one in three patients are dissatisfied.

“

*There should be more done against pollution by industry and traffic.*

Germany

”

“

*The public authorities could do more to control air pollution.*

France

”

“

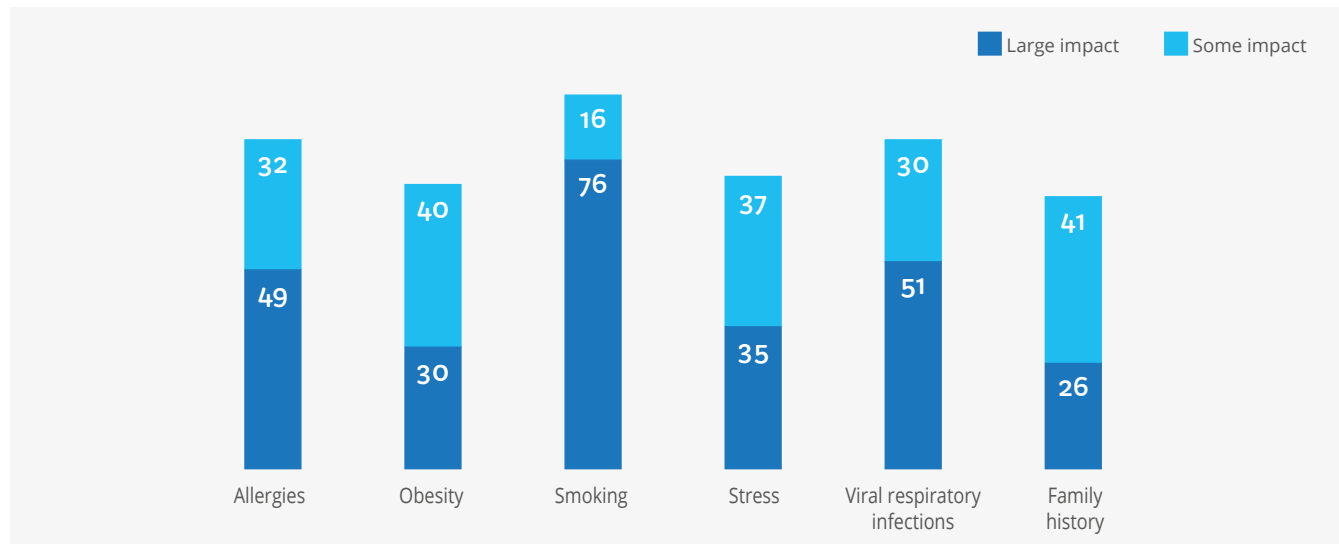
*There should be more specific smoking zones, even outside. There should be bans on smoking in public places.*

Germany

”

Up to nine in ten patients consider smoking as the factor that impacts the most their asthma and COPD (Figure 10). **Alarmingly, 51% of asthma patients and 76% COPD patients stated that their parents smoked.**

**Figure 10. Patients' perception of impact of health-related factors on asthma and COPD (%)**



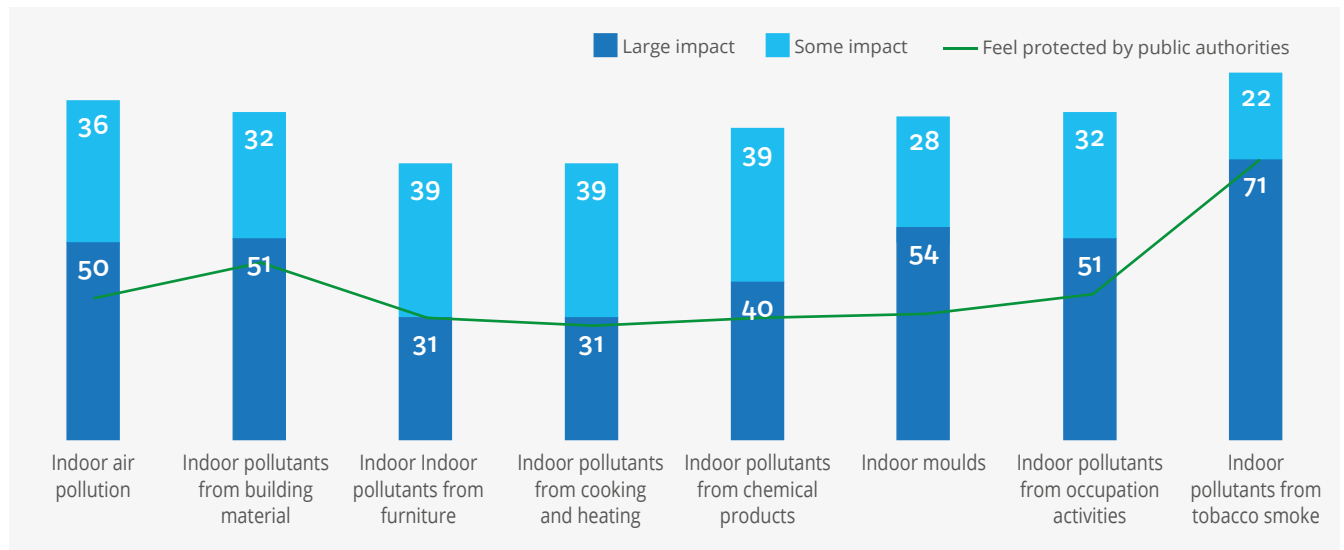
The awareness of viral infections as risk factor is high because 81% of the patients see it as highly influential in harming their health condition (Figure 10), no doubt mainly from personal experience. In fact, 51% of asthma patients and 35% of the COPD patients report having suffered from many respiratory infections during childhood.

Given that allergies are the most common comorbidity for asthma patients in our survey, nine in ten patients appropriately perceive allergies as a risk factor impacting their disease. In general, 81% of all patients feel that allergies are a relevant individual risk factor for their asthma and COPD, as well as stress, obesity and family history (67%-72%) (Figure 10). Looking at two common co-morbidities, allergy and obesity, and patients' perception of risk and perception of protection, 70-80% of patients think that allergies and obesity have an impact on asthma and COPD. However, eight in ten patients do not feel protected by the public authorities against these risk factors (Figure10).

## Tobacco smoke indoors continues harming patients

Nearly nine in ten patients with asthma or COPD believe that indoor air pollution impacts their respiratory health. However, more than one in two patients think that authorities are not doing enough to protect them against unhealthy air indoors.

**Figure 11. Perception of asthma and COPD patients: indoor pollutants vs. protection by public authorities (%)**



Tobacco smoke is patients' biggest concern. **Nine in ten patients consider tobacco smoke as *the* indoor pollutant that triggers the most asthma and COPD symptoms.** They believe that authorities did a good job in protecting citizens against tobacco smoke in indoor spaces through the the promotion of smoke-free environments, as agreed on Art. 8 of the 2003 Framework Convention on Tobacco Control<sup>29</sup>, and the 2009 European Union Council Recommendations on smoke-free environments.<sup>30</sup>

From a policy perspective, the EU has adopted various other control measures in the form of legislation and guidelines. These include a ban on cross-border tobacco advertising and sponsorship through the Tobacco Advertising Directive of 2003; the EMA guideline on the development of medicinal products for the treatments of smoking (2008); and the flagship Tobacco Products Directive (TPD) of 2014, which lays down rules governing the manufacture, presentation and sale of tobacco and related products, including e-cigarettes, amongst others. Tackling the tobacco epidemic, including indoor smoking, is gaining traction in EU policy discourse. This comes in a period that precedes the application report of TPD, which will be published by the European Commission by 2021, potentially leading to further initiatives in the near future.

However, given that exposure to second-hand smoke indoors is still too high<sup>31</sup>, one in three patients thinks authorities should do more to protect citizens against tobacco smoke indoors. This aligns with the latest Eurobarometer survey that found that one in five Europeans witnessed people smoking inside bars.<sup>32</sup>

“

*Heating - reduce coal combustion and towns and villages - large cities - smoking stacks  
- covered with a pollution jacket.*

Poland

”

## **People with asthma and COPD do not feel protected against indoor air pollution**

Apart from tobacco smoke, four in five patients are aware that indoor pollution caused by moulds, chemical products, occupational activities, building materials, furniture, and cooking and heating systems can have adverse effects to their health.

Direct references to indoor air quality are found in a number of EU policies. For example, in the revised Energy Performance of Buildings Directive<sup>33</sup>, the Commission acknowledged the health dimension of building renovation policies, asking for indoor air quality aspects to be taken into consideration. Furthermore, Construction Products Regulation<sup>34</sup> prescribes that construction work must be designed and built in a way that they will not be a threat to the health and safety of workers, occupants or neighbours, in particular as a result of the emissions of dangerous substances, volatile organic compounds (VOC), greenhouse gases or dangerous particles into indoor or outdoor air. Meanwhile, the recently adopted European Parliament resolution<sup>35</sup> addresses indoor air quality calling upon the Commission to take an all-inclusive approach to air pollution. It proposes the introduction of a compulsory indoor air quality certificate for all new and renovated buildings, based on the EN 16798-1 standard<sup>36</sup> as well as the WHO indoor air quality guidelines.<sup>37</sup>

Nevertheless, it remains a fact that indoor pollutants have a big impact on a patient's condition, with one in two patients not feeling protected by the authorities against indoor pollution. Their perception raises the question on whether the current EU legal framework is sufficient in safeguarding human health.

Moreover, even though the World Health Organization (WHO) has extensively studied and recommended measures to improve indoor air quality<sup>38 39 40</sup>, two in three patients do not feel protected against indoor pollutants exposure caused by furniture, cooking and heating, chemical products and moulds.

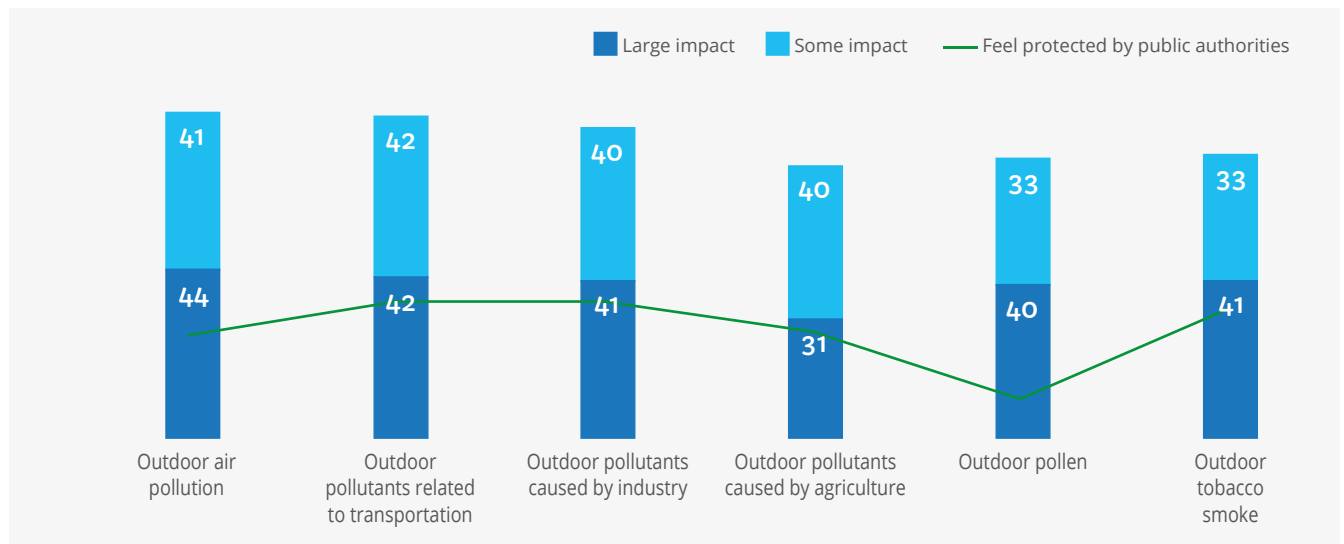
Depending on where they live, asthma and COPD patients perceive differently the risks from indoor air pollution. While in Poland patients consider risk factors have a large impact on their asthma and COPD, patients from the UK assume indoor air pollution has a milder effect, especially for indoor moulds and pollutants stemming from chemical products.

In Germany, asthma and COPD patients feel overall better protected by their government against indoor pollution, while in France and Spain patients feel less supported by their public authorities. In Poland, while they feel more protected against indoor pollutants from heating and cooking system, they feel less protected towards indoor pollution coming from chemical products and moulds. In Finland, patients perceive more impact of indoor moulds and less from furniture, cooking and heating.

## Governments are not protecting patients enough from outdoor air pollution

A strong majority (85%) of patients state that outdoor air pollution has a high impact for asthma and COPD. In addition, 47% of Europeans think air quality has deteriorated in their country in the last 10 years<sup>41</sup> and seven in ten asthma and COPD patients are not satisfied with public authorities attempts to protect them from outdoor pollutants.

**Figure 12. Perception of asthma and COPD patients: outdoor pollutants vs. protection by public authorities (%)**



For example, four in five asthma and COPD patients identify pollution from industry and transport as the main outdoor risk factor for patients' health. Moreover, three in five patients do not feel protected.

Most patients (75%) think that outdoor tobacco smoke and agricultural pollutants have a harmful effect on asthma and COPD. Only one in three patients feels reassured by the governments' efforts to reduce their exposure.

Patients also identify pollen as a relevant risk factor, especially for asthma patients who often live with a respiratory allergy. Unfortunately, four in five asthma and COPD patients feel that authorities do not do enough to protect them from pollen, and this concern is raised as increasing scientific research confirms global warming is extending the growing season and increasing aeroallergenic pollen.<sup>42</sup>

Overall, patients in the United Kingdom see less impact on their health from outdoor factors while Polish patients see a larger impact. Compared to the patients in the rest of the countries, patients in Finland are more confident regarding the protection against outdoor pollution, while in Poland they feel the least protected. This may be explained by the fact that Poland has 33 of the 50 most polluted cities in Europe.<sup>43</sup>

In general, asthma and COPD patients would like the authorities to focus their work on the reduction of pollution. **Concretely, patients are aware of the risk factors and call for more indoor and outdoor environmental protection, less air pollution in cities and the reduction of the level of particulate matter (PM210) resulting from traffic.** At the EU level, the outdoor air quality policy is framed by the two EU Air Quality Directives.<sup>44 45</sup> In a policy environment where health is increasingly regarded by both policymakers and civil society as interlinked with environmental considerations, many people are calling for the EU to engage in a more ambitious air quality strategy by meeting the WHO Air Quality Guidelines standards.<sup>46</sup>

Moreover, as the recent evaluation of the 7<sup>th</sup> Environmental Action Plan<sup>47</sup> demonstrates, there is a considerable mismatch between air quality law and implementation at national level, with several Member States failing to commit to legally binding air quality standards, as ambient air pollution continues to be a major environmental threat to human health.

### Governments could do more on mental health, healthy lifestyles and vaccination

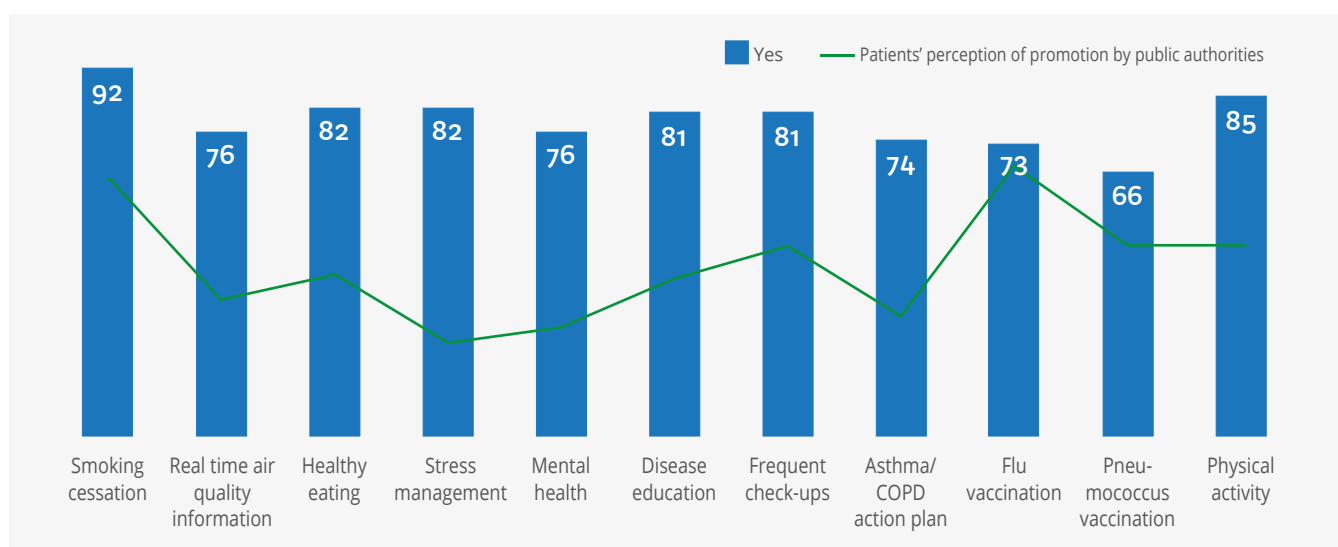
“

*Depressions affect the whole life – in such phases I have difficulties to breathe.*  
Germany

”

An overwhelming majority (92%) of patients report that avoiding active and passive smoking is the top prevention measure that could most improve the situation of asthma and COPD patients. They also identify good mental health and promoting and enabling a healthy lifestyle as contributors to a better situation for patients. This includes physical activity, eating healthy and avoiding stress. Other factors intimately linked to disease management, such as frequent check-ups, disease education or access to real life information on air quality can also enable a better health condition.

**Figure 13. Patients’ perception of factors’ impact on improving the situation of asthma and COPD patients vs. promotion by public authorities (%)**





What is worrisome is that asthma and COPD patients perceive action plans and access to flu and pneumococcus vaccines as least beneficial in improving their situation compared to other factors mentioned.

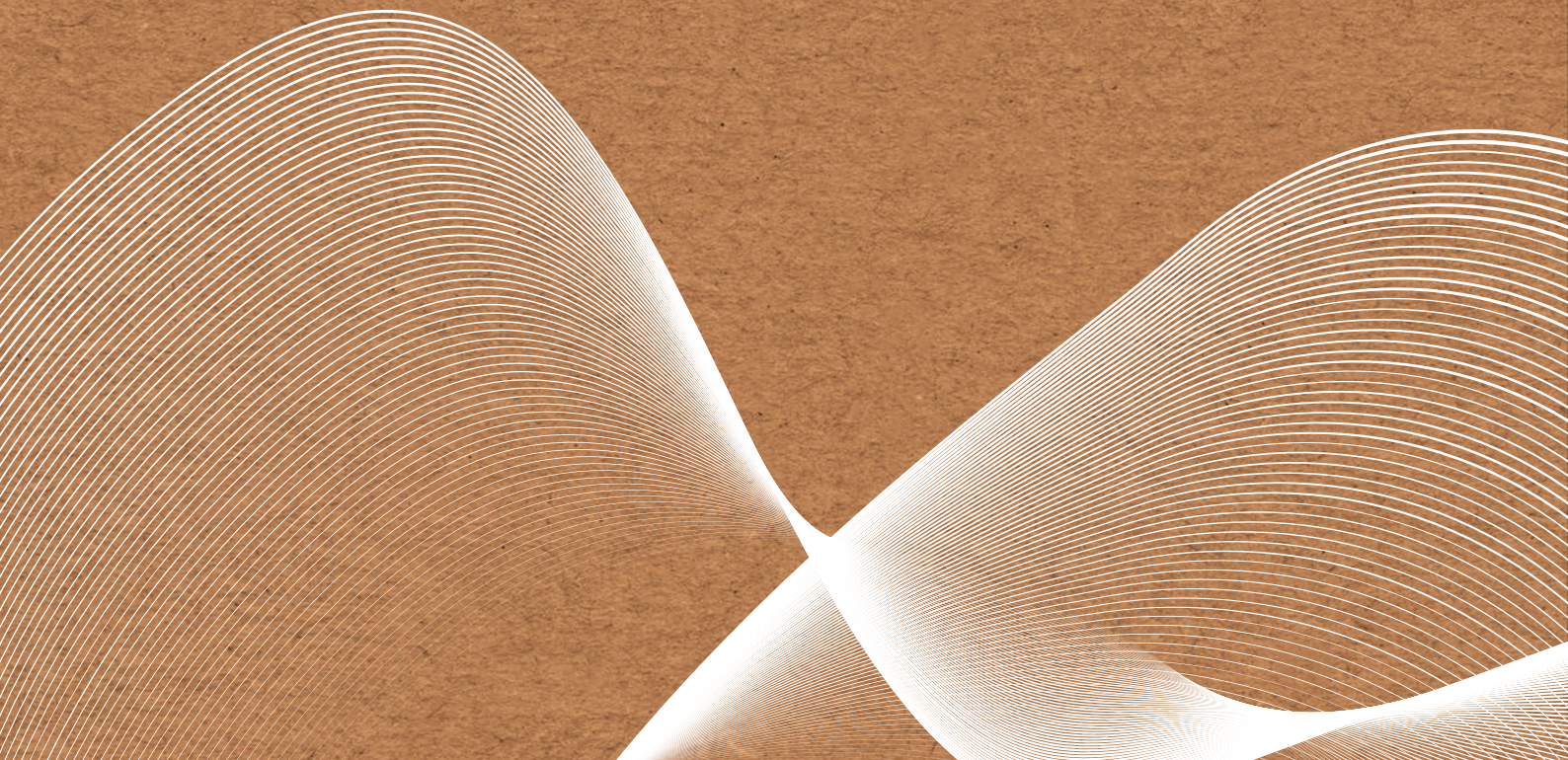
In fact, there is a clear gap between the factors asthma and COPD patients find as improving their situation, and the perceived support for these factors by public authorities. More than one in two patients feel that public authorities do not promote enough factors that are linked to their disease management and prevention or healthy lifestyle. These include such factors as frequent check-ups, disease education, access to real time air quality information, physical activity, healthy eating and pneumococcus vaccination.

Most patients (three in four) assess that disease action plans, mental health and stress prevention are not promoted at all by public authorities, a finding which is of concern when coupled with frequent emergency room visits, and that may deserve further policy consideration. Flu vaccinations and tobacco smoke avoidance are more promoted by authorities in comparison to other factors, but most patients feel these actions are still not enough. Coupled with declining confidence in vaccination in several EU countries<sup>48</sup>, this observation has driven immunization high in the EU policy agenda, with multiple actions at the EU level, including a Global Vaccination Summit co-organised by the Commission and WHO in September 2019. Furthermore, on the basis of the Council recommendations of 2018<sup>49</sup>, EU initiatives will focus on actions that promote vaccine coverage, the fight against misinformation and the launch of a shared vaccination card.

In Germany and Poland, patients perceive their governments as more active in health promotion than in other countries. In Italy, patients find authorities encourage more asthma and COPD actions plans whereas in France, the flu vaccination and real-time information to air quality seem to be less promoted.



# EMPOWERMENT



## ASTHMA AND COPD PATIENTS ARE NOT SUFFICIENTLY EMPOWERED

The European Patient Forum (EPF) defines Patient Empowerment as a process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important. Aspects of empowerment include self-efficacy, self-awareness, confidence, coping skills and health literacy.<sup>50</sup>

“

*I didn't know Disease Management Plans existed.*  
Spain

”

Therefore, in addition to patients being able to access appropriate and timely diagnosis, care and treatment, **it is essential that patients have equal access to the tools and means that have the potential to strengthen the way they cope and live with asthma and COPD.**

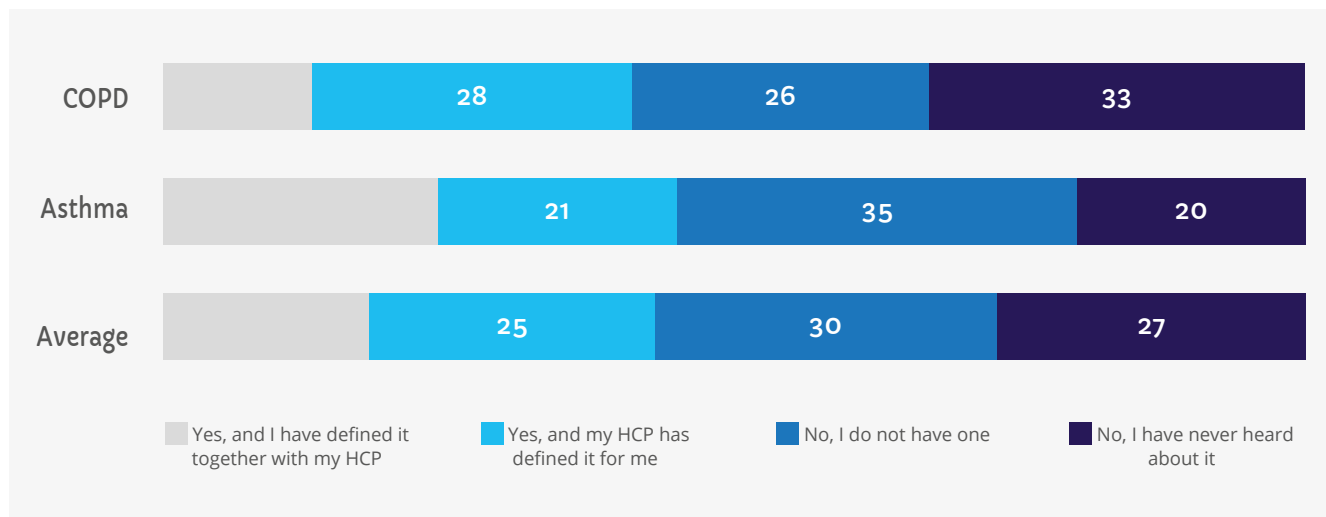
In our survey, we investigate some aspects that we believe essential to actually empower patients. The results are homogenous for both diseases, with a slightly lower involvement in the management of their health from patients with COPD, which may be for many reasons, such as the progressive nature of COPD to older age.

### **Patients are not sufficiently involved in their written action plan**

Self-management is not just a buzzword used about chronic diseases. Patients actually live with their disease 24/7 and their healthcare professional does not live with them. There is also extensive evidence proving that actions supporting self-management among asthma and COPD patients reduces exacerbations and hospital admissions and improves patient Quality of Life (QoL).<sup>51 52</sup> **It is disconcerting that one in three asthma and COPD patients do not feel involved in decisions towards their therapy.**

Asthma and COPD patients are not presented with the personalised tools to be able to self-manage their disease. Less than half of respondents have a written management plan and, even worse, many patients with COPD (33%) and asthma (20%) indicate that they have “never heard about” written management plans. Many patients do not know they have a role in their treatment and the potential benefits to their QoL. However, patient information and training for proactive self-management is a key factor to prevent exacerbations. If you are able to recognise the first signs of an exacerbation, then you can proactively increase the medications according to the individual self-management plan and/or immediately contact your healthcare professional. In fact, asthma and COPD patients who reported that they have a written management plan also pointed out that the plan was more often defined by the doctor rather than agreed together with them. Patient input and perspective seems much reduced, although patients with asthma (24%) are more likely to define their management plan with their healthcare professional (Figure 14).

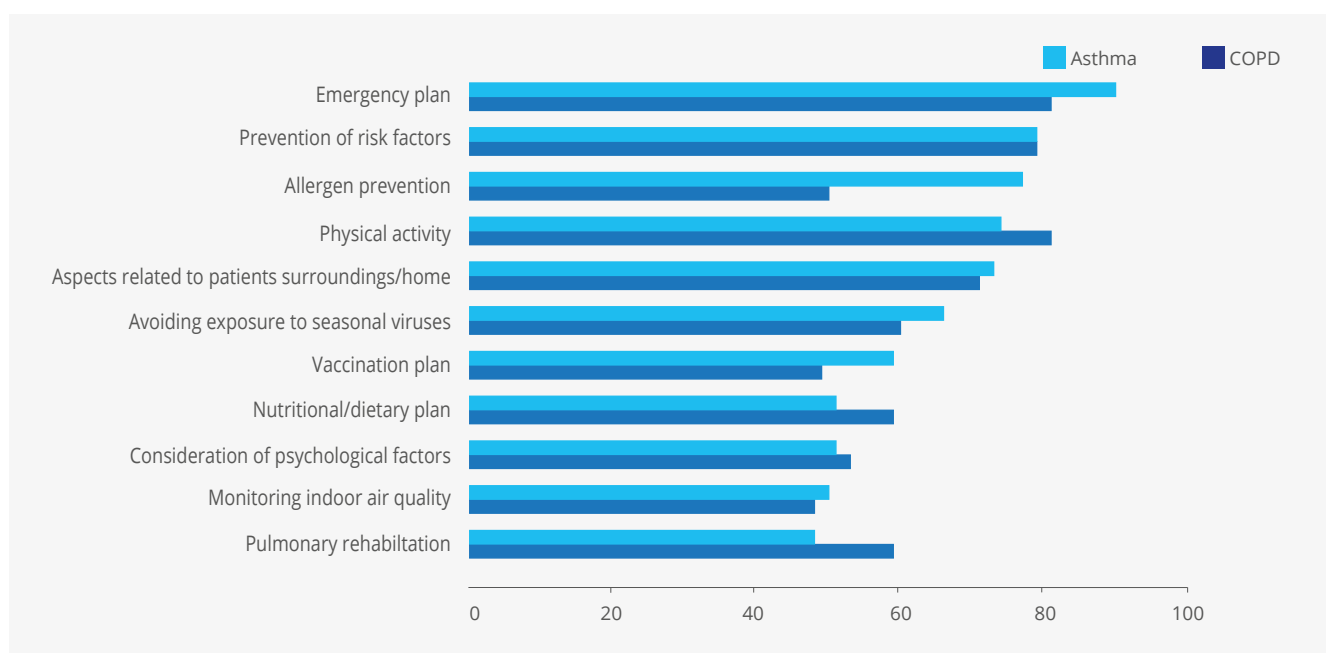
**Figure 14. Asthma and COPD patients with a written management plan (%)**



The limited involvement of patients in their management plan is striking for the patient community. Written management plans for both asthma and COPD patients include crucial information such as advice on how to react to asthma or COPD exacerbations and emergencies, how to prevent risk factors and how to integrate physical activities (Figure 15).

For those patients who have a written management plan, it is monitored electronically for half of those with asthma and for 43% of those with COPD. The transformation towards digitalised health care has the potential to empower citizens to not only to control their health information, but also to engage in the management of their diseases and, crucially, reduce the worry and the need for face-to-face consultations each time.

**Figure 15. Aspects considered in the written management plan of asthma and COPD patients (%)**



## Patients do not have access to asthma and COPD Disease Management Programmes

Apart from individual written management plans that are developed by or agreed with the healthcare professionals, some countries have established Disease Management Programmes (DMPs): structured plans that aim to help people better manage their chronic disease and to maintain and improve quality of life and concern all patients with a specific disease or chronic diseases in general and involve healthcare professionals in a structured way of dealing with patients and care.<sup>53</sup>

DMPs are tools often funded by health insurances and offered to patients in cooperation with doctors. They can also be national or local programmes including continuous education for patients and healthcare professionals. Patients enrolled in these DMPs are often guided towards regular follow up and medical examinations, as well as to trainings and educational courses for patients. DMPs also promote the collaboration between specialists and institutions that deliver care to patients, such as hospitals and rehabilitation centres. **The involvement of asthma and COPD patients in DMPs is currently very low for both asthma and COPD (18%), with fewer than two in ten patients involved.** This is first and foremost probably because they simply do not exist in some of the countries. However, even in countries like Germany, where DMPs for asthma and COPD have existed since 2002, most patients report that they are not involved (29%) or have never heard about DMPs (35%).

## Patients are not trained to deal with their disease as often as they should

Adherence to treatment is one of the first essential aspects to gaining control over a disease and to feeling empowered.<sup>54</sup> Nonadherence to treatment can result in increased mortality, morbidity and higher healthcare costs. Unfortunately, adherence rates to asthma and COPD treatment are around or below 50% in both diseases.<sup>55 56</sup>

**Inhaling correctly is one of the main barriers behind poor adherence in asthma and COPD.** For example, poor inhalation technique leads to poor asthma control, increased risk of exacerbations and adverse effects.<sup>57</sup> Most COPD and asthma patients, eight in ten, do not know how to use their inhaler correctly – most of them are not even aware that they are using it incorrectly – and many healthcare professionals are unable to demonstrate correctly how it should be used.<sup>58</sup>

The good news is that training on how to inhale is provided to the vast majority of the asthma and COPD patients - only 6% of patients report never having received this training. The bad news is that one out of three patients received training or advice on how to inhale only once, and this was probably right after the diagnosis.

People living with a chronic disease such as asthma or COPD should have check-ups on inhalation technique and training where necessary. Although training in person with a healthcare professional cannot be completely replaced, nowadays there are many resources online and video tutorials on how to inhale, especially made by patient organisations.

In stark contrast to the high non-adherence to treatment, three in four asthma and COPD patients (75%) feel sufficiently trained on how to manage their disease. They report that people around the patient, like partners or caregivers, are rarely trained on how to support a person with asthma or COPD (only 22% of them).

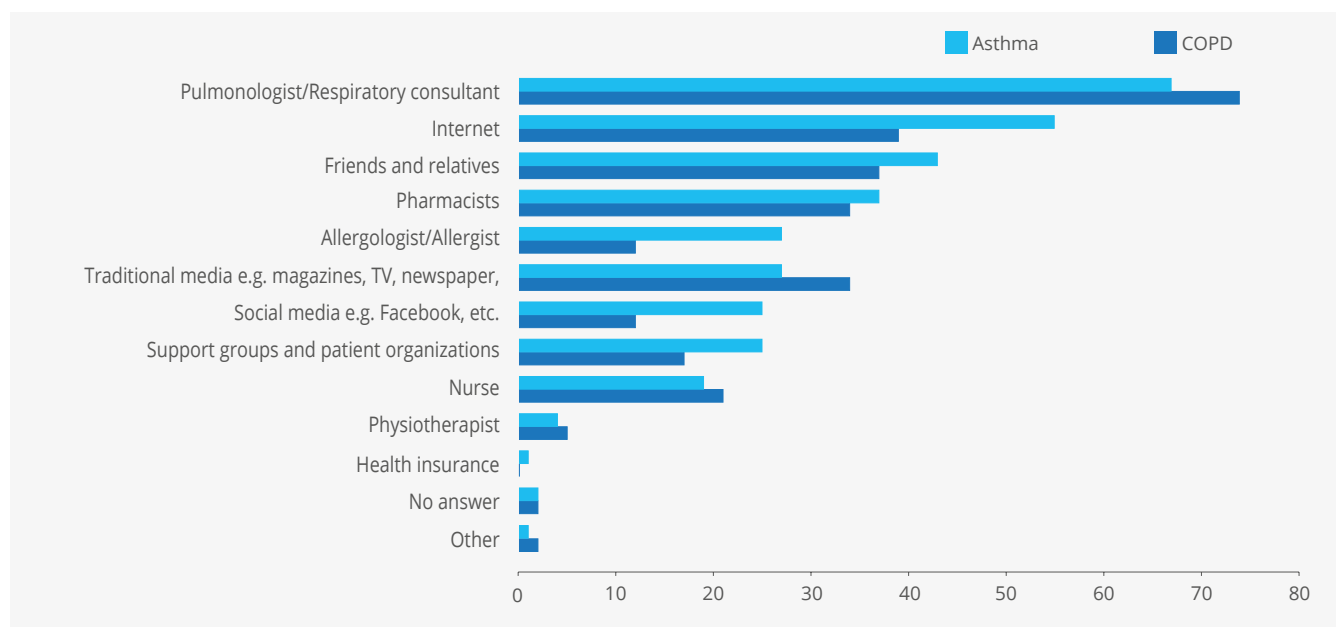
## Patients feel informed but don't have sufficient access to support

A majority (70%) of asthma and COPD patients report that specialist doctors and general practitioners are their main source of information. This suggests that patients trust their doctor. However, this finding might be influenced by the survey recruitment methodology (see Introduction).

It is no surprise that the majority of asthma patients (55%) and almost half of COPD patients (39%) use the internet as a source of information, second to their healthcare professionals. Patients also often rely on friends and relatives (40%), pharmacists (35%) and traditional media (31%) for information about asthma and COPD.

Only one in five patients report patient organisations as a regular source of information about their disease (Figure 16). This lack of information can be attributed to the fact that one in three patients report that they have access to patient organisations or other support groups. This means that patient organisations that provide patient centred information are an underused resource.

**Figure 16. Sources of information used by asthma and COPD patients (%)**

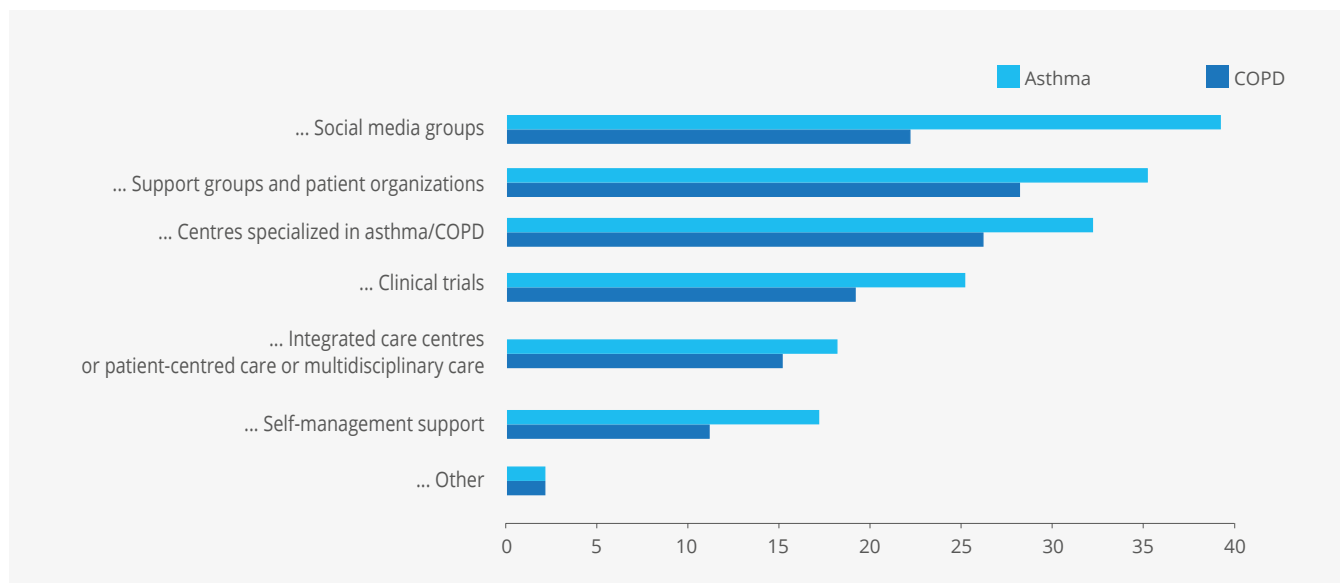


In general, 81% of asthma and COPD patients feel well-informed about their condition and 70% are aware of the long-term consequences of exacerbations. This is good news, but could be improved, especially when coupled with proper empowerment and care.

**It is worrisome that two in three asthma and COPD patients do not feel able to access, or do not seek, external support:** only one in three patients report that they have access to social media groups, specialised centres, clinical trials, integrated/patient-centred/multidisciplinary care or self-management support programmes (Figure 17).

We can assume that most of the patients do not even know about the existence of these resources, which reveals a large potential for initiatives in support of better access and awareness. This is especially true when 70% of asthma patients and 73% of COPD patients feel that "others don't know how difficult it is to live with the disease".

Figure 17. Patients' access to... (%)



Patient involvement in research has potential to deliver better outcomes<sup>59</sup>, but the level of involvement is still below desired standards: only 16% of asthma and COPD patients have previously taken part in medical research or clinical trial. Interestingly, half of all patients would like to participate in further studies and share their data with researchers and healthcare professionals. This has great potential for researchers and can be a source of empowerment for patients.

Last, digital solutions and applications have the potential to enable patients to manage their disease, access their health data and reduce restrictions based on their condition. Electronic health (eHealth) and mobile health (mHealth) have been widely accepted by the EU as factors that facilitate such development. For example, the eHealth Action Plan 2012-2020 identified specific barriers and challenges that prevent the integration of ICT solutions in the national healthcare systems, such as the lack of awareness, fragmented legal frameworks and high upfront costs. By enabling eHealth solutions, the Plan envisioned improving chronic disease management; enhancing patient empowerment; and supporting research and innovation for the benefit of more personalised medicine. Furthermore, in 2014, the Commission published a Green Paper on mHealth, which identified safety, transparency of information, and the reliability of data from mHealth apps as some of the main problems hampering mHealth uptake.



## CONCLUSIONS

In Europe, 30 million children and adults less than 45 years old have asthma<sup>60</sup> and between five and 10% of adults aged over 40 years have COPD.<sup>61</sup> The promotion of preventative measures by public authorities and ensured access to good quality care through public services is of great importance to avoid the increase of asthma and COPD prevalence and improve the Quality of Life of patients (and their families) living with these diseases.

Overall, patient access to general practitioners and specialists is good. However, asthma and COPD patients generally receive a late diagnosis and the treatment options fail to prevent the worsening of patients' conditions, contributing to consequent visits to the hospital, especially for asthma and COPD patients with the severe form, impacting directly their quality of life. Improvements in asthma and COPD management and new therapeutic options are needed to relieve the burden of both diseases.

Our survey shows that diagnostic processes are ineffective. On average, it takes more than three years for asthma and COPD patients to receive a first diagnosis after noticing the first symptoms. Still 16% of asthma and COPD patients initially receive a wrong diagnosis and only receive the right one after four and a half years and a half for asthma and more than five years for COPD.

Throughout the care process, general practitioners and pulmonologists are the healthcare professionals mostly involved in the patients' disease management. Nevertheless, some patients do not involve the specialist mainly because they do not feel the need or because it was not suggested by their general practitioner. In addition, our results reveal that still nowadays nurses have a small role in both asthma and COPD management processes.

Generally, asthma and COPD patients have good access to their main specialist in terms of distance, except for patients living in rural areas where distances can be up to 300km. Additionally, in contrast with several studies, the patients of this survey spend on average 20 minutes with their doctor or nurse in consultation. In fact, good access to care is relevant considering that the majority of asthma and COPD patients visit a healthcare professional in one year up to five and six times, respectively, and more importantly the number of visits increases with disease severity.

Luckily, patients do not need to pay for most of the services they use. COPD patients only pay fully for 7% of the services rendered and asthma patients pay fully or partially for 1/3 of services. Most likely, payment for services occurs primarily for prescriptions and antibiotics. In addition, asthma patients pay for medical devices and COPD patients for medical aids and transportation.

In term of prevention, and this is a positive note, asthma and COPD patients are aware of what triggers their health condition, especially when it comes to individual risk factors and air pollutants. Nevertheless, patients think that public authorities are doing too little to avoid public exposure to common risk factors. Patients would like authorities to mainly work on measures to improve the situation with pollution in general, especially environmental protection, to reduce the air pollution in cities and reduce the level of particulate matter coming from traffic.



A clear gap exists between the perceived factors that can improve the situation of patients and their promotion by public authorities. Factors linked to disease management or healthy lifestyle are not promoted enough, including frequent check-ups, disease education, access to real time air quality information, physical activity, healthy eating, as well as the pneumococcus vaccination.

Overall, the opportunity of increasing patients' capacity over their disease and life through empowerment processes is low. Patients are not involved enough in decision-making over their treatments. Written management plans are only available for 30% of the patients and only 20% are involved in Disease Management Programs. In contrast, most patients feel well-informed about their disease and sufficiently trained on how to handle it.

Last, over half of patients feel that asthma and COPD are not getting enough attention compared to other chronic diseases and that better diagnostic tools and more efficient therapies are needed. Moreover, despite the key role patients have in research to improve future treatments, their involvement in medical research is fairly low, yet half of the patients are willing to share their clinical data with researchers and healthcare professionals (HCPs).

## RECOMMENDATIONS

The Patient Access Partnership, the PACT has defined measuring access with five A's.<sup>62</sup> The five principles to measure accessible care are whether the care is:

**Available, Adequate, Accessible, Affordable and Appropriate.**

Asthma and COPD patients report that care is available and accessible when it comes to access to healthcare professionals, but it is too often not adequate and appropriate. On affordability, we only investigated out of pocket payments, which are common.

The following recommendations are for those who have a role to play in the diagnosis, care, prevention and empowerment of people with asthma and COPD in Europe. This includes decision-makers on resources, policy and the implementation of that policy: care-providers for asthma and COPD, researchers and of course, patients themselves, who bear the daily burden in managing and living with asthma or COPD.

“

*How to stop the diseases progression?*  
Italy

”



## #SHOWLEADERSHIP ON THE DIAGNOSIS AND ACCESS TO CARE OF ASTHMA

### **For HCP, such as general practitioners (GPs), allergologists and pharmacists, etc.:**

- Education should be championed and improved for the correct recognition of respiratory systems:
  - Education for use and interpretation of diagnosis tests;
  - Specialised centres equipped with the latest diagnosis tests and specialists;
  - Referral to a specialist, or contact with a specialist in an uncertain diagnosis and not go for trial and error path on care;
  - Precision/personalised medicine care approach when needed, and always in case of severe asthma;
  - Doctors should prescribe and follow the right treatment for the right patient, according to international guidelines and shared decision-making. This includes avoiding the overuse of SABA.
- Two-way digital tools should be used for follow-up and adherence to treatment.

### **For healthcare systems:**

- A patient-centred detection and reward chain should be put in place that leads to early correct diagnosis.
- Multidisciplinary care/centres (especially for comorbidities/allergies) and higher involvement of asthma nurses in asthma care (this requires also programmes for specialising nurses).

### **For policy makers and payers:**

- Promotion and placement of structured national and regional plans on chronic disease detection and surveillance, including asthma.
- Upscaling the use of medical devices, including e-m/Health, and placing targeted therapies placing them in asthma care with rationale of achieving good control over asthma for all kinds of asthmas, and reducing the need for reliever medication and burdensome exacerbations.

### **For patients:**

- Access to patient education either personally or using digital tools on asthma, its causes and treatment and living with a chronic disease.
- Understanding and balancing the side-effects and benefits of medicines. For later referral, information on asthma needs to always be available in written form.

### **For researchers:**

- Better diagnostic tests and more funding for research in diagnostics and patient registries on asthma.
- Further research on the root reasons for patients visiting their doctor's clinic frequently and relying on emergency services at least once a year.
- More emphasis on research to develop more efficient and faster therapies with fewer side effects, and the cure for asthma.

## #SHOWLEADERSHIP ON THE DIAGNOSIS AND ACCESS TO CARE OF COPD

“

*If the doctor at the clinic had done suitable tests, asthma might not have developed – there were some symptoms for 3 years, but they were not taken into account.*

Poland

”

### For HCPs:

- Deliver spirometry testing in regular checks for people at risk of developing COPD.
- Increase access to home-based management programmes (also known as “hospital-at-home”).
- National and seasonal vaccination plans and smoking cessation support needs to be included in chronic disease care, including targeted information for doctors and COPD patients to prevent and ease COPD and COPD exacerbations.

### For policy makers and payers:

- Improve access to preventative therapies to limit COPD progression. Pulmonary rehabilitation should especially be recommended to recover lung capacity after exacerbations or respiratory infections.
- Need to promote and put in place structured national and regional plans on chronic disease detection and surveillance, including COPD.

### For patients:

- Access to preventative therapies such as smoking-cessation programmes or pulmonary rehabilitation is fundamental to limit COPD progression.
- Access to treatments to prevent respiratory infections, and to tackle chronic inflammation, stabilise the lungs and allow people to enjoy their lives and to remain in the workforce.

“

*People should try to reduce the impact on the environment. In particular, industrial pollutants must be reduced.*

France

*Forbid smoking in public places.*

Italy

*Guidance for the use of fragrances in public indoor spaces.*

Finland

”

### For researchers:

- Urgent need to develop more effective and curative treatment for COPD to prevent hospitalisations, exacerbations and decrease in lung function.



## #SHOWLEADERSHIP ON PREVENTION

### For HCPs:

- Include mental health issues in chronic disease management.
- Following up on self-management plans with patients.

### For policy makers:

- Tackle indoor and outdoor risk factors, with health in all policies principle: tobacco, building materials, furniture, cooking, heating, moulds, chemicals, pollen, agriculture, industrial and transport emissions and occupational activities.
- Support healthy life and living well and making it part of good self-management.
- Continue to support and dissuade misinformation about vaccination.

### For everyone:

- Introduce measures and support to increase access to frequent check-ups, disease education, access to real-time air quality information, physical activity, healthy eating, and flu and pneumococcus vaccination. Everyone around people with asthma or COPD can moderately to substantially improve patient QoL.



## EMPOWERMENT

“

*Authorities should support patients better and provide more education.*

Italy

“

*Many drugs have serious side effects. Additional research into new drugs is required.*

France

”

”

### For HCPs:

- Involve patients in decision-making and provide and agree with patients on clear asthma and COPD action plans to support self-management, which can be tailored. This plan can be digitally recorded and monitored.
- Provide or refer to continuing, or renewed, education on care techniques, especially training and checking regularly on inhalation techniques to motivate patients to get in contact with local patient organisations or support groups. By doing so, HCPs empower patients to get patient-friendly information, peer support, access to educational tools and materials, patient empowerment opportunities and trainings.

### For policy makers and payers:

- Include empowerment in chronic disease management programmes in a structured way, in collaboration with patients and healthcare professionals.
- Facilitate digital transformation towards digitalised health and care has the potential to empower citizens not only to control their health information, but also to engage them in the management of their diseases.
- Develop regional or national disease-specific management programmes, following best examples already implemented (i.e. Finland), to further patient empowerment.

**For patients:**

- Empowerment to ask for the latest and appropriate diagnostic test if they feel their diagnosis is not correct. This includes the mHealth and internet-based options 'test if you have asthma' and 'test if you have COPD'.

**For researchers**

- HCPs, researchers and patient organisations could do a great service by getting rid of the invisible barrier preventing meaningful patient involvement in all stages of research, from the design of the study, via participation, to the dissemination of research findings.

EFA invites everyone to join forces with patients to ensure that people with asthma and COPD in Europe have available, adequate, accessible, affordable, and appropriate care, and are empowered to take charge of their disease and prevent exacerbations; and furthermore, to prevent asthma and COPD altogether and to support the development of a cure.



**COPD:** Chronic Obstructive Pulmonary Disease

**CT scan:** Computerized Tomography

**DMPs:** Disease Management Programmes

**eHealth:** Electronic Health

**EMA:** European Medicines Agency

**EPF:** European Patient Forum

**FeNO test:** Fractional Exhaled Nitric Oxide test

**FEV1:** Forced Expiratory Volume (the amount of air a person can force out of lungs in one second)

**GINA:** Global Initiative for Asthma

**GOLD:** Global Initiative for Chronic Obstructive Lung Disease

**GPs:** General Practitioners

**HCPs:** Health Care Professionals

**IgE level:** Immunoglobulin E level

**LABA:** Long-acting Beta-adrenoceptor Agonist(s)

**LAMA:** Long-acting Muscarinic Antagonist(s)

**mHealth:** mobile Health

**PACT:** Patient Access Partnership

**QoL:** Quality of Life

**SABA:** Short-acting Beta Agonist(s)

**U BIOPRED:** Unbiased BIOMarkers in PREdiction of respiratory disease outcomes

**VOC:** Volatile Organic Compounds

**WHO:** World Health Organization.



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