



European Federation of
Allergy and Airways Diseases
Patients Associations

A European patient perspective on severe asthma

Fighting for breath



Contents

“On a bad day I feel like I’m drowning and I can’t reach the surface of the water and I am going to burst, yet a tiny, tiny bit of air keeps me alive. It’s very scary - I feel like I’m living with a time bomb and if I have a bad attack I say to myself: Is this the one that will kill me?”



Catherine Tunnicliffe

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EFA would like to dedicate this report to all those people with severe asthma who took part in the project. We would also like to offer a special thanks to Asthma UK – namely Martin Dockrell and Donna Covey - and all the patient organisations who have been involved in lending their support: Association Asthme & Allergies, Deutscher Allergie-und Asthmabund e.V. DAAB, Asociación Asmáticos Madrileños (ASMA) and Astma-och Allergiförbundet. Special recognition also goes to all those who have lost loved ones to asthma, including Leo Campbell and Maria Vico.



“People with asthma merit significant attention from health services. We live with the heartache of social, health and political isolation”



Jesús Baglietto

Executive summary

Millions of Europeans suffer uncontrolled serious asthma symptoms, and thousands die of the disease every year. Severe symptoms such as chest tightness and breathlessness affect around 6 million people in Europe¹, taking their toll at work and at home, reducing the capacity for personal and economic fulfilment, and aggravating a sense of isolation. Exclusion from work, from physical activity and even from public spaces (where the right to smoke is more important than the right to breathe) – each of these slices away at people's well-being, undermining their capacity to take control of their own asthma. A severe attack is a terrifying experience, leading to emergency hospitalisation and even in the case of 12,000 Europeans a year, to death.²

In the majority of patients, severe asthma symptoms should be manageable, although there is still a smaller number of around 1.2 million in Europe for whom current treatment approaches are not enough.⁴

Asthma control in Europe has improved significantly in recent years but still falls well below international treatment goals, and those with severe asthma symptoms expect their symptom control to worsen in the next five years. They have become accustomed to compromising their lives on a daily basis, without expecting – or demanding – any improvement.

Any optimism about future treatment choices is tempered by pessimism about national healthcare systems' capacity to keep pace. Most recognise that their doctor is trying to achieve treatment targets but many feel they are failing to meet them. Greater patient involvement and two-way communication may help to address this and allow patients to feel more in control of their asthma. As it is, lack of empowerment adds to their feelings of isolation and contributes to their pessimism about their future care.

Severe asthma

The hard facts:

- Every hour, at least one person dies of asthma in Western Europe²
- 32 million people have asthma in Europe¹ - 6 million of whom live with severe asthma symptoms, which can include waking at night breathless or coughing, frequent shortness of breath, regular attacks and limitations on daily activity
- Fewer than half feel they are close to achieving international treatment goals
- People with asthma are being widely exposed to second-hand smoke and pollutants which can trigger a serious attack
- More women die of asthma than men
- More adults have severe asthma than children, but significantly more children are admitted to hospital
- The total cost of asthma in Europe is €17.7bn per year, and productivity lost to poor asthma control is estimated at €9.8bn per annum³

The personal experience:

- At least one in five live in fear that the next attack could kill them
- Three in four have disturbed sleep at least once a week due to night-time breathlessness, often leading to exhaustion the next day
- Once a week, one in four have attacks so severe they cannot even call out for help
- One in five feel disadvantaged at work or study
- Almost 70 percent have to restrict their physical activities
- One in three miss going out socially because of the fear of an attack
- The three most common words used by people to describe severe asthma were 'breathlessness', 'suffocation' and 'fear'
- Others expressed how they felt ignored by society, encaged by their asthma and lived with a sense of shame and embarrassment

National differences:

- Sweden has high hospital admission rates in children but one of the lowest rates in adults. They also report one of the lowest mortality rates

- The UK has one of the highest rates of both emergency and mortality rates in adults and children
- Annual treatment reviews are rarely reported in France but commonly reported in Germany
- French respondents seem the most concerned about potential side effects of their medication
- Ninety-nine percent of French respondents rely on reliever medications - an indicator of poor control
- German respondents are more pessimistic than other countries about the possibility of asthma care deteriorating in five years. They also report the highest level of emergency visits
- Spanish respondents are concerned about access to specialist care. Although the majority are failing to reach current treatment goals, they are the most optimistic about improvements in the future
- Swedish respondents are the most likely to feel that they have missed out on career opportunities because of their asthma

Expectations for the future:

- One in three expect their prospects to deteriorate over the next five years
- Fewer than half expect asthma management to improve, although they do expect treatments to get better

What people with asthma want:

- One in three want to see more investment in research for new treatments
- Many want a total ban on smoking in public places, particularly in the UK
- People in Sweden want free prescriptions
- Input into treatment plans, better access to a specialist and new more effective medicines are all considered essential to improving asthma symptoms
- Other priorities include experiencing fewer limitations because of their asthma, fewer night-time attacks, having more energy and being less exposed to environmental pollution and fumes at work

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Introduction

'Asthma, that's something kids get, isn't it? Makes them wheeze a bit but they grow out of it.' The reality of asthma is far from popular misconceptions. Few such common, chronic conditions can be so misunderstood. Asthma affects 32 million people across Europe, mostly adults, and the number has doubled over the last decade. One in six of them live with severe, debilitating symptoms, although treatments to alleviate these are improving. Asthma kills more than 12,000 people a year in Western Europe alone. That's at least one person every hour, yet 90% of these deaths could be prevented. What is going wrong?

Much of the problem can be put down to lack of information and regulatory support at national and European levels. Unfortunately, public health initiatives to tackle asthma are unlikely to be implemented or improved upon as long as the extent of the problem remains hidden and governments fail to adequately monitor the overall impact of care, treatment goals, hospital admission rates and mortality.

EFA, the European Federation of Allergy and Airways Diseases Patients' Associations, commissioned this report to give a voice to the millions of Europeans with severe symptoms, to help them express the true impact of living with the burden of this disease and understand how we can address their concerns and views in an effort to improve things for the future. We also commissioned a review of hospital admission and mortality data to establish how the clinical consequences of asthma compare across Europe. In this way, we hope to dispel some of the misconceptions about asthma, and spur governments and the EU to action.

Our report has uncovered a worrying number of people who are living with uncontrolled, severe asthma symptoms, including breathlessness, sleepless nights and regular wheezing attacks, all of which can have a devastating impact on their quality of life. Under EU legislation, citizens should be able to integrate fully within society and within the workplace, yet our research shows that this is often not the case for people with severe asthma symptoms. They feel stigmatised by a serious and life-threatening condition that is often dismissed as a 'bit of wheezing'. Exposure to pollutants in the workplace and smoking at social occasions can trigger an attack, condemning them to unemployment and social isolation. Worst of all is the continued fear that their next attack could be the one that kills them.

With diverse healthcare systems across Europe, it is no surprise that people's experiences and opinions are equally diverse. The epidemiology shows us that there are not only striking differences in management but also in the way the disease manifests itself from one country to the next. Some countries seem better equipped than others at tackling the situation and involving patients in their treatment, but all need to make more effort to enable people with asthma to take greater control of their own symptom management.

We need to act now in order to protect and empower people with asthma, especially as the number has increased to such a large extent. We want to see partnerships being built between physicians and their patients whilst governments and health authorities need to provide affordable, good quality care, including access to specialist healthcare. They also need to enforce legislation on environmental pollution and make more funds available for research. Most of all, they all need to *listen* to people with asthma.


EFA is dedicated to help its member organisations to improve the lives of people with allergy, asthma and COPD (chronic obstructive pulmonary disease), but we cannot do this alone; we need your help.



Svein-Erik Myrseth
EFA President



Donna Covey
EFA Acting Vice-President



“I would like the air to be cleaner, to make breathing easier, and I would like children with asthma to grow up to have a future without the problem of environmental pollution”



Soledad Alonso Mostaza



Severe asthma symptoms in Europe – the scale of the problem



An estimated 32 million people in Europe are affected by asthma, six million of them with severe symptoms. Of these six million, one in five live in constant fear that the next suffocating attack will be their last. Because of huge differences in the ways that countries collect data on national mortality and hospital admissions, and the lack of data on the impact of interventions such as healthcare and the environment, the effects of this debilitating condition are often hidden or ignored.

The European Federation of Allergy and Airways Diseases Patients Associations (EFA) asked the Lung and Asthma Information Agency at St George's, University of London, to summarise existing epidemiological data about severe asthma to compare the situation across Europe, concentrating on France, Germany, Spain, Sweden and the United Kingdom – all countries with a high prevalence of asthma. We were alarmed by the lack of standardised national data available from government bodies particularly as surveillance data is the bed-rock for any successful healthcare policy programme. Comparative data were largely reviewed from independent research institutions.

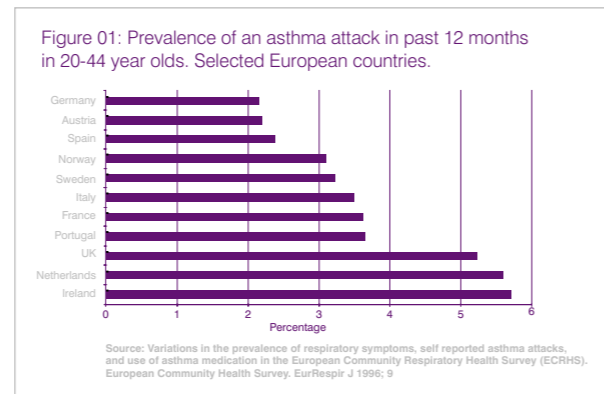
Prevalence of symptoms

The most recent relevant population sample data come from the European Community Respiratory Health Survey (ECRHS), which surveyed adults aged 20-44 years across Europe in the early 1990s, and the International Study of Asthma and Allergies in Childhood (ISAAC), which surveyed representative samples of schoolchildren from most regions of the world, in 1994 and 1995. Both studies asked about more severe symptoms, and the results are shown for those European countries where admission or mortality data were also available.

The ECRHS survey monitored night breathlessness and asthma attack. Prevalence of an asthma attack in the last 12 month was highest in Ireland, the Netherlands and the UK, which all reported rates above 5% - well above the reported prevalence for the other countries. (Figure 1)

We reviewed the prevalence of three different symptoms: frequency/number of wheezing attacks, sleep disturbance and speech-limiting wheeze among children in the ISAAC study. For all three, the UK reported by far the highest rates for all symptoms. In particular, it had more than double the prevalence of frequent wheezing attacks than in France (9.3% vs 4.1%) and most of the other European countries.

In both age-groups, the UK had consistently higher prevalence rates than France, Germany, Spain and Sweden. Other notable results include the relatively high prevalence of 'severe speech-limiting wheeze' reported among German children, and the percentage of adults in Spain who reported breathlessness at night. Overall, adults reported higher prevalence of symptoms compared to children.



Hospital admissions for asthma

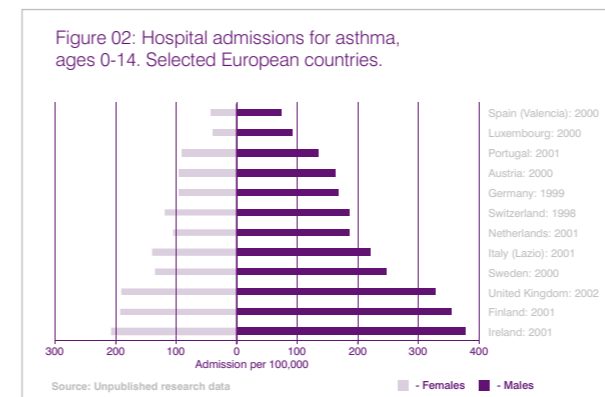
Data on hospital admissions are not routinely published in most countries. However, as part of a separate research project admissions for asthma in certain countries have been obtained through approaching national registries.*

Although according to the prevalence data, adults were more likely to report wheezing and asthma symptoms, hospital admission rates were higher in children.

For example, in Sweden, the admission rate in boys was more than 15 times the rate in men. In all countries studied, boys had higher admission rates than girls, but women had higher admission rates than men. Once again the UK had some of the highest admission rates both in children and adults

In children, the highest admission rate was in Ireland, with the UK only slightly lower at around 330 per 100,000 in boys and 190 per 100,000 in girls, while Valencia in Spain reported the lowest rates (figure 2).

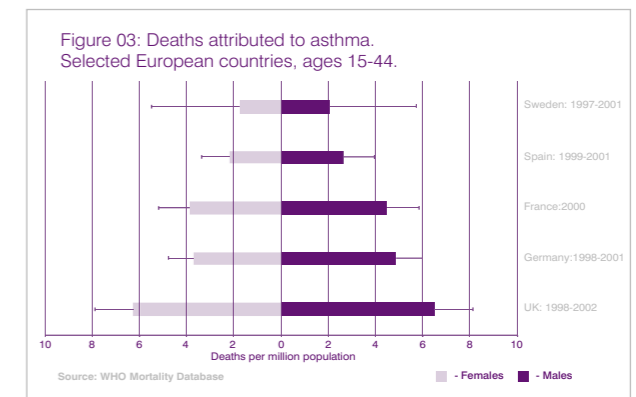
Switzerland and Finland had the highest admission rates in adult males, followed by Ireland, the UK and Austria. Switzerland also had the highest admission rate in adult females, at more than 150 per 100,000, much higher than the rate of about 100 per 100,000 in the UK and Ireland, the next highest figures.



Mortality from asthma

Although statistics on causes of death for countries worldwide are routinely published on the World Health Organization (WHO) website, asthma deaths have only recently been listed separately, rather than being included together with deaths from some other respiratory tract diseases.** As a result accurate information is not available for all European countries. Mortality rates for only the under-45's were looked at, where diagnosis of asthma is most reliable. However, we know the rates are even higher for older people but these data are not so easily available.

Asthma deaths in children are relatively rare, and occur mostly among boys, with only a few countries (France, Germany, Spain and the UK) reporting deaths in girls. Death among adults aged 15-44 are more common and all countries reported some asthma mortality in this age-group, with broadly similar rates for both sexes - The Netherlands and Sweden had the lowest rates in this age group. The UK had high mortality rates in both children and adults.



Country variance

There appear to be some notable differences between countries. For example, the UK reported consistently higher prevalence rates of severe wheezing and asthma symptoms in both children and adults, high hospital admission rates and high asthma mortality rates compared with the other four countries. Conversely, Sweden had higher hospital admission rates in children than Germany and Spain, though similar rates in adults, but its mortality rates were the lowest of the five countries.

In order to affect and improve healthcare policy in asthma, national governments should make greater efforts to collate and publish surveillance data in asthma at regular intervals.

* Population estimates for each country and age group studied were obtained from the WHO website and rates per 100,000 population were calculated
 **All deaths recorded on the WHO website are coded to the International Classification of Diseases, but although the most recent revision of this classification does code deaths from asthma separately, many countries are still reporting in ICD9, which aggregates asthma deaths with deaths from bronchitis and emphysema

To improve statistical reliability, numbers of deaths over several years were used rather than single years. Data on asthma deaths were available for five years for most countries. However, not all countries had not been compiling individual asthma data for that length of time



“I changed job a little while ago, but after only a few days, I had to take time off sick because of my asthma. This caused bad feeling at work and made me feel very defeated”



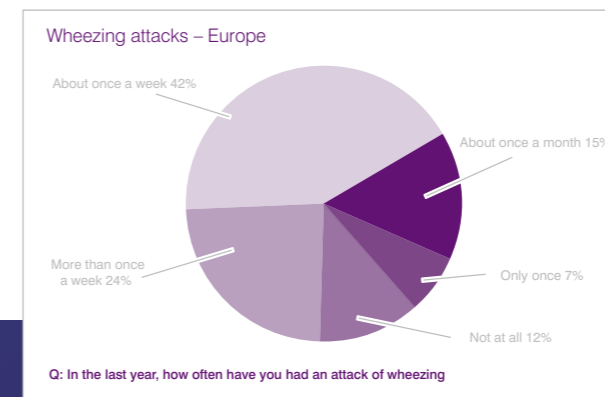
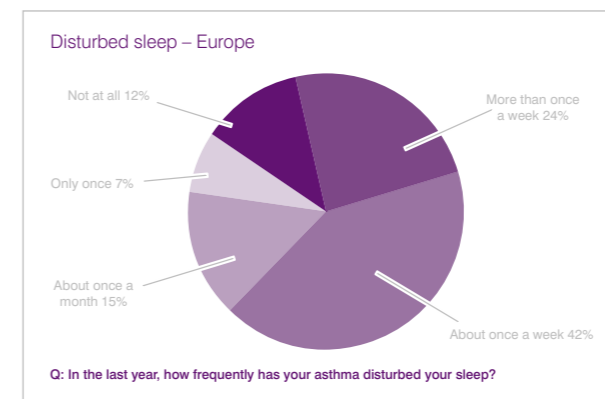
Genoveva Villar

The patients' experience – Europe

We asked 1,300 people with severe asthma in five countries – France, Spain, Germany Sweden and the United Kingdom – to describe how their symptoms affect their daily lives and to share their thoughts on what the future might hold for them.

Sleepless nights

For many people with severe asthma, symptoms are worse at night than during the day, and constant coughing and gasping for breath make it hard to have a decent night's sleep. Two thirds of our participants (66%) say they cannot go through a week without a disturbed night. Anyone who has ever suffered a disturbed night knows how it can spoil the following day. How much worse would it be to have your sleep disrupted not one night but several, week in week out? That is the experience of one in four of the people who participated in our study.



‘My picture represents me lying in bed at night to show how the attacks always come so unexpectedly and at a bad time’ [Germany]

‘I don’t have a partner, because who would want to put up with me coughing all night and bringing up phlegm?’ [UK]

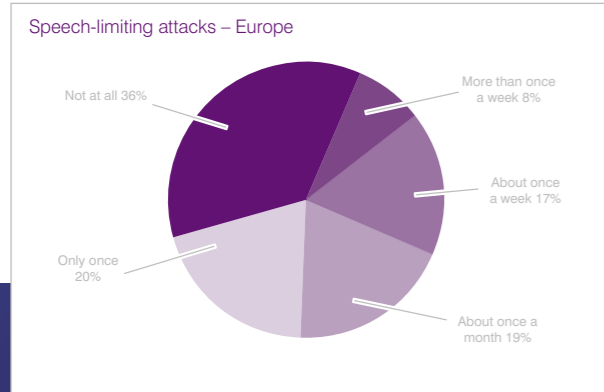
People within the report were classified with severe asthma if they met with one or more of the following traditionally-used criteria:

- Sleep disturbance once a week or more often in the last year
- A wheezing attack once a week or more often in the last year
- One or more speech-limiting attacks in the last year

The patients' experience – Europe

continued

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So breathless you can't call for help

As a person with asthma, you may know that the disease kills thousands of Europeans every year and a severe speech-limiting attack can make you feel that this time it could be you. For 25% of those who took part in our survey, this frightening experience is a weekly occurrence, and another 20% have such attacks at least once a month.

'Try putting a straw in your mouth and breathe through it – that's what asthma is like' [Sweden]

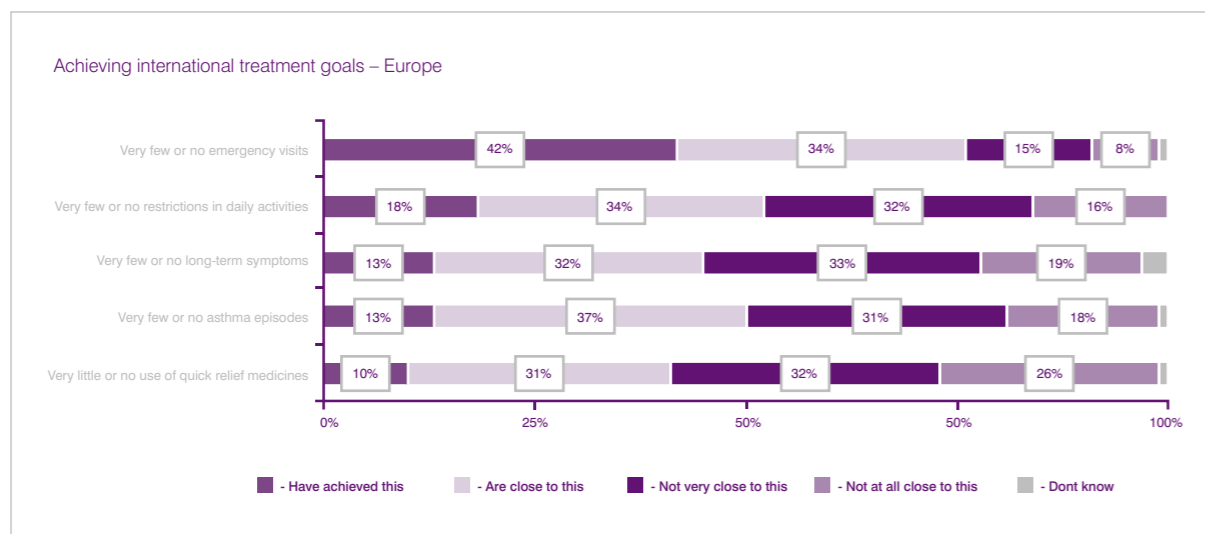
'When it happens I can't walk or talk easily. I feel like I'm drowning' [UK]

International treatment goals – a fantasy?

GINA, the Global Initiative on Asthma, has identified goals for asthma treatment, the health outcomes that people with asthma should reasonably expect.⁵ Most participants in the group discussions, especially in Germany, think that their doctor is aiming towards these goals. Very few, however, feel they are achieving them, and several respondents think they are simply not realisable.

One measure of asthma control is how often someone has to use their 'reliever' medicine. Only one in ten participants say they are achieving the GINA goal of 'very little' or 'no use' of quick-relief medicines, and the number falls to one in 100 in France. More than half (55%) report being 'not close' or 'not at all close' to achieving this goal.

If not needing reliever medicine is a reliable day-to-day marker for good asthma control, then the 'blue light' emergency is perhaps the most dramatic marker of poor control. Although for most participants emergency visits are infrequent, one in five (22%) feel they are 'not close' or 'not at all close' to achieving the GINA treatment goal of 'very few or no emergency visits'.



'Normally they are very good. Being in an emergency room, helpless and fearful, it is such a relief when someone's friendly and helpful' [Germany]

Stigma and stress

Despite disrupted school attendance and exam-time allergies, there is little evidence that an asthma diagnosis is linked with poorer school results,⁶ and only 5% of our participants feel that their education has been harmed (Figure 20). Nonetheless, stigma and stress at school are obstacles to be faced and 14% report missing out on social and sporting activities at school and college.

'Before an exam I often had more attacks. It was an extra source of stress, but I managed to cope.' [France]

'I had to finish my studies in a rush – I had steroid injections and three attacks a week when I was taking exams' [Germany]

'People think you are silly just because you cannot take PE classes; I have been hearing that all my life... They always assumed you were lazy' [Sweden]

Disadvantage at work is common. Overall, nine percent say their asthma has cost them a promotion, and the percentage rises to 16% in Sweden. The sense of constrained opportunities is even greater, with one in five reporting missing out on job opportunities – this rises to one in three in Sweden.

The group interviews generated a range of possible explanations for this. There were frank instances of a particular job or workplace being incompatible, because of allergens such as chemicals or dust. In other cases, asthma had a direct impact on a worker's attendance or performance.

'I was a chef for 15 years and cooking fumes made it impossible to breathe, so I had to change jobs and become a janitor' [Sweden]

'I used to work in a paint factory and had to quit the job because of my asthma' [Spain]

'I used to do secretarial work and experienced difficulties using photocopier materials which triggered coughing' [Germany]

The problem of second-hand smoke is a recurring theme:

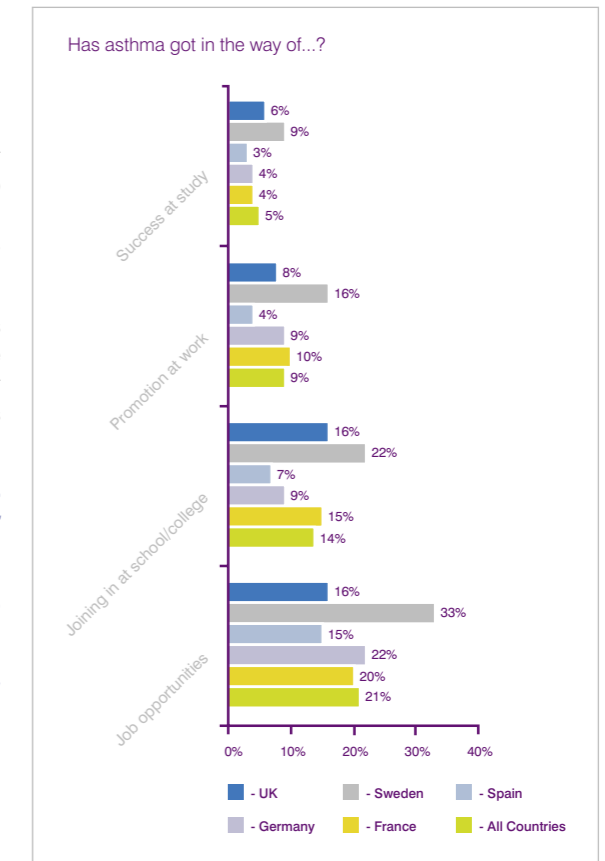
'When I worked in day care I had colleagues who smoked and who didn't want to open a window to clear the air because they thought it was too cold' [Sweden]

Disrupted sleep also takes its toll in the workplace:

'They know that once or twice a month I won't come in because I'll have had a bad attack in the morning' [France]

'It affects your concentration – medication makes me drowsy and makes my heart go strange' [Spain]

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The patients' experience

– Europe *continued*

Isolating factors

More than one in three (38%) say that fear of an attack curtails their social life, preventing them going out with friends or even having holidays. A picnic in the country can expose them to unavoidable triggers. Worse still, there is the entirely man-made hazard of exposure to cigarette smoke. The sad thing is that better management of their asthma could help many of these people cope in these situations.

'You have to stop doing all kinds of things. I used to love the smell of hay or horses but I can't do that any more' [Sweden]

'I cannot spend the whole night in a bar, I have to keep popping outside. Most places you go to have smokers and many places have very small no-smoking areas, or people just don't care and smoke next to you' [Spain]

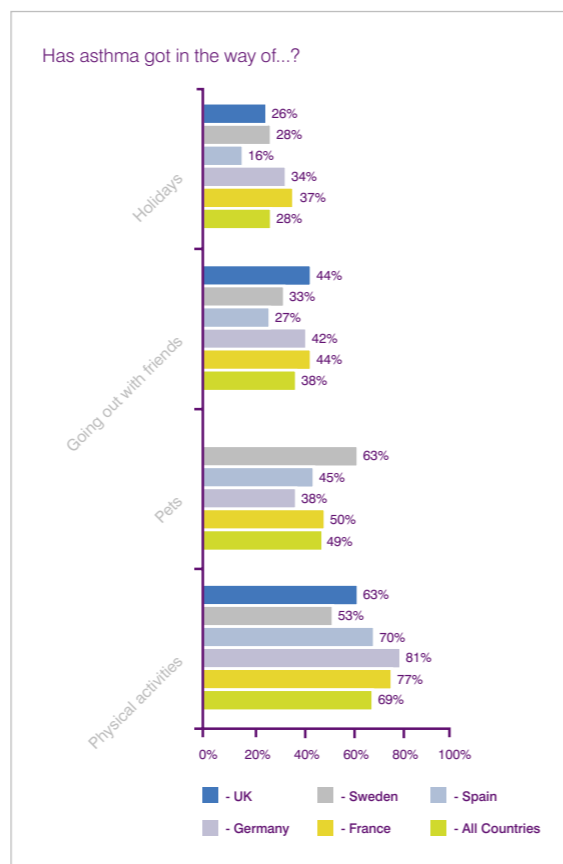
Even keeping pets becomes an impossibility. This may seem like a trivial matter but for half our participants it is yet another way that their asthma leaves them feeling isolated.

Almost seven in ten (69%) of our participants say that their asthma prevents them taking part in sport or other physical activities. This need not be the case. While it is true that exertion can trigger an asthma attack, using the right medicines can normally help to prevent this.

There are those who believe that exercise can actually reduce asthma symptoms, though this has yet to be proven. What we do know is that exercise does have well-documented physical, social and psychological benefits, and a recent review of research found 'the overwhelming majority of studies demonstrated the capacity for asthmatic subjects to exercise safely and significantly improve their cardiovascular fitness and quality of life'.⁷

The critical issue is quality of life. Exclusion from exercise marks another avenue of social interaction closed down by asthma.

'I can't do activities like swimming or going to the gym. Also I used to like dancing a lot, but these all became too difficult to do' [Germany]



Some participants make compromises to have at least some kind of active life.

'I know that exercise triggers my asthma so I would be tempted not to do anything. But I try not to let it stop me. I dance and when I dance a lot I take precautions and bring my inhaler with me' [France]

'I still do sports but have reduced it. I used to climb mountains, now it is more hill walking' [Germany]

My asthma, my treatment and me

Most patients with long-term conditions develop a complex relationship with their medication. Their understanding, experience and aspirations for their medicines can be strikingly different from those of their practitioners. Asthma is no exception.

Reliever inhalers are highly valued for the immediate 'rescue' they provided, though many participants question the efficacy of the delivery device, with strong and contradictory opinions expressed in the various groups.

'Quick relief, feeling better, no more anxiety, being able to breathe normally again' [Germany]

'Inhalers have to be used properly and sometimes I wonder if I have taken it properly. I can't see anything and it is not reassuring' [France]

Because taking preventative medication has no immediately visible result, some are sceptical about its benefits. Many are wary of possible or actual side effects, such as weight gain, osteoporosis and diabetes. Asked (at the request of the French patients' organisation) how much they worried about possible side effects, on a scale of 1 to 10, 11% of French participants gave a score of 10 out of 10, and 50% gave a score of 7 or more.

'I wanted to ask if it was normal to sit and shake after taking the medicine' [Sweden]

'It's like a choice between two evils. If I take [the medication] I get the shakes and if I don't I can't breathe' [Sweden]

When it came to discussing the goals of treatment, many participants describe very positive and collaborative relationships with their health practitioner.

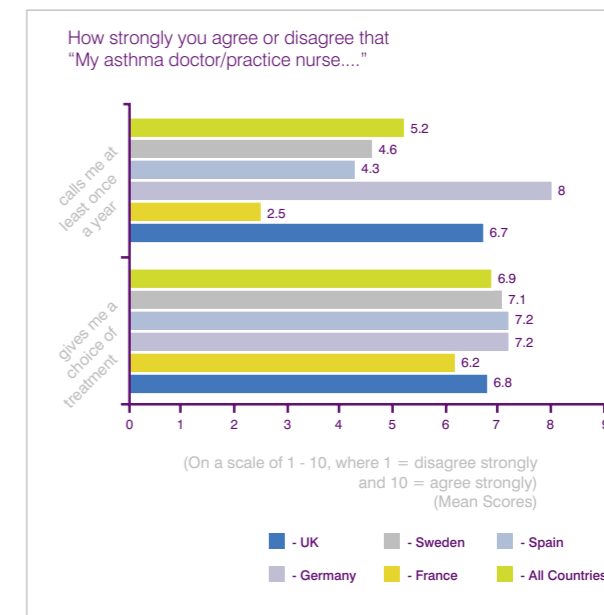
'I have a discussion with the pulmonologist. He prescribes in a way that matches my expectations and modifies the treatment according to the benefit I receive' [France]

'My doctor always asks me how I'm getting on and takes notes. He compares my monitor results with the previous ones and, depending on how I'm doing, will give me appropriate advice' [Germany]

But that experience is far from universal.

'I don't feel I have any influence over treatment. They just listen to my breathing and tell me what to take' [Sweden]

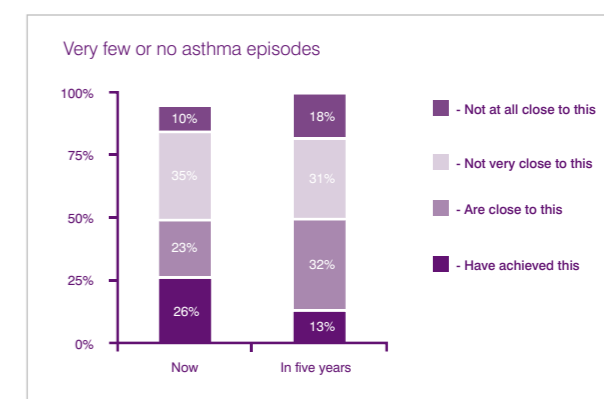
'I just see my GP for five to ten minutes and go for repeat prescriptions every three months' [France]



My asthma, my future

Expectations of treatment outcomes vary greatly between countries, with conspicuous optimism in Spain and pessimism in Germany and Sweden. This may reflect changes in the state's involvement in the management of long-term conditions more than any medical advances. Most people hope that treatments will improve in the future but there seems to be a general scepticism that asthma care will keep up with these advances. People's expectations for the future also seem to be dampened by a feeling of powerlessness over the control of their asthma.

Overall, although there seem to be reduced expectations of achieving the goals of 'few or no asthma episodes' and 'no long-term symptoms', the combined totals of those expecting to achieve or be close to achieving the goal remains much the same.



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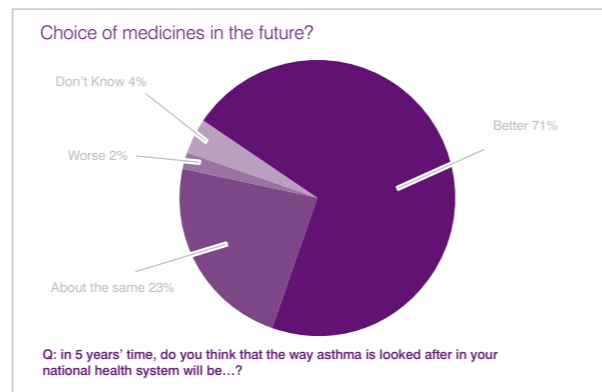
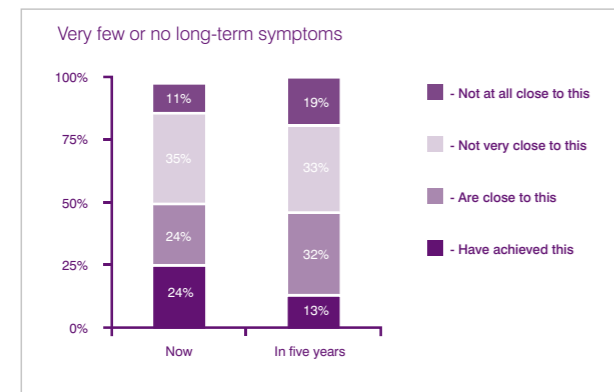
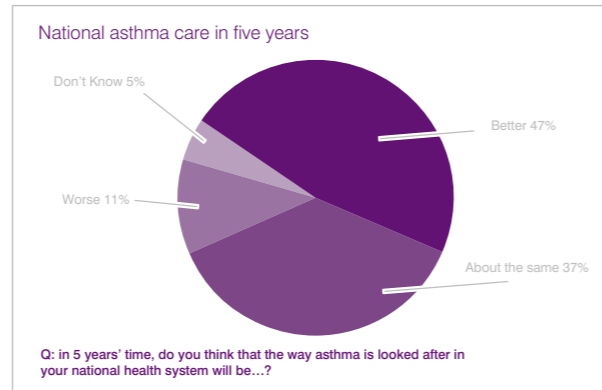
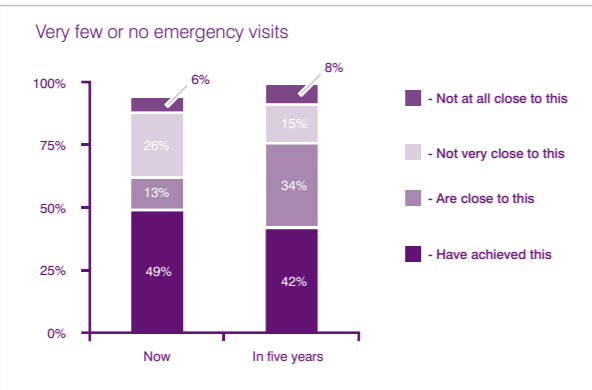
The patients' experience

– Europe *continued - My asthma, my future*

The language prevalent in the group interviews appears to mask an underlying belief that on a daily basis asthma control is slipping away.

The exception is the goal of 'very few' or 'no emergency visits'. Almost half of our participants consider themselves to be achieving this goal. While there is still a slight decline in their expectations of maintaining this, there is a marked rise in those expecting to be close to achieving 'very few' or 'no emergency visits' in the future – bringing the total to 76%.

A clearer pessimism emerges when we look at 'treatment inputs' rather than 'treatment outcomes'. Fewer than half our participants expect that their national healthcare system will be providing better asthma care in the next five years, and one in ten (11%) expect the standard of care to deteriorate. By contrast, seven in ten (71%) are pinning their hopes on a better choice of asthma medicines in the years to come.



“The severity of my asthma means I don't have much of a social life and so I feel very isolated. It's also embarrassing to have to [use] your nebuliser in public. I've lost a lot of friends because of my illness. My relationship with my partner broke down because of my asthma.”



Wendy Williams

The patient's experience

– national differences

Patients' experiences, treatment and expectations can differ hugely between countries.

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France

The situation here seems pessimistic. Few of our participants report achieving international treatment goals – only 1% manage with "little or no" use of reliever medicines (compared with 10% across Europe); they use emergency services more than most, and are less likely to be free of asthma episodes. Annual reviews are far from the norm, and generally they seem gloomy about their prospects. There seems little expectation that either their health or their care will improve over the next five years, without more investment in treatment research.

Spain

Despite reporting more episodes than average, Spanish respondents report fewer restrictions on daily life than average, and their expectations for the future far exceed the rest of Europe. Almost one in three (29%) expect to have few or no long-term symptoms within five years, although only 8% currently achieve that goal. Seven out of ten are confident that their healthcare system will be significantly better within five years, and even more (79%) expect that asthma medication will improve over that period. Their main complaint is difficulty of access to specialist medical care.

Germany

Germany's record on achieving international goals for asthma care could be considerably better. Only 3% of German participants report "little or no use" of reliever medicines; only 7% (half the European average) say they are free of asthma symptoms; and only one in four currently achieve the goal of no emergency visits, the lowest score of the five countries studied. Worse, although many (48%) are already receiving annual reviews, almost one in four expect that their healthcare service will actually deteriorate over the next five years. This is the highest level of pessimism in the study and twice the European average.

Sweden

Sweden has some of the best treatment outcomes in the five countries surveyed and although one in three Swedish participants think their asthma has affected their career (as opposed to an average of one in five across Europe), they are generally optimistic about the future. Two in three expect to achieve, or be close to achieving, the goal of no long-term symptoms within the next five years; almost half (45%) think that by then they will have few restrictions in their daily activities; and four in five think they will be at least close to achieving the goal of no emergency visits. Almost half of those interviewed (45%) expect to be better served in their national healthcare systems in future. Free prescriptions are the most important asthma policy issue for them.

The UK

Few British participants expect their asthma to improve significantly over the next five years, and many who do not currently need emergency care envisage needing it in the future. The majority (88%) are confident that new, more effective treatments would improve their symptoms, although they are more sceptical about the possibility of improvements in National Healthcare Services (NHS) asthma care. Three in four say that easier access to an asthma specialist would improve their care, and two out of three would like more input into how their asthma is managed.

Time to act

Millions of people across Europe continue to live in fear and isolation due to their asthma and feel that their rights and viewpoints are being ignored. Exclusion in the workplace and from public places add to this sense of powerlessness, allowing asthma instead of the individual to take control of their lives. More can be done to improve the lives of people with severe asthma and prevent this burden but we need to recognise this challenge and act now.

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While many enjoy a productive partnership with their healthcare practitioners and have access to good quality care, others find that their concerns are not dealt with and their preferences ignored. Different people have radically different treatment preferences, and they do not know what kind of treatment outcomes they can rightfully expect.

Although their asthma should be manageable, most of our participants expect a steady ebbing away of their symptom control in the years to come. Their experience suggests that with age come poorer asthma outcomes, but many also believe that national healthcare services will fail to keep pace with medical advances.

We call on governments, European Institutions and health authorities to help us to:

- Foster belief among asthma patients and their families that, for most patients, a symptom-free life is achievable and they can rightfully expect it
- Provide patient access to decent quality, affordable care, and prevention
- Encourage healthcare professionals to develop in partnership with their patient a written, easy to understand, personalised action plan, that provides advice on self-management of dosing, coping with worsening symptoms and emergencies
- Educate patients on a continuous basis about their treatment options, through 're-education' programmes via clinics, surgeries and patient groups, supplemented by telephone helplines and dedicated internet sites where possible
- Encourage healthcare professionals to proactively enquire about patients' symptoms, quality of life and expectations
- Increase patient awareness of advances in treatment, to allow them to control their own symptoms
- Involve patients in setting the research agenda, with more attention given to prevention, lifestyle, social and environmental factors and health care
- Provide independent funding into research, enabling us to find a cure
- Involve patients in setting the public health agenda, including health-care services, with focus on patient centred, integrated care
- Increase awareness of asthma among the public
- Monitor the prevalence and impact of asthma across Europe, including its economic and social consequences
- Improve regulations and standards on air pollution indoors and out, including a ban on smoking in public places and the workplace



“You try to live as normal a life as possible but this means listening to your body, taking your medicine, managing your symptoms and always, always thinking about what might be around the next corner”



Sylvie Yassur

EFA mission statement

EFA is a European network of patient organisations that share responsibility for substantially reducing the frequency and severity of allergies, asthma and COPD (chronic obstructive pulmonary disease). We aim to minimise their societal implications, improve health-related quality of life and ensure full citizenship of people with these conditions - whilst pursuing equal health opportunities in the field of allergy and airways in Europe.

OBJECTIVES

To accomplish its mission, EFA focuses on the following **strategies**:

1. To influence European Union policymaking in; such a way that it will result in
 - appropriate regulations for healthy (indoor and outdoor) air in Europe
 - appropriate regulations about the quality (including accessibility) of healthcare for people with allergies, asthma and COPD
 - appropriate regulations about societal participation of people with allergies, asthma and COPD
 - adequate funding of demand-driven research on allergies, asthma and COPD
2. To support the realisation of a European network of strong and professional national organisations of people with allergies, asthma and COPD and a strong and professional EFA
3. To empower member organisations to reach a comparable level of serving the interests of patients by exchanging experiences on:
 - influencing national policymaking on public health, healthcare, societal participation and research in relation to allergies, asthma and COPD
 - products and services for people with allergies, asthma and COPD
 - increasing health awareness

CENTRAL VALUES

- Patient perspective
- Involvement
- Sharing knowledge and experience
- Partnership and co-operation
- Visibility and presence
- Health equity in Europe





Appendix 1

Appendix 1: Methodology

Three distinct kinds of data have been brought together for this report: analysis of existing epidemiological data; qualitative investigation into the opinions and experiences of people with severe asthma symptoms; and quantitative data to indicate how widely these views are held.

Epidemiological data

A team of researchers at the Lung and Asthma Information Agency in London investigated existing epidemiological sources (appendix 2), including published research papers and data from the International Study of Asthma and Allergies in Childhood (ISAAC) and the European Community Respiratory Health Survey (ECRHS), were also used.

The ISAAC carried out standardised simple questionnaire surveys among representative samples of schoolchildren in centres in most regions of the world, including many European countries. A simple self-completed questionnaire was administered to approximately 3,000 children aged 13-14 in each centre. Most centres carried out their data collection in 1994 and 1995.

The ECRHS surveyed adults aged 20-44 years across Europe. Self-administered questionnaires were posted to randomised samples of adults (1,500 males and 1,500 females) in centres across Europe. The survey was carried out in the early 1990s and data submitted to the co-ordinating centre by December 1994.

In both studies, some countries had more than one centre; in these cases, the prevalence estimates have been averaged for the country. Both studies asked about more severe symptoms and the results are shown for those European countries where admission or mortality data was also available.

The patients' experience

The views of people with asthma were explored first through qualitative research and subsequently through structured questionnaires. This work was conducted in two waves. The first pilot wave was conducted in 2004 in the UK. The second wave was conducted in France, Spain, Germany and Sweden in early 2005.

People with severe asthma symptoms were recruited if they met one or more of following criteria:

- Sleep disturbance once a week or more often in the previous year
- A wheezing attack once a week or more often in the previous year
- One or more speech-limiting attacks in the previous year

Focus groups were conducted with people with severe asthma symptoms in the capitals of each participating country. Three focus groups were conducted in the pilot phase and a further eight in the main study.

The results of the first focus groups were used to construct a brief structured questionnaire, which was administered by telephone. In the pilot phase 500 interviews were conducted and a further 800 were conducted subsequently. In the UK, France and Sweden patients were recruited using random-digit dialling. In Germany the field interviewers selected patients randomly and in Spain both doctors and field interviewers selected patients randomly.

Appendix 2-3

Appendix 2: Sources of data

Prevalence

Children: Worldwide variations in the prevalence of asthma symptoms: the International Study of Asthma and Allergies in Childhood (ISAAC). The International Study of Asthma and Allergies in Childhood (ISAAC) Steering Committee. *Eur Respir J* 1998; 12:315-335

Adults: Variations in the prevalence of respiratory symptoms, self-reported asthma attacks, and use of asthma medication in the European Community Respiratory Health Survey (ECRHS). European Community Respiratory Health Survey. *Eur Respir J* 1996; 9:687-695

Hospital admissions

Unpublished research data from national registries

Mortality

World Health Organization Mortality Database www3.who.int/whosis/menu.cfm
Office for National Statistics (UK data)

Population estimates

World Health Organization Mortality Database
Office for National Statistics (UK data)

Appendix 3: List of countries by source of data

Prevalence

Children (ISAAC study): Austria, Finland, France, Germany, Ireland, Italy, Portugal, Spain, Sweden, United Kingdom

Adults (ECRHS study): Austria, France, Germany, Ireland, Italy, Netherlands, Norway, Portugal, Spain, Sweden, United Kingdom

Hospital admissions:

Austria, Finland, Germany, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden, Switzerland, United Kingdom

Mortality:

Austria, Denmark, Finland, France, Germany, Luxembourg, Netherlands, Norway, Portugal, Spain, Sweden, United Kingdom



“Asthma and COPD patients must be better informed about their illness. Due to the health reform in Germany, specialists are under constant time pressures and this limits the amount of information they can provide to a patient. It took me over 20 years to accept and effectively manage my asthma”



Ralf Kernebeck



European Federation of
Allergy and Airways Diseases
Patients Associations

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