“Fighting for breath”

European patients’ perspective on severe asthma symptoms

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Our approach

Reflecting and reporting people’s experience

1. Patients’ groups working together
2. Europeans with asthma in their own words
3. Europeans with asthma speak in their hundreds
Our Sample

- UK, France, Germany, Spain & Sweden

- “Severe asthma symptoms”
  - Disturbed sleep on a weekly basis
  - Attacks of wheeze at least monthly
  - One or more speech limiting attack in the last year
The content

Quantitative survey generated and supported with qualitative group interviews

- Your experience of asthma
- Your experience of asthma care
- Your hopes for the future
Achieving International Treatment Goals

“On a bad day I feel like I’m drowning and I can’t reach the surface of the water and I’m going to burst, yet a tiny, tiny bit of air keeps me alive. 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’s going to kill me?”

Very few or no emergency visits: 12%
Very few or no restrictions in daily activities: 34%
Very few or no long-term symptoms: 32%
Very few or no asthma episodes: 33%
Very little or no use of quick relief medicines: 32%

Have achieved this: 15%
Are close to this: 16%
Not very close to this: 31%
Not at all close to this: 16%
Don’t know: 26%
Experience of asthma 2

Very little or no use of quick relief medicines:
France

“I don’t have a partner, because who would want to put up with me, coughing all night and bringing up phlegm”
Experience of asthma 3

Very few or no asthma episodes:
Now and 5 Years Time

“You have to stop doing all sorts of things. I used to love the smell of hay and horses but I can’t do that any more”

“I can’t go swimming or to the gym. I used to like dancing but these all became too difficult”
Experience of care 1

My asthma doctor/ nurse...

Takes time to make sure my medicines are right for my life and my asthma

Involves me in making the most important decisions about my asthma

Gives me a choice about ways to treat my asthma

“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”

“IT wanted to ask if it was normal to sit and shake after taking the medicine”

Calls me at least once a year to talk about my asthma
My asthma doctor/nurse calls me at least once a year to talk about my asthma.

"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."

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

Europe

France

Spain

Sweden

UK

Germany
The big differences

- In Germany and Sweden, 1/5 expect asthma management to be worse in 5 years
- Annual treatment review is rare in France but common in Germany
- Only 1% of French participants achieve international treatment goals
In 5 years’ time, do you think that the way asthma is looked after in your national health system will be...

Spain
- Worse: 2%
- About the same: 68%
- Better: 25%

UK
- Worse: 5%
- About the same: 55%
- Better: 38%

Sweden
- Worse: 17%
- About the same: 36%
- Better: 44%

Germany
- Worse: 22%
- About the same: 39%
- Better: 35%

France
- Worse: 7%
- About the same: 49%
- Better: 34%
Few French participants achieve international treatment goals

French people with asthma expect only a modest improvement over the next 5 years

French participants were least likely to anticipate improvements in the way asthma is managed by their national health care system

1 in 10 French respondents expect to be free of symptoms in 5 years, less than half the European average

French participants report higher than average use of emergency services, and unlike the rest of Europe, expect no improvement in the next 5 years

French participants are much less likely to report annual reviews
Very few or no asthma episodes France: Now and 5 Years Time

ALL COUNTRIES 5 YEARS
- Expect to/ have achieved this: 26%
- Expect to be/ are close to this: 23%
- Expect to be/ are not very close to this: 35%
- Expect not be/ not at all close to this: 10%

FRANCE 5 YEARS
- Expect to/ have achieved this: 9%
- Expect to be/ are close to this: 37%
- Expect to be/ are not very close to this: 34%
- Expect not be/ not at all close to this: 14%

ALL COUNTRIES NOW
- Expect to/ have achieved this: 13%
- Expect to be/ are close to this: 37%
- Expect to be/ are not very close to this: 31%
- Expect not be/ not at all close to this: 18%

FRANCE NOW
- Expect to/ have achieved this: 3%
- Expect to be/ are close to this: 27%
- Expect to be/ are not very close to this: 41%
- Expect not be/ not at all close to this: 30%
Although Spanish respondents report more episodes than average now, they expect to beat the European average within 5 years

7 out of 10 Spanish participants expect their healthcare system to deliver better asthma care in the future compared to only 1 in 50 who expect it to get worse

4 in 5 Spanish respondents expect a better choice of asthma medicines within 5 years

Spanish participants were more concerned than average by poor access to asthma specialists
Spain

Very little or no use of quick relief medicines Spain: Now and 5 Years Time

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<td>Don’t know</td>
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Germany

- 7% of German participants (half the European average) reported being free of asthma symptoms but 70% expect to achieve this goal or be close to it within 5 years.
- Only 1 in 4 German participants currently achieve the goal of “no emergency visits”, the lowest score of the 5 countries studied.
- 1 German in 3 expects national asthma care to improve within 5 years but 1 in 4 expect it to get worse.
- Half of Germans (48%) agree completely that they receive annual asthma reviews compared to 1 in 4 (24%) overall.
Very few or no asthma episodes Germany: Now and 5 Years Time

- **ALL COUNTRIES 5 YEARS**
  - Expect to have achieved this: 26%
  - Expect to be close to this: 23%
  - Expect to be not very close to this: 35%
  - Expect not to be at all close to this: 10%
  - Don’t know: 0%

- **GERMANY 5 YEARS**
  - Expect to be close to this: 18%
  - Expect not to be at all close to this: 51%
  - Expect to be not very close to this: 17%
  - Expect not to be close to this: 9%

- **ALL COUNTRIES NOW**
  - Expect to have achieved this: 13%
  - Expect to be close to this: 37%
  - Expect to be not very close to this: 31%
  - Expect not to be at all close to this: 18%

- **GERMANY NOW**
  - Expect to have achieved this: 7%
  - Expect to be close to this: 38%
  - Expect to be not very close to this: 36%
  - Expect not to be at all close to this: 19%
  - Don’t know: 10%
Sweden

- Sweden has some of the best treatment outcomes in the countries surveyed and Swedes with asthma expect further improvements.
- 2 out of 3 Swedes expect to achieve, or be close to achieving the goal of no long-term symptoms within the next 5 years.
- Almost half (45%) of Swedes expect within 5 years to virtually eliminate restrictions in daily activities.
- Free prescriptions are the most important asthma policy issue for Swedes with asthma.
Very few or no asthma episodes Sweden: Now and 5 Years Time

ALL COUNTRIES 5 YEARS
- 26% Expect to have achieved this
- 23% Expect to be/are close to this
- 35% Expect to be/not very close to this
- 10% Expect not be/not at all close to this
- Don’t know

SWEDEN 5 YEARS
- 52% Expect to have achieved this
- 24% Expect to be/are close to this
- 11% Expect to be/not very close to this
- 12% Expect not be/not at all close to this
- Don’t know

ALL COUNTRIES NOW
- 13% Expect to have achieved this
- 37% Expect to be/are close to this
- 31% Expect to be/not very close to this
- 18% Expect not be/not at all close to this
- Don’t know

SWEDEN NOW
- 39% Expect to have achieved this
- 30% Expect to be/are close to this
- 18% Expect to be/not very close to this
- 14% Expect not be/not at all close to this
- Don’t know
Three wishes

If you could make your government do one thing for people with asthma...

“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”

- 31% Invest in new research
- 22% Provide free prescriptions for people with asthma
- 14% Ban smoking in public places
- 13% Access to an expert when needed
Thanks

- Associacion Asmaticos Madrilenos
- Association Asthme & Allergies
- Asthma och Allergiforbundet
- Asthma UK
- Deutscher Allergie und Asthmabund
- NOP Europe for managing the European fieldwork
- Novartis for providing an educational grant