



European Federation of Allergy and Airways
Diseases Patients' Associations

HEY YA!

HEalth Literacy, Young Patients with Asthma and Adherence to treatment:

EFA Report and European Recommendations





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Young people with asthma in Europe have something to say

Executive Summary

Asthma is one of the major non-communicable diseases worldwide with an increasing prevalence. According to the World Health Organisation (WHO), it may affect as many as 334 million people around the world. It is estimated that in Europe 30 million children and adults less than 45 years old have asthma (Gibson, Loddenkemper, Sibille, & Lundbäck, 2013) and approx. 15,000 people die each year from asthma attacks (Chung & Cullinan, 2012).

Asthma is the most common chronic disease in childhood although symptoms and disease can cease before adulthood with adequate treatment. Asthma means recurrent episodes of breathlessness and wheezing, and the frequency and severity of these episodes varies between and within individual patients. The burden caused by asthma can be substantial and lead to reduced quality of life for patients.

Despite availability of effective treatment options, for most patients adherence to treatment remains a challenge. Because the underlying causes for non-adherence of adolescents are less known and studied in comparison to other age groups, EFA identified the need to find real reasons for poor or non-adherence with adolescents by asking the young people directly, and not only their parents.

EFA's multi-national survey included items on 'Health Status', 'Asthma Severity', 'Attitude', 'Treatment', 'Role of physicians' and 'Health Literacy' and was conducted with 200 adolescents from four European countries - France, Germany, Spain and the United Kingdom - from July to October 2015.

50 adolescents between 12-17 years were involved in each country. During the recruitment phase, measures were taken to guarantee that the interview was definitely held with an adolescent patient aged 12-17 years. The results of this study can support the development of strategies to strengthen the adherence of adolescent asthma patients (12-17 years).

Maybe surprisingly there was no significant difference in adherence for any of the demographic variables such as age and gender, nor for the severity of asthma. The German adolescents with asthma reported the highest degree of adherence. Attitude and daily impact are two factors identified that could explain the variety of adherence widely, especially in association with forgetfulness, rebellion, good-days, support, carelessness, and ignorance. Attitude also showed a weak but meaningful interconnection with health literacy. Based on this link, we can assume that health literacy may not directly impact adherence, but rather in an indirect way. To improve adherence, health literacy needs to be very efficacious in order to have a relevant change in attitude and thus an increase in adherence. The study revealed that adolescents have high trust in healthcare professionals and this encourages healthcare professionals to play a mentoring role in advising young patients in their everyday decisions on managing their asthma.

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Asthma in Europe and why this survey

Introduction

As defined by WHO, asthma is a chronic respiratory disease that affects millions of people of all age groups, and often starts in childhood. According to a survey conducted between 2000 and 2003 by the International Study of Asthma and Allergies in Childhood (ISAAC), 14% of the children in the world were likely to have experienced asthma symptoms in the past year (Gibson, Loddenkemper, Sibille, & Lundbäck, 2013). Ongoing monitoring is needed to follow the asthma epidemic and its management.

According to research, children between 7 to 9 years old are more likely to adhere to treatment than young adolescents between 10 and 16 years old (Lindsay & Heaney, 2013). The reasons for this are unknown. Among EFA members as well as healthcare professionals there is a wide consensus that this age group proves to be among the most difficult or in fact the most difficult to reach or to have any kind of impact on. So far research on adherence in asthma and mechanisms focused on the views of parents and physicians, while adolescents' own reflections on their adherence to treatment is lacking.

Therefore EFA decided to give the voice to young people with asthma and explore the underlying mechanisms for adolescents' lack of adherence to treatment. EFA commissioned GfK¹, one of the largest market research companies worldwide, to conduct a survey in four European countries, France, Germany, Spain, and the United Kingdom, to collect data on adherence of adolescent asthma patients. 200 adolescents between 12 and 17 years of age took part in the EFA survey, 50 from each country. The majority of them were boys and from urban city areas.

This survey provides an important missing link to the understanding of adherence in asthma therapy: the view of adolescent patients. It aims to bridge the gap by assessing the views of young asthma patients themselves on the enabling and obstructing factors for adherence and to identify the real reasons for poor adherence and concordance of adolescents with asthma.

Building on the results of the validated adolescent-patient-centred survey, EFA developed recommendations for improving adherence to treatment among adolescents with asthma in Europe. This report summarises in lay-language the EFA Project results and is addressed to EFA networks of patients and patient organisations, NGOs, policy makers and healthcare professionals. In parallel a scientific publication will be submitted covering all scientific details.

Figure 1: Demographic characteristics of participants (Adapted from the original EFA-commissioned GfK Report)

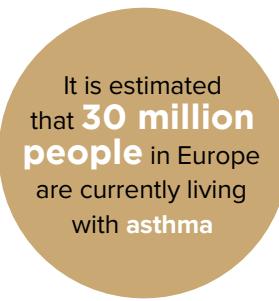
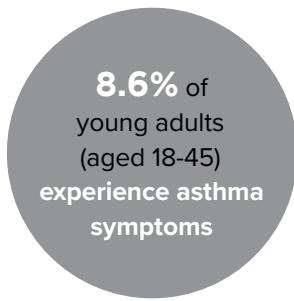
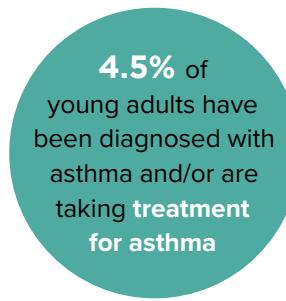
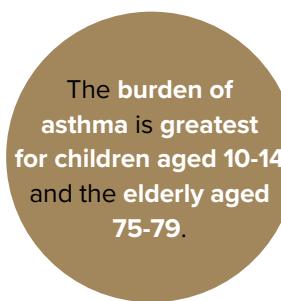
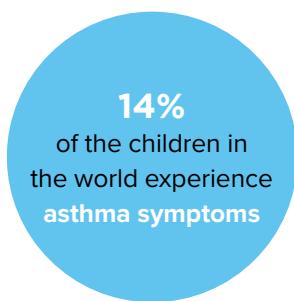
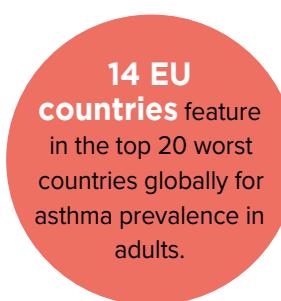
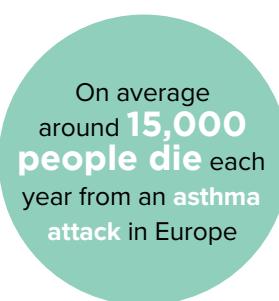
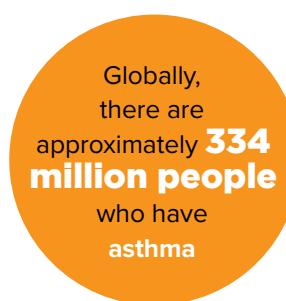
	Germany	France	Spain	UK
Gender				
Male	48%	68%	60%	70%
Female	52%	32%	40%	30%
Area				
Rural/Village/Smal City	20%	52%	46%	36%
Big city/sururb/inner city	80%	48%	54%	64%
Age				
Average	14,5 years	13,8 years	14,0 years	14,7 years

¹ GfK is a market research agency that reports in medical, high-tech, consumer, industrial, and services markets. It is the biggest German market research institute and one of the four biggest market research organisations in the world.

Objectives

- To improve the **focus on adolescents with asthma** and their challenges.
- To **increase understanding** of doctors, nurses, pharmacists, health managers, policy makers, health industry, patient groups and parents of the thinking of young people with asthma
- To contribute to the follow-up of the **EU Polish and Cyprus Presidencies of the Council of the European Union conclusions on children with allergy and asthma** and healthy ageing (Council of the European Union, 2011) (Council of the European Union, 2012) and EU and WHO initiatives and policies sharing best practices on and guidance on Chronic Diseases and EU member states initiatives on asthma and sustainability of healthcare systems
- To contribute to the Global Initiative on Asthma (GINA) and European guidelines on asthma management to take into consideration different target groups, including young people in patient education
- To identify parallels between the challenges faced by adolescents in Europe
- To develop recommendations for empowerment and education of adolescents with asthma to promote and improve patient-centred **adherence**

Asthma Facts



Source (Marks, Pearce, Strachan, & Asher, 2014)

Self-Assessment of Health and Adherence Situation

Respondents were asked to assess their own health in general (ranked as follows: (1) very good to (5) very bad. The majority of participants felt very healthy and considered their health very good or good (83%). Only a small percentage (18%) assessed their health as fair (16%) or bad (2%).

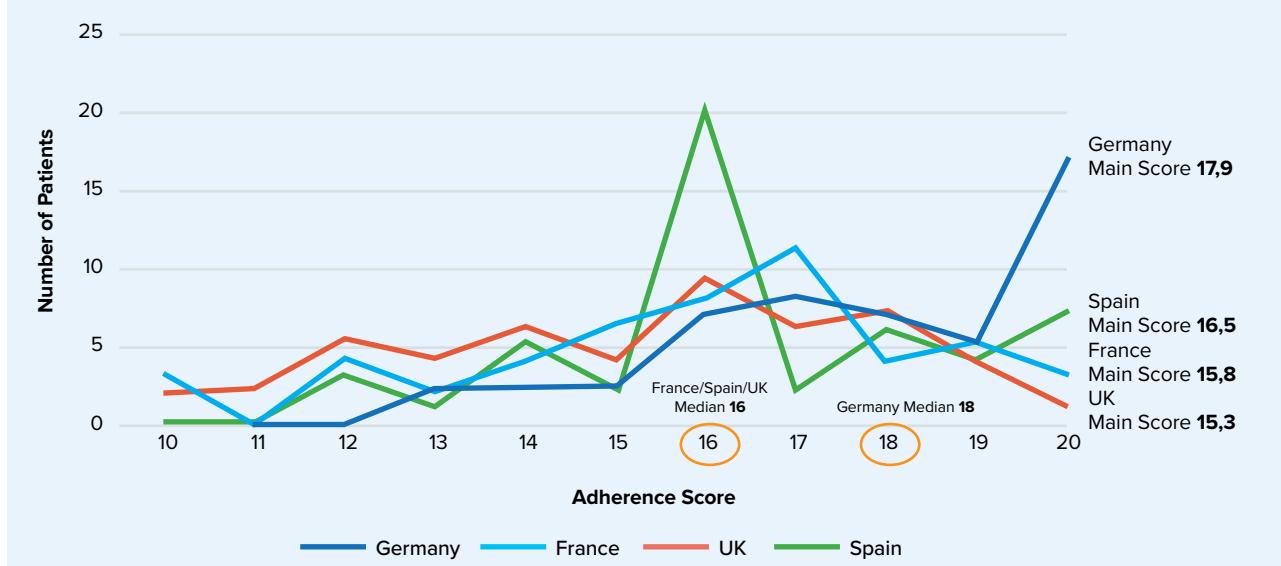
There is a clear inverse relation between asthma severity and how the participants perceived their own health. Adolescents with moderate to severe asthma reported significantly more often fair/bad health than very good health. Those with mild asthma significantly more often think their health as very good or good than fair/bad health.

Adherence was looked at it 3 different steps: first the factors and themes that influence adherence overall, then those that do not and finally each issue that influences adherence separately on how adherence changes when there is a change in a given theme (see annex x methodology). The total Adherence Score was used as a measure for the overall adherence.

Overall the majority of participants accept the doctor's advice (87%) and trust that their medication will have an activating effect (78.5%). In all countries the vast majority (82%) do not experience any problems in taking their asthma medication as prescribed by their physician. For most patients (81.5%), a busy life is no hindrance to taking their medication. German young people with asthma have a good adherence (2-point higher median² in Germany). Every third of them also had the maximal Adherence Score and experienced little hindrance in taking asthma medication as prescribed by the doctor.

If the medication has to be taken several times a day, adherence to following this vital instruction decreases how often you need to take medication. 82 out of the 200 young people in this survey need to take their medication at least 2 times per day, while only 62 (75%) actually did. This means that 1 out of 4 adolescent patients do not adhere to their treatment as they should.

Figure 2: Adherence Score per Country (Adapted from the original EFA-commissioned GfK Report)



² See section 'Key terms' n° 03.

Majority of
youngsters with
asthma accept
their doctor's
advice

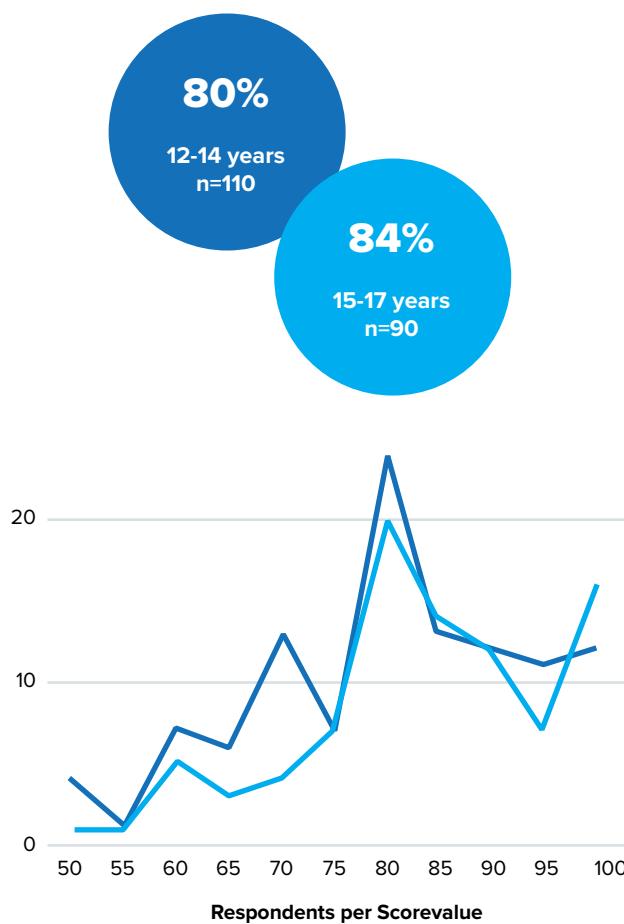
What impacts Asthma Adherence for young people?

Adherence is a multidimensional phenomenon that is impacted by interplay of multiple factors ranging from environmental risk factors, behaviour and personality traits. (Ahmad & Sorensen, 2014).

There is no one single factor to explain non-adherence with adolescents. As expected, it is more complex. As expected, it is more complex than that. This is why the EFA Survey looked at how adherence of adolescents, their adherence score, changes per age, gender, smoking status, sporting activity, asthma confrontation, attitude, social support and daily impact of asthma.

Figure 3: Adherence Score per Age

(Adapted from the original EFA-commissioned GfK Report)



Age is not a defining factor among young people with asthma

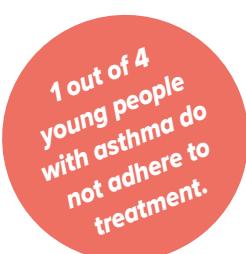
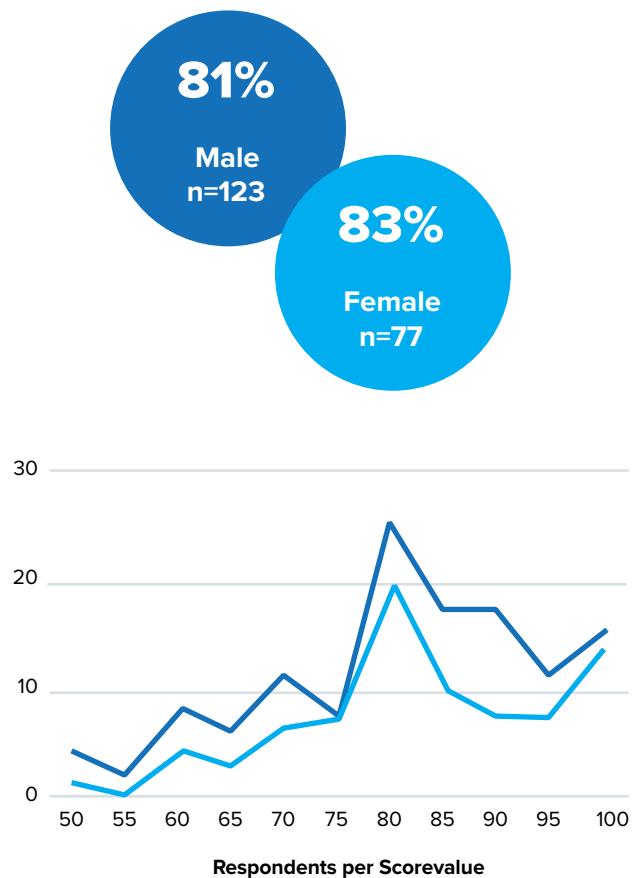
Out of the 200 respondents, 110 are between 12 and 14 years old and 90 patients between 15 and 17 years old. The two age groups do not significantly differ in their overall adherence.

Whether you are a boy or a girl, it does not matter

123 respondents in EFA survey are male and 77 female. Gender showed no correlation with adherence, there was no systematic difference between boys and girls.

Figure 4: Adherence Score per Gender

(Adapted from the original EFA-commissioned GfK Report)





We don't know if smoking status has an influence on adherence

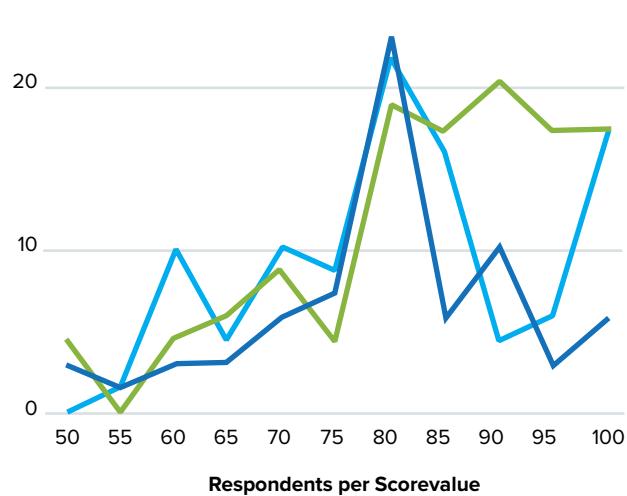
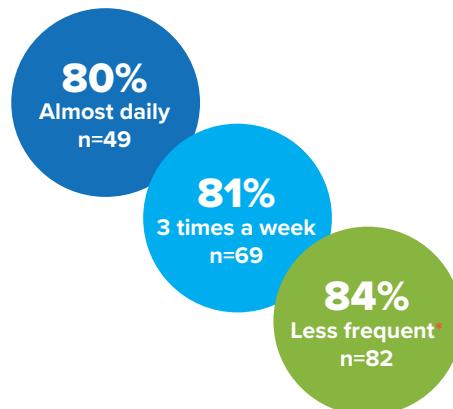
When comparing smokers and non-smokers, there is no difference regarding their adherence. However, only 5% of respondents confirmed they are smokers, which in itself is good news! Therefore it is not possible to make any conclusions.

The more sport, the less adherence to medication

It is very interesting that there is an inverse connection between practising sports and adherence. Young people with asthma who practice sports less than 3 times a week or less frequent are more adherent when compared to those who practice sport on ‘almost a daily basis’.

Figure 5: Adherence Score per Sporting activity

(Adapted from the original EFA-commissioned GfK Report)

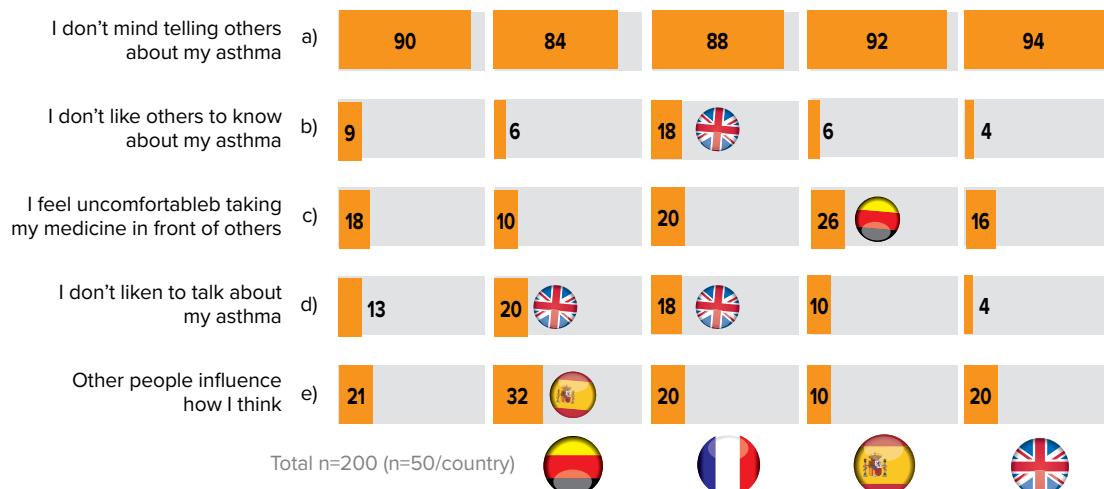


Confronting asthma is not a problem!

Almost all young people with asthma in Germany, France, Spain and the U.K. state they have no problem revealing they have asthma and speaking about it. It has to be noted that in Germany, adolescents' thinking about their asthma is influenced by other people

in 32% of the cases, and 1 in 5 adolescents don't like to talk about their asthma. While in Spain, 1 in 4 adolescents feel uncomfortable taking their medicine in front of other people.

Figure 6: Adherence Score per Asthma confrontation (Adapted from the original EFA-commissioned GfK Report)



There are differences between the countries on attitude

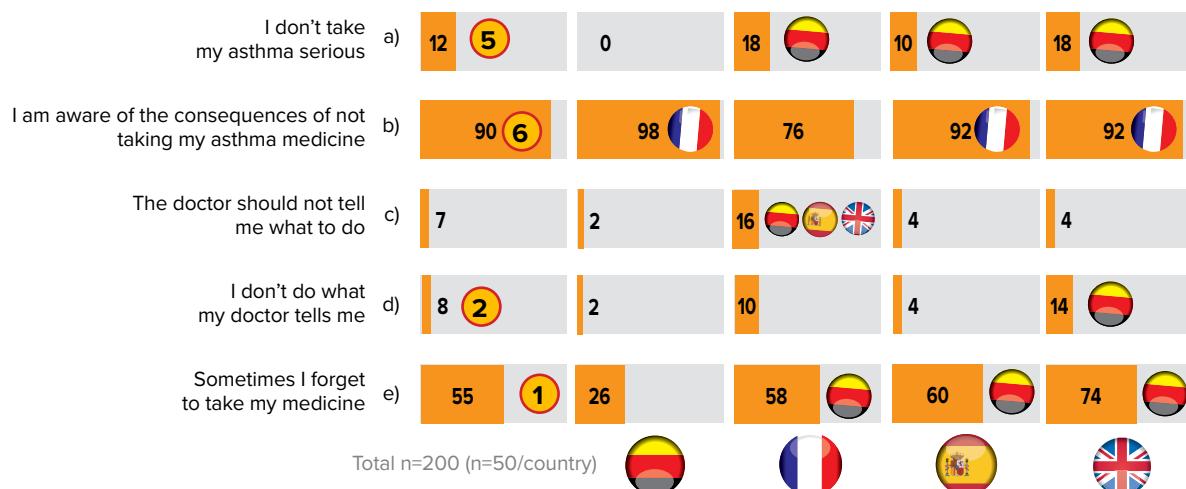
Young people with asthma differ regarding their 'personality traits' among the four countries surveyed.

- **Forgetfulness** is significantly higher in France (58%), Spain (60%) and the UK (74%) in comparison to Germany with only 26% of respondents forgetful.
- There is also a significantly higher percentage of French respondents (16%) that are of the opinion that **doctors should not tell them what to do**, in

comparison to Germany (2%), Spain (4%), and the UK (4%).

- The majority of adolescents with asthma (90%) believe that they are **aware of the consequences of not taking their asthma medication**, especially in Germany (98%), Spain (92%) and the UK (92%).
- Most of the patients (88%) also report they **take their asthma seriously**, especially in Germany (100%).

Figure 7: Differences in Attitude between the Countries (Adapted from the original EFA-commissioned GfK Report)



Young people are not left alone with their asthma

Most young people receive broad social support for their asthma and its treatment from their parents (95%), friends (79%) and the physician (96%). The majority of them (73%) report not being teased by friends because of their asthma and indicate that their friends understand their asthma problems. Parents and physicians are supportive of adolescents in dealing with their asthma and adherence with the treatment.

Influence of daily impact of asthma into adherence differs among countries

Especially German young patients say that they aware of the implications that are part of having a chronic disease. Young patients in France (60%), Spain (80%) and the UK (86%) report more fluctuations in their asthma symptoms in comparison to Germany (34%). The British young patients (66%) are significantly more prone to stop taking their asthma medication when feeling better in comparison to all other countries (Germany: 12%; France: 42%, Spain: 38%).

**Parents, friends
and doctors support
young people to
deal with
their asthma**



Adolescents Health Literacy and their Asthma

Confident enough to find suitable health information

Only a small percentage of young patients (15%) experienced situations where they could help others, family members or friends with questions concerning health issues.

Almost half of them believe that they are competent to search information independently on the internet (47%). The majority (76%) feel to be competent in choosing advice and offers that fit their needs.

Knowledge of how to find health information is not the same in all countries

In all countries the majority of young asthma patients (78%) know where to find information relating to

their disease. Especially patients from the United Kingdom (92%) report knowing where to find relevant information regarding their health in comparison to the other countries (Germany: 66%; France: 62%; Spain: 74%).

Doctors' advice turns out to be useful

Almost all young people with asthma have had good experiences following instructions provided by their physician. Most patients (96%), especially in Germany (100%), Spain (100%) and the United Kingdom (98%) have a good understanding of their doctor's instructions on how to take their asthma medication.



Missing Medication Doses is not because of fear of side-effects, nor embarrassment

Young people in the survey were asked about potential causes for frequently missing a dose in the medication regime.

Very few (2%) reported that they were worried about the side effects or embarrassment of taking their medication in front of other people as reasons for not taking their treatment as prescribed. Also very few (8%) reported missing a dose, because they were unable to renew their prescription in time.

The most popular reason was the availability of the medicine, not being at hand when needed. However there were differences between countries. In France (58%) and the UK (50%) medication not being at hand when needed has a much higher impact on frequently missing a dose, in comparison to Germany (30%).

There is a difference between countries on a preferred time to take the medication. Young people with asthma in 'Northern countries', Germany and the UK, prefer to take their medication in the morning. In 'Southern countries', France and Spain, the preferred time is in the evening.

Only a minority in all four countries prefer taking their medication in the afternoon (Fig 8). The afternoon is also the most likely time of day to miss a dose, especially in Germany and the United Kingdom. In Southern countries the mornings are very likely times to miss a dose. In the U.K. every third adolescent will also miss a dose in the evening.

Figure 8: Preferred Time to take the Medication

(Adapted from the original EFA-commissioned GfK Report)

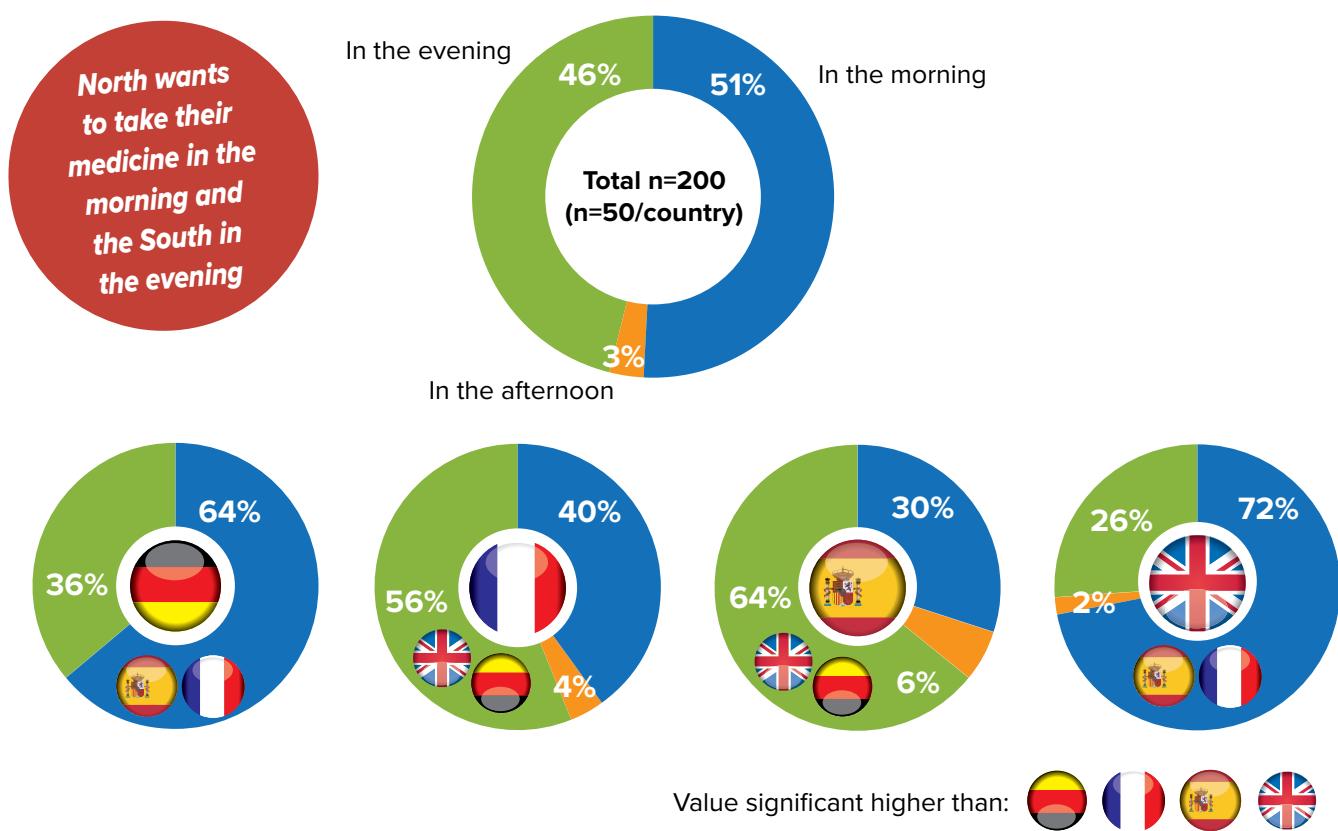
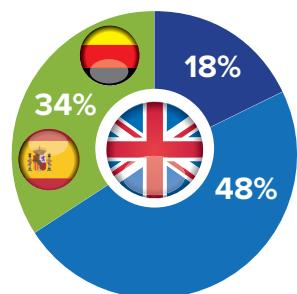
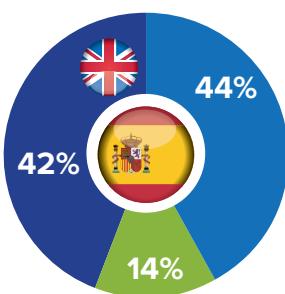
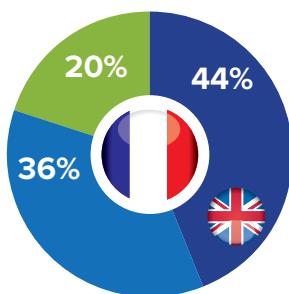
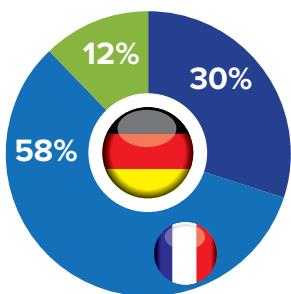
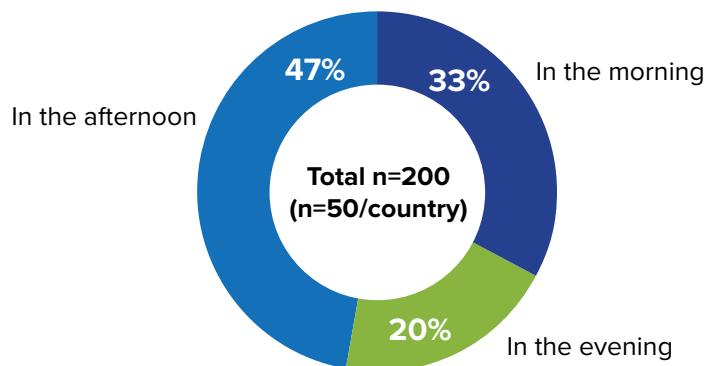


Figure 9: More likely Time to miss a Dose

(Adapted from the original EFA-commissioned GfK Report)



Value significant higher than:



In France and
the U.K. medication
not being at hand
causes much
missed doses



Impacts of different factors on asthma adherence of young patients in Europe

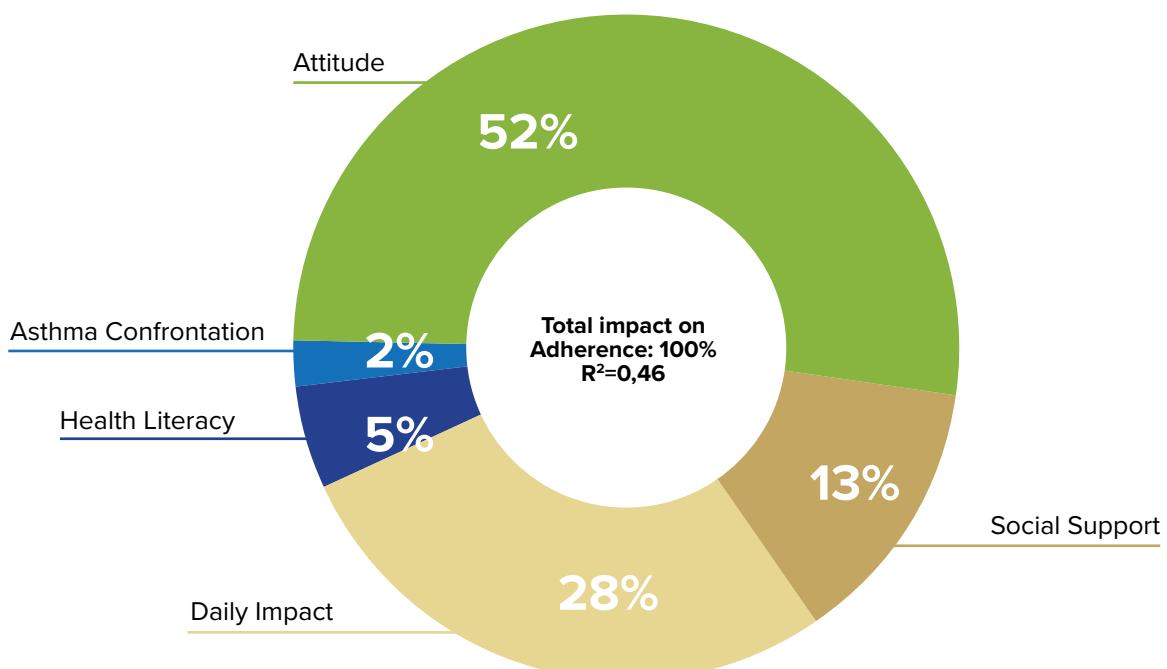
The impact of the different factors on adherence of adolescents is an important topic to explore. The five touch points identified are health literacy, asthma confrontation, attitude, social support and daily impact of asthma.

Attitude and daily impact of asthma are the two most important factors explaining variance in adherence. Health literacy, asthma confrontation and social support have only a limited impact.

Attitude is the strongest driver of adherence. It is interesting to note that health literacy had a weak, but 'significant' in scientific terms, correlation with attitude. While 'health literacy' has less direct impact on adherence, it can be assumed that the effects are more indirect because of the interconnection between 'health literacy' and 'attitude'.

Figure 10: Touch Points for Adherence

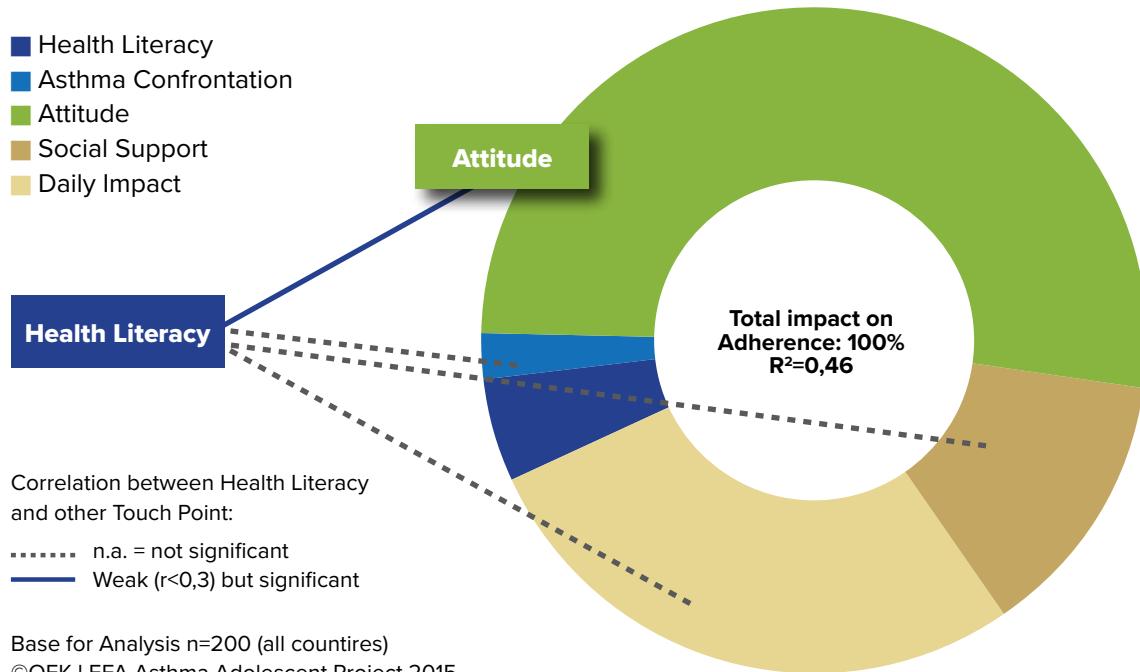
(adapted from the original GfK report)



Attitude and perceived daily impact of asthma impact most adherence

Figure 11: Correlation between Health Literacy and other Touch Points of Adherence

(Adapted from the original EFA-commissioned GfK Report)



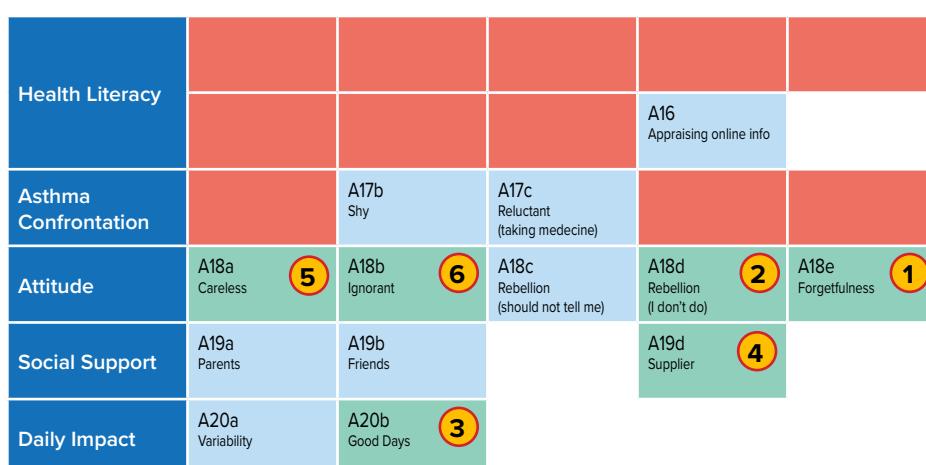
Total Impact on Adherence (ring): 100% $R^2=0,46$

Figure 12: Six most influential factors to explain adherence among adolescents

(Adapted from the original EFA-commissioned GfK Report)

The most important items that cover almost 90% of explanation of adherence of young people with asthma are and in order of importance:

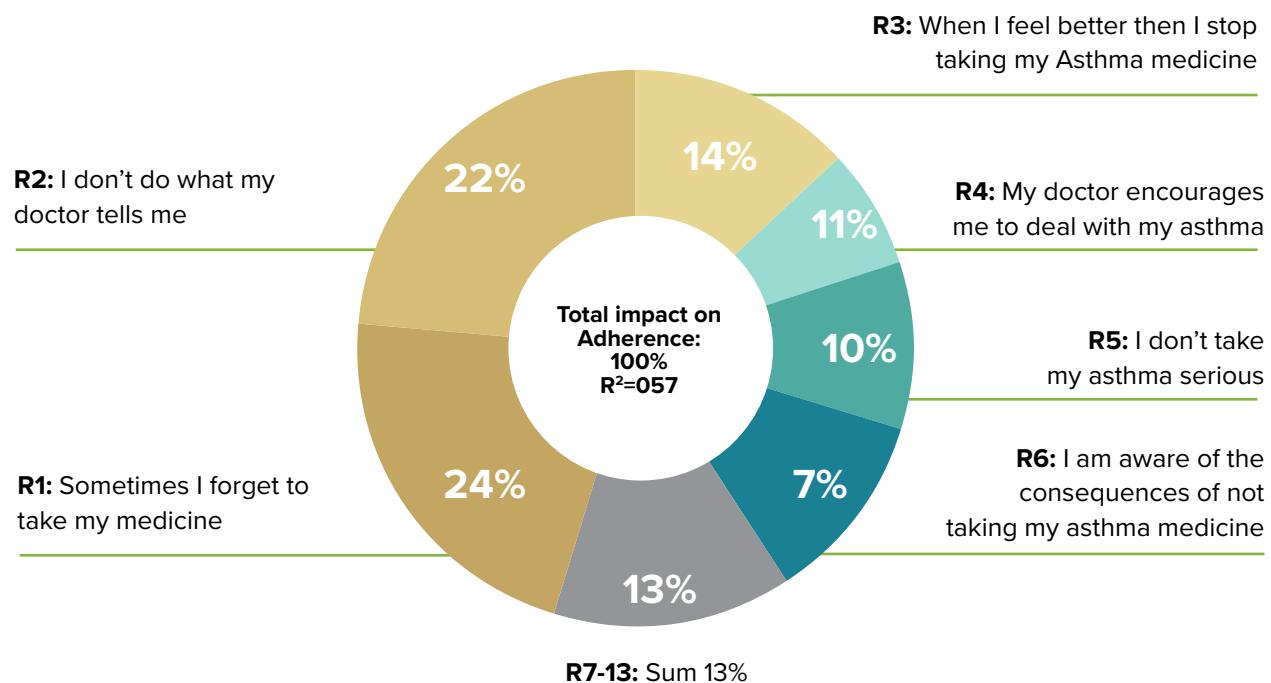
1. **Forgetfulness:** Sometimes I forget to take my medicine
2. **Rebellion:** I don't do what the doctor tells me
3. **Good days:** When I feel better I stop taking my asthma medicine
4. **Support:** My Doctor encourages me to deal with my asthma
5. **Carelessness:** I don't take my asthma serious
6. **Ignorant:** I am aware of not taking my asthma medicine



Base for Analysis nmin=120; $r^2=0,57$

RED FIELDS: Low relevance (not significant) **GREEN FIELDS:** Group of six most important adherence driver **X** = RANK

Figure 13: Item evaluation (Adapted from the original EFA-commissioned GfK Report)



In Summary

The survey outcomes revealed that most young asthma patients (83%) assess their health positively: either very good or good. However this implies that 17% face health problems.

In all countries young people report high adherence of 79%-87%. Adherence is highest in Germany. 13-21% of young people with asthma in Germany, France, Spain and the U.K. have difficulties to adhere to their asthma treatment as prescribed. The adherence scores are lower than the estimates of the WHO (up to 50%) or other studies indicating the non-adherence between 30 to 70% (Lindsay & Heaney, 2013).

Age (12-14 years and 15-17 years) and gender do not affect adherence. Also severity of asthma is not the defining factor.

Remarkably, 'Attitude' and 'Daily impact of asthma' can largely (80%) explain the variety of adherence. In particular six topics explain non-adherence: (1) Forgetfulness, (2) Rebellion attitude, (3) Good days with asthma, (4) Support from your treating doctor, (5) Carelessness, and (6) Ignoring the impact of not taking your medication. 'Health Literacy' as an anticipated driver of adherence, has a weak, but significant correlation with 'Attitude'.

Limitations of the EFA Survey

1. The survey was conducted with 200 participants from four countries. From each country, there were 50 participants. The number of participants thus impacted on the power of analysis (e.g. too small sample size to make accurate presumptions about impact of smoking on adherence).
2. It is important to note that all items are self-reported. We also need to take into account that not all problems are reported and the study did not include a check on the answers with the patient medical files or social desirability bias³.
3. The thorough recruitment process through physicians ensures that all participants have been diagnosed with asthma and are under medical treatment confirming high accuracy to this step of the design.
4. Future research should include a stronger focus on the attitude and behaviour of young people, in close association with clinical research concerning adherence to asthma medicine and include further countries.

The EFA Survey proves several important learnings that can support further strategies, actions and interventions to improve medical adherence among adolescents. Using the six factors identified as a starting point, the following recommendations arise.

³ According to the definition of Philips and Clancy (Philips & Clancy, 1972), 'social desirability' as a response determinant refers to the tendency of people to deny socially undesirable traits or qualities and to admit to socially desirable ones



Recommendations to support adherence of young asthmatics

The main goal of the EFA Asthma Adolescents project survey was to identify key factors that impact the adherence to treatment among young people with asthma. By increasing adherence, we are confident that existing problems with their health can be minimised.

The following priorities and recommendations arise from the 6 key impact factors identified in this survey; forgetfulness, rebellion, good days, support, carelessness and ignorance that explain 90% of the adherence among our young asthmatics from this survey.

1. Forgetfulness

'Sometimes I forget to take my medicine'

Forgetfulness is one of the most common, non-intentional causes for non-adherence. Adolescents themselves can develop tips and tricks to use in daily life to improve adherence.

- One way of combating forgetfulness is by implementing *reminders* in the daily routine. MHealth is a perfect tool but need to be co-designed with the young people themselves.

Taking into account the differences in **preferred times of taking medication** during the day, for adolescents living in Northern countries this could mean that taking their asthma medication could be done as something that is already part of their morning routine (e.g. before brushing the teeth, or going to school), while for adolescents living in Southern countries medication can be taken as part of their evening routine (e.g. after dinner, before going to bed).

- Setting an (audio-visual) *alarm* can be beneficial as well. Many gadgets and apps have been developed that can help patients to set alarms (inhaler alarm that fit on your inhaler, watches with medication reminders) that indicate when they are advised to take their medication.

- A higher involvement of the carers (i.e. healthcare professionals, and direct family members) in this process may also help to take care of forgetfulness. The use of information and communication technology, and gamification has the opportunity to address this challenge without requiring too much effort from young people. Patients can be advised to use a peak flow meter on a daily basis, where the measurements are sent directly to the healthcare professional, with immediate feedback if possible. If no data is measured, the device will produce an electronic reminder. If this still does not activate the patient, someone from the healthcare professionals' office (e.g. secretary) can contact them directly.

2. Rebellion

'I don't do what the doctor tells me'

Poor adherence may reflect rebellion against medical advice. Minimizing conflict between adolescents and their parents, while sustaining parental involvement, can support in adhering to treatment. Understanding the underlying motivations behind the opposing attitude of adolescents can help increase adherence. In case the underlying motivations of this rebellious behaviour can't be understood, a psychologist can be involved to identify the reasons for the rebellion and to discuss the consequences of a reduced quality of life that stem from not adhering to the treatment. Parents need to be motivated to request adherence in a motivating way. A self-management app that includes features that give you immediate feedback on both the benefits and bad consequences of non-adherence could be useful.

3. Good days

'When I feel better I stop taking my asthma medicine'

Non adherence to medication also occurs on a good day because patients perceive it to be unnecessary, because they feel better. In this context we can speak of planned non-adherence as a reward: 'a gift for being healthy'. Health literacy can in this case be a very useful tool to support a proper communication between adolescents and their physician.

The inverse relation between frequency of engaging in a sporting activity and adherence (i.e. adolescents who sported less frequently have significantly higher Adherence Scores, when compared to adolescents who practice sport on almost a daily basis), may result from these adolescents feeling 'healthy' or experiencing more 'good days'.

Young people with asthma need to be made aware that sport is excellent for them, also for their asthma, but a sportive lifestyle does not replace their treatment. Both support each other in order to feel good and strong and this could be part of the self-management plan. By encouraging carers (healthcare professionals and parents) and trainers of sporty adolescents to be involved in motivating adherence to their treatment, we can support adolescents in staying adherent. Should patients wish to adjust their medication dose, as part of their self-management plan, this should always be done in consultation with healthcare professionals or be clearly planned with instructions.

4. Support

'My Doctor encourages me to deal with my asthma'

Trust to healthcare professionals is high and their support is vital. Healthcare professionals need to be encouraged and equipped with the skill to engage in a symmetric relationship with the patient to ensure that the treatment plan can be properly incorporated in their daily life. Establishing a positive supportive trusting relationship with the physician, who showed to be the main communication channel for young people with asthma, can support them in dealing with their asthma and increasing the adherence.

Also, the involvement of family members in the management of asthma, and the referral to a support group can drive increased adherence.

We need to encourage healthcare professionals to act as mentors in supporting adolescents to increase adherence, especially since they evoke a high degree of trust from adolescents.

5. Carelessness

'I don't take my asthma serious'

Poor knowledge about their condition and medication may lead to becoming careless about the prescribed treatment. The patient-doctor educational relationship also plays a significant role in adherence to treatment. It is thus very important to understand the emotions behind the adolescent not taking their condition serious and discuss scenarios face to face or in relevant fora for low and high adherence in terms of health and quality of life.



6. Ignorant

'I am aware of not taking my asthma medicine'

The efficacy of health literacy needs to be improved to inform young people about the consequences of poor adherence to treatment. Healthcare professionals can explore the underlying causes for non-adherence and not taking your treatment, despite knowing the consequences. The Healthcare Professional can present and discuss scenarios for low and high adherence in terms of health and quality of life face to face or in relevant fora.

Health literacy does not have a direct impact on adherence, but there is a connection between health literacy and attitude. We can think of health literacy as a communication strategy and a tool that channels communication that can influence the drivers of adherence (i.e. attitude).

In order to support the adherence of asthmatic adolescents, the efficacy of today's Health Literacy needs to be improved. In doing so, we can drive a change in attitude, that can lead to young people being empowered, equipped for adherence. Healthcare professionals can play a very strong role in advising and mentoring adolescents in their treatment and health literacy can play a role to support the communication between physicians and adolescents.

Informative communication strategies, campaigns and novel innovative tools with a focus on the 6 priorities identified, can be designed for local, national and European level, together with the young people themselves. We need to enhance the interactive and active involvement of young people in all decisions regarding their health, by setting up panel discussions on peer-to-peer basis, appointing young well-informed ambassadors that can serve as role models and good examples for other adolescent patients on how to overcome the struggle against non-adherence to decrease the impact of asthma in their daily life.

Non-intentional non-adherence to treatment follows from attitudes that are linked with emotions, such as rebelliousness, carelessness and ignorance. These are closely related to adolescent behaviour in general. Therefore healthcare professionals can approach medical adherence among adolescents more broadly than to focus solely on the doctor-patient setting.

Adherence among adolescents can be strengthened with ongoing support that is provided to them in an adequate manner, which matches their language, personality traits, cultural settings and specific needs. By educating adolescent patients regarding their condition, in a patient-friendly way, they can be empowered to change the attitude towards their treatment and to make well-informed decisions regarding their health.

European Health Policy Recommendations to drive Adherence

The following policy recommendations and specific action items to promote better medication adherence and improved health outcomes for adolescent patients with asthma arise from the EFA Survey.

1. Multidisciplinary care coordination

- Determine criteria to identify when ‘rebellious patients’ should require extra support, psychological or otherwise to address and understand the specific case of young people with asthma.
- Use of suitable drivers to support the coordination of care among the different healthcare professionals, the family and to improve medication adherence.
- Patient organisations and healthcare professionals can support the sharing of best practices and the education of patients tailored to their needs.

2. Health Information Technology

- Use of smart ICT tools to support self-management, including patients’ dose tracking, immediate feedback and consequence scenarios for non-adherence and adherence and share personal health records to improve medication adherence and optimal use.
- Use of health information technology to identify patients who are at risk for poor adherence to treatment.

3. Patient empowerment, education and management:

- Use of electronic and telephonic reminders, to help patients improve adherence and eliminate forgetfulness.
- Case management by healthcare professionals designed to educate patients how their medication can be taken correctly, what it means to have asthma and engaging into taking responsibility of their own health, in supportive environment of treating professionals and family.

- Promotion and development of educational plans, training on shared-decision making and patient communication strategies, tailored to an audience of adolescent patients, to improve medication adherence with this age group.
- Guidelines on health literacy can help make health information accurate, accessible and actionable and make health literacy tools more efficacious.
- Sharing of best practices among patients’ groups to accurately and clearly explain to adolescents with asthma the need to have their inhaler with them at all times.

4. Additional research on medication adherence

Additional research on medication adherence with adolescents with asthma is needed.

- Expand to further countries, the EFA survey was conducted in Germany, France, Spain and the U.K.
- Additional research should include the identification of factors that can improve the efficacy of health literacy.
- Additional research is needed to gain insight in the costs and (long-term) consequences associated with poor adherence.
- When researching sports promotion, a potential connection to non-adherence needs to be explored.

These recommendations should be integrated into EU initiatives and policies on chronic diseases and the EU members states health care coordination and sustainability plans and inform healthcare professionals, patient groups and all health stakeholders, recognising that young people with chronic diseases are a specific target group.

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Key Terms

1. **Correlation:** A correlation is a co-relation, or relationship between variables, without indicating a causal connection.
2. **Driver Analysis:** A key driver analysis is the statistical technique used to identify the level of impact of one or more questions (independent variables) on one specific question (dependent variable).
3. **Median:** The median is the middle number in a given sequence of numbers, taken as the average of the two middle numbers when the sequence has an even number of numbers
4. **Regression analysis:** in statistical modelling regression analysis is a statistical process to estimate the relationships among variables.
5. **Touch Point:** A Touch Point is a point of contact or interaction. In this case when treatment options come into contact with a patient.

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Annex 1: Methodology

To research this issue, a structured interview methodology was used. The structured interview was developed by Maastricht University by the summer of 2014. Adolescents with asthma between 12 and 17 years of age from Germany, France, Spain and the United Kingdom were recruited by GfK, from July to October 2015, by means of a two-step approach through physicians to ensure that only adolescents in the right age frame and with approved asthma diagnosis participated to this study.

Physicians received an informative letter with a short description of the research background, targeted to physicians, and to the patients and their parents. A consent form was provided as well, that permitted the physician to share relevant details of parents and patients (address, age and severity of asthma) willing to participate in the research. A second consent form was added that served as a letter of acceptance to take part in an interview and to provide all necessary contact details.

Based on the contact details received from the physicians, patients who had expressed interest were contacted by telephone. From July to October 2015 data was collected from 50 telephone interviews of 15-20 minutes in the four countries, totalling at 200 subjects interviewed.

Given the importance of the age barriers to the subject pool, the voice of the respondent was assessed, to double-check the respondent's age (to make sure they did not sound 'too old'); corresponding to the predefined thresholds (12-17y). Interviewers were briefed in advance, to be adequately prepared for this type of age/voice assessment.

The questionnaire was completed by four different cohorts, of 50 adolescents each, in France, Germany, Spain and the United Kingdom. It consisted of 36 questions, concerning potentially relevant factors for non-adherence to treatment with asthmatic adolescents. The questions that were included in the questionnaire followed a closed multiple choice format.

All items of the questionnaire ranged from totally agree (1) to totally disagree (5) or very good (1) to very bad (5) on a 5-point Likert scale⁴. For each scale a mean score was calculated. The minimum score to these four questions is 4, while maximum score is 20 (5 in all questions). The maximum score could be set to 100%.

⁴ A scale used to represent people's attitudes to a topic.

⁵ All available data for adherence of adolescent patients was collected by GfK on behalf of EFA.

⁶ See section 'Key terms' n° 02.

⁷ See section 'Key terms' n° 05.

The analysis of the collected data was done in three different steps:

To be able to identify which items had low and which items had high relevance for adherence among adolescents with asthma, the collected data⁵ was subjected to a descriptive analysis of characteristics as well as an advanced three-step driver analysis⁶.

A driver analysis, also known as an importance - performance analysis, is a study of the relationships among many factors, to identify which ones have the most impact on the strategic characteristic you want to explain. A driver analysis, unlike a regression analysis is not conducted to find correlations, but rather cause and effect between variables. As a result of this analysis, we can differentiate the items we used as strong or weak drivers of adherence.

The driver analysis was conducted with 24 items in 5 Touch Points⁷.

1. The first step in the driver analysis '*driver analysis of touch points overall*' shows which factors and themes can be identified as Touch Points influencing the adherence overall.

2. The second step '*Identification of Items with low Relevance*' involves the identification of items with low relevance within the Touch Points. In this step the correlation between each item and the adherence is calculated. Those items, which show no significant correlation (and where we thus can conclude that they have only low relevance for adherence) are excluded from the third step.

3. The third step '*Driver Analysis of Items*' includes a regression analysis of all items with significant correlation to adherence. A regression analysis (RA) is a statistical approach to forecast change in a dependent variable (e.g. adherence) on the basis of change in one or more independent variables (e.g. age, gender, and smoking). Relationships depicted in a regression analysis are associative only, and any cause-effect (causal) inference is purely subjective.

Building on the results of the driver analysis, we can then set priorities and develop recommendations for strategies and actions to improve the adherence among adolescents with asthma.

Annex 2: Master Questionnaire Template

Place: _____ Date: _____ ID Number: _____

Dear Participant. This research study explores how European young people follow their asthma treatment. The study is organized by the European Federation of Allergy and Airways Diseases (EFA) with support from Maastricht University, the Netherlands. The aim is to investigate the factors that hinder or enable young people between 12-17 years in following the treatment. This study is a pilot study that can help us design a bigger study in five different studies. The outcome of the research will be used to ensure better support to young people with asthma and allergies in Europe.

Informed consent: By contributing in this survey you are giving your informed consent to use the data for the purpose of this study. All contributions are anonymized. The survey takes 10 minutes to complete.

Place, Date, Signature

Age					
Gender	<input type="radio"/> Male <input type="radio"/> Female				
In which grade are you in?					
Do you smoke?	<input type="radio"/> Yes / No				
How often do you visit your Asthma specialist (pulmonologist)? <input type="radio"/> monthly <input type="radio"/> every 2 months <input type="radio"/> every 6 months <input type="radio"/> once a year <input type="radio"/> less frequent					
How often did you do sport for at least 30 minutes in the last week? <input type="radio"/> almost daily <input type="radio"/> 3x a week <input type="radio"/> less frequent					

Health	Very Good	Good	Fair	Bad	Very Bad
1. How good is your health in general?	<input type="radio"/>				

Adherence to Asthma Medicine	Daily	5x a week	3x a week	Less frequent
2. How often do you have to take your medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How often do you actually take your medication?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Health Literacy I	Very Good	Good	Moderate	Bad	Very bad	I do not make use of this kind of information
4. How well do you understand instruction leaflets for medication?	<input type="radio"/>					
5. How well do you understand information brochures on health issues?	<input type="radio"/>					

6. When I have questions on diseases or complaints, I know where I can find information on these issues

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I do not have experience with these issues

7. When I want to do something for my health without being sick, I know where I can find information on these issues

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I do not have experience with these issues

8. How often were you able to help your family members or a friend if they had questions concerning health issues

- Never
- Seldom
- Sometimes
- Often
- Always
- There have never been any questions

10. How well are you doing in choosing the advices and offers that fit with you the most

- Very Good
- Good
- Moderate
- Bad
- Very Bad
- I have not been interested in these issues

11. Regarding information on health on the Internet, I'm able to determine which sources are of high and which of poor quality

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- I do not have experience with these issues

Health Literacy II	Very easy	Easy	Difficult	Very difficult	I don't know
12. It is easy for me to find information concerning my asthma	<input type="radio"/>				
13. It is easy for me to understand information about my asthma	<input type="radio"/>				
14. It is easy for me to judge if the asthma information I get is relevant	<input type="radio"/>				
15. It is easy for me to use information about asthma	<input type="radio"/>				

Attitude	Totally agree	Agree	Neutral	Disagree	Totally disagree
16. I don't mind telling others about my asthma	<input type="radio"/>				
17. I don't like others to know about my asthma	<input type="radio"/>				
18. I feel uncomfortable taking my medicine in front of others	<input type="radio"/>				
19. I don't like to talk about my asthma	<input type="radio"/>				
20. Other people influence how I think about my asthma	<input type="radio"/>				

Behavior	Totally agree	Agree	Neutral	Disagree	Totally disagree
21. I don't take my asthma serious	<input type="radio"/>				
22. I am aware of the consequences of not taking my asthma medicine	<input type="radio"/>				
23. The doctor should not tell me what to do	<input type="radio"/>				
24. I don't do what my doctor tells me	<input type="radio"/>				
25. Sometimes I forget to take my medicine.	<input type="radio"/>				

Support	Totally agree	Agree	Neutral	Disagree	Totally disagree
26. My parents support me in taking my medication	<input type="radio"/>				
27. My friends understand my asthma problems	<input type="radio"/>				
28. My friends don't tease me because of my asthma	<input type="radio"/>				
29. My doctor encourages me to deal with my asthma	<input type="radio"/>				

Daily Impact of Asthma	Totally agree	Agree	Neutral	Disagree	Totally disagree
30. My asthma symptoms come and go	<input type="radio"/>				
31. When I feel better then I stop taking my Asthma medicine	<input type="radio"/>				
32. When I feel worse, I take my Asthma medicine	<input type="radio"/>				

Adherence	Totally agree	Agree	Neutral	Disagree	Totally disagree
33. I follow my asthma treatment as I am told by the doctor	<input type="radio"/>				
34. It is difficult for me to take my asthma medication as my doctor told me	<input type="radio"/>				
35. Taking my medication enables me to be active	<input type="radio"/>				
36. My busy life hinders me from taking my medication	<input type="radio"/>				

Remarks about the questionnaire	Totally agree	Agree	Neutral	Disagree	Totally disagree
It was difficult for me to understand and answer the questions	<input type="radio"/>				
Which question(s) did you not understand or were difficult to answer? (Multiple answers possible)	Question No. -----				

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