



Working for Better Asthma Control: How Can We Improve the Dialogue Between Patients and Healthcare Professionals?

Kevin Gruffydd-Jones · Kjeld Hansen

Received: September 23, 2019 / Published online: October 29, 2019
© The Author(s) 2019

Abstract: Asthma is a chronic disease affecting more than 300 million people globally. Poor asthma control that leads to unnecessary symptoms is estimated to affect nearly half of people with asthma. A critical way to address poor control is for healthcare professionals (HCPs) and patients to enter a shared dialogue on treatment and asthma management. This article explores the views of both patient and HCP to better understand how to achieve asthma control. From the patient's perspective, being a person with asthma has ramifications to one's sense of identity, and thus one's ability and willingness to actively manage their asthma. Furthermore, lack of education and concerns about the effectiveness of treatment can also ultimately lead to poor control, a term that can be understood differently by patients

and HCPs. One goal is to help to normalise life for people with asthma. For this, HCPs need to align on what this means for each individual and then work together to produce a plan that can be applied to the patient's daily life. Training for HCPs on good communication skills and empowering patients to be involved in their asthma management are both critical to ensure effective shared decision-making and, ultimately, improved quality of life for people with asthma.

Funding: Boehringer Ingelheim.

Plain Language Summary: Plain language summary available for this article.

Keywords: Asthma; Decision-making; General practitioners; Goals; Patient participation; Self-management

Enhanced Digital Features To view enhanced digital features for this article go to <https://doi.org/10.6084/m9.figshare.9994856>.

K. Gruffydd-Jones (✉)
Box Surgery, Box, Wiltshire, UK
e-mail: k.gruffydd-jones@nhs.net

K. Hansen
Copenhagen Business School, Frederiksberg,
Copenhagen, Denmark

K. Hansen
Kristiania University College, Oslo, Norway

Key Summary Points

Asthma is a chronic disease affecting more than 300 million people globally, of whom nearly half are estimated to have poor asthma control that leads to unnecessary symptoms.

This article explores the views of both patient and HCP to better understand how to achieve asthma control.

To achieve good asthma control, it is important to align on shared goals at the outset of treatment, taking into consideration the beliefs and experiences of people with asthma.

It is vital that patients and HCPs discuss the importance of both current control and reducing future risk.

Regular review should include discussion of treatment goals and any concerns, needs and priorities that patients may have, ensuring a greater involvement of patients in the shared written action plan.

PLAIN LANGUAGE SUMMARY

Asthma is a long-term lung condition that can affect people's daily lives. Treating asthma involves routinely taking medicine, even when symptoms are not present. This can be difficult. Over half of patients do not have good enough control of their asthma. We need ways to improve this control to achieve better quality of life. In this article, both a healthcare professional and a person with asthma discuss some of the issues. They look for solutions that can be gained by sharing treatment decisions with patients. Talking about asthma with a doctor is an important part of making people's lives better. This helps doctors and patients agree on treatment goals. Doctors should receive training on the best ways to talk openly with patients. People can then be empowered to be in charge

of their asthma. Ultimately, people should be able to enjoy doing regular activities unburdened by asthma. Patients and doctors talking together is key to success with asthma.

INTRODUCTION

Globally, more than 300 million people of all ages are believed to have asthma, a chronic disease characterised by airway inflammation and respiratory symptoms [1–3]. The characteristics and intensity of asthma symptoms vary between people and over time [3]. Despite detailed asthma management strategies and available treatments, it is estimated that around half of people with asthma have poor asthma control [3–6]. One important way of improving outcomes is for healthcare professionals (HCPs) and patients to have a shared dialogue on treatment and asthma management. Indeed, asthma guidelines emphasise collaborative decision-making [3], and this article will mirror this by being co-authored by an HCP and a person with asthma. Dr. Gruffydd-Jones is a general practitioner in the UK and member of the International Primary Care Respiratory Group, and Mr. Hansen is a person with asthma who, amongst other activities, has represented people with asthma in European Lung Foundation activities.

Evidence from randomised controlled trials and meta-analyses show the benefit of shared decision-making in improving quality of life, disease control, lung function, adherence and patient empowerment [7, 8]. However, to achieve this, HCPs may need further guidance on the best approach to shared decision-making. Many previous articles evaluating patients' attitudes and beliefs about their asthma utilise survey data, which may make assumptions from an HCP's perspective [6, 9–11]. It is important for patients to have a voice to share their challenges and to exchange ideas with HCPs to together develop innovative approaches and achieve fresh insight.

We aim here to take a qualitative approach and discuss issues facing both patients and HCPs in order to achieve good asthma control through optimised management. By exploring

the opinions of both patient and HCP, we seek to make suggestions for improved care using shared decision-making. Although we recognise that it is a limitation that we only present the views of one patient and one HCP, rather than seeking a larger sample, we feel that the viewpoints are still of interest and will stimulate further debate and research.

Finally, while the scope of this article will be from a European perspective, it should be noted that patients' and HCPs' experiences and perspectives across Europe are diverse and culturally influenced; therefore, readers should consider their own experiences as well as local guidance. However, we find that many of our approaches could be generalisable, and that globally all patients and HCPs who face similar problems can benefit from this article and apply the learning within their own healthcare system.

This article is based on previously conducted studies and does not contain any studies with human participants or animals performed by any of the authors.

WHAT DOES GOOD ASTHMA CONTROL MEAN?

Patient's Perspective (Kjeld Hansen)

It can be difficult for people with asthma to always perceive exactly how treatment and medicines improve their lives, especially when people may have difficulties grasping where their asthma begins and ends. For example, if you have grown up with asthma, it may be a core part of who you are, and you may not know what to expect in a life without symptoms.

Some people with asthma might focus more on feigning normality over achieving asthma control. For example, a person may be embarrassed to display their asthma in front of friends, colleagues or sports teammates. Another example may be a person who is reluctant to report too many symptoms to their HCP, and instead modify their daily behaviour so they only report a manageable number of symptoms.

While people may have a good understanding of and attitude to asthma, it may not be a top priority in their life at a given time. I believe that many people manage their asthma for the present rather than the future, partly because they manage their asthma on the basis of past experiences, but also because they may not fully appreciate the impact of their current actions on their condition in the future.

My own perception of what it means to live with good asthma control has changed a lot over the years; previously, I would restrict myself to certain activities, whereas now I have an expectation of a normal (i.e. stable, unrestricted) life, and this drives my attitude and actions towards asthma management.

HCP's Perspective (Kevin Gruffydd-Jones)

HCPs' perceptions of what constitutes good asthma control are led by national and international guidelines [3, 12]. Table 1 shows the Global Initiative for Asthma (GINA) criteria for assessing asthma control [3]. There is undoubtedly a mismatch between HCPs' and patients' perceptions of control, with many patients overestimating their level of control compared with expert definitions [13]. A survey of 517 patients with mild-to-moderate asthma showed that while 91% of patients initially felt their asthma was under control, only one-third met the guideline definition of control [3, 13]. Many patients remain unaware of what asthma control means and that they can expect to live a normal life if their asthma is well managed. Another key aspect, which is not appreciated by many HCPs, is that asthma control is not just assessed by current symptom control, but also by assessing future risk of exacerbations.

BARRIERS TO ACHIEVING GOOD ASTHMA CONTROL

Patient's Perspective (Kjeld Hansen)

The process of achieving good asthma control through appropriate asthma management should not be regarded as a straightforward

Table 1 GINA assessment of asthma control in adults, adolescents and children aged 6–11 years [3]

A. Asthma symptom control		Level of asthma symptom control		
In the past 4 weeks, has the patient had:		Well controlled	Partly controlled	Uncontrolled
<ul style="list-style-type: none"> • Daytime asthma symptoms more than twice/week? Yes <input type="checkbox"/> No <input type="checkbox"/> • Any night waking due to asthma? Yes <input type="checkbox"/> No <input type="checkbox"/> • Reliever needed for symptoms* more than twice/week? Yes <input type="checkbox"/> No <input type="checkbox"/> • Any activity limitation due to asthma? Yes <input type="checkbox"/> No <input type="checkbox"/> 	}	None of these	1–2 of these	3–4 of these
B. Risk factors for poor asthma outcomes				
Assess risk factors at diagnosis and periodically, particularly for patients experiencing exacerbations.				
Measure FEV ₁ at start of treatment, after 3–6 months of controller treatment to record the patient's personal best lung function, then periodically for ongoing risk assessment.				

©2019 Global Initiative for Asthma, available from www.ginasthma.org, reprinted with permission [3]

FEV₁ forced expiratory volume in 1 s, GINA Global Initiative for Asthma

linear process. As patients' needs and lifestyles change, so too may symptoms develop, and therefore regular review and management is required, even in the absence of symptoms. One major barrier to achieving good asthma control is failure to take medication as prescribed. Poor adherence can have multiple causes, but perception of the medicine and how it works plays a major role. Furthermore, there can be the perception that asthma management involves restrictions on life or containing the damage, instead of focusing on what can be achieved with good asthma management. Taking medication regularly and correctly involves accepting the label of having asthma into one's sense of identity. Furthermore, not having an immediate positive feedback response from asthma medication may cloud a person's perception of its effectiveness.

A particular challenge with long-term asthma management is that people with asthma can form false habits and perceptions about what they can achieve. Some may not have experienced long-term positive changes to their asthma symptoms, which may reinforce their negative expectations. This can lead to thinking that it is not possible to improve with treatment and that another follow-up visit is a nuisance.

Whilst there are some people with asthma who are keen and able to take their own initiative, others may face difficulties making

themselves understood by their HCP, and this can make shared decision-making between patients and HCPs challenging. If patients are to self-manage more, then they would also gain more authority over their own health situation. However, this changing relationship might be a scary proposition for some patients, who are more confident with their HCP telling them how they feel rather than trusting their own judgement. In my experience, many patients worry about how to explain a certain observation or problem to their doctor in a way that is perceived as intended. Hopefully, with improved professional healthcare training on methods of dialogue and enhanced expectations from patients, this will improve both patients' asthma control and their quality of life.

HCP's Perspective (Kevin Gruffydd-Jones)

A particular barrier to good control is poor adherence, which can be either unintentional or intentional [14]. Patients with unintentional non-adherence are unaware that they are not complying with their treatment regimen; this can be due to misunderstanding the regimen, incorrect inhaler technique or language barriers. Intentional non-adherence involves a conscious decision from the patient (e.g. altering

the amount of medication taken), and is critically linked to their perception of their asthma and concerns about a treatment's potential side effects. Poor adherence with inhaled corticosteroids (ICS) and other long-term asthma medication is linked with an increase in asthma symptoms and the risk of death [14, 15]. In a UK-wide cross-sectional study, surveyed clinicians vastly underestimated the prevalence of side effects experienced by the surveyed patients, and this compromised adherence [16].

A major barrier to achieving good asthma control is a lack of regular asthma review. Proactive asthma review in the context of a supported self-management programme, including personal action plans, improves asthma outcomes [17]; however, the 2014 UK National Review of Asthma Deaths highlighted that nearly half of patients had not received an adequate asthma review or a personal action plan in the year before their death [15]. Furthermore, a recent survey of 1809 physicians across six countries estimated that only 37% of their patients were issued with a personal action plan [18].

There are also other barriers: in terms of shared decision-making, there must be the will and ability on both sides to ensure effectiveness. Barriers to this include the relationship between the individual HCP and the patient, lack of knowledge/skills on behalf of the HCP, and a perceived lack of time for the process.

FINDING COLLABORATIVE SOLUTIONS TO ACHIEVE ASTHMA CONTROL (JOINT DISCUSSION)

Table 2 shows our suggestions for use of joint decision-making in achieving better asthma control. Firstly, it is important to understand the patient's view about what they would like to achieve and what they perceive as good asthma control. Asthma control should be contextualised with other aspects of the patient's life; for example, are there other comorbidities, including psychosocial problems? Is asthma control a current priority? An individual's goals may differ from conventional medical goals; for example, they may be focusing on short-term

management. Therefore, it is important to start discussions by aligning on the patient's goals, moving away from a symptoms treatment process towards a more holistic approach to healthcare. The HCP should then share their aims for good asthma control in terms of current control and reducing future risk. A shared aim can then be developed and incorporated into the individualised self-management plan. To improve adherence, emphasis should be on the benefit of taking regular medication. Also, any medication concerns should be explored; for example, discussing the trade-off between symptoms and side effects may lead a person with asthma choosing to accept some symptoms to keep a lower ICS dose. Such decisions can be implemented in the action plan. It is also vital to employ practical solutions to overcome causes for unintentional non-adherence such as incorrect inhaler technique. While shared decision-making can initially take up more consultation time, this can be facilitated by a longer appointment to formulate a treatment plan or the use of an extended consultation (several short consultations over a period of time).

Achieving shared goals should be considered a never-ending process, perhaps akin to life-long learning. It is helpful to signpost towards resources, such as educational materials supplied by national asthma support groups or collaboration with local asthma support networks and patient groups. For people with asthma, education on how therapy works and how to accept the disease can be very empowering.

Furthermore, written asthma action plans are key for successful shared decision-making in asthma management [17]. They provide an opportunity to state what normal looks like for the patient, and to formulate treatment plans for when the patient is either stable or unwell. The plan should be individualised to consider shared decisions, and adapted to cultural and language factors. Patients' perceptions, skills and aims change, so it is vital that plans are reviewed at each regular follow-up appointment.

Different strategies have been used to improve access to routine reviews.

Table 2 Our recommendations to achieve shared goals for asthma control

Actions for HCPs	Questions and prompts for successful dialogue
Understand the patient's perspective	What does a normal lifestyle look like to you?
Discuss patient/HCP perspectives of what good control should look like both in the short and long term	Do you feel restricted by your asthma? If so, how? What is your goal for treatment and management? How do you prioritise your asthma treatment?
Discuss perceptions of the benefits and risks of a particular treatment regimen	Do you have any concerns about taking your medication? How does taking your medicine help you? What do you feel are the key factors in your treatment that can help you to keep your asthma under control?
Address concerns about potential treatment side effects and include in the action plan	There often needs to be a trade-off between symptoms and side effects—what are your short-term and long-term concerns?
Open up the discussion by looking at the impact of comorbidities, including rhinitis, psychological, social, etc.	How much does asthma affect your daily life in relation to any other potential health problems? Is managing your asthma a current priority for you?
Emphasise the value of discussion and support with peers with asthma, family/friends and other support networks	What asthma support networks do you have? It can be helpful to be supported by people in a similar situation It is really important that you are supported when you are healthy as well as when suffering symptoms
Share patient educational materials from third-party organisations such as ELF/Asthma UK	Have you explored any online asthma education resources? Would you like to get in touch with patient groups or health organisations?
Ensure that regular medical reviews are in place; set up follow-up appointments immediately after each appointment	We will need to regularly check up on how this treatment is helping you. Please book in your next review and check-up appointment
Create an individualised written action plan together with all patients	Please remember to keep a copy of your action plan handy at home, maybe on your fridge, and bring it along to the next appointment
Factor in literacy, language barriers and cultural differences	
Update it at each appointment	
Check understanding of the plan	

ELF European Lung Foundation, *HCP* healthcare professional

Teleconsultations by nurses can increase the number of patients reviewed for their asthma control, and allow individualised asthma plans to be discussed and written versions to be

received by the patient [19]. Use of telemedicine may improve outcomes in selected patients in the context of clinical trials [20], although expense may limit its use in a broader

Table 3 Communication strategies for healthcare professionals [3, 21–23]

Key strategies to facilitate good communication
<ul style="list-style-type: none"> • A congenial demeanor (friendliness, humor and attentiveness) • Allowing the patient to express their goals, beliefs and concerns • Empathy, reassurance, and prompt handling of any concerns • Giving encouragement and praise • Giving appropriate (personalized) information • Providing feedback and review
Specific strategies for reducing the impact of impaired health literacy
<ul style="list-style-type: none"> • Order information from most to least important • Speak slowly and use simple words (avoid medical language, if possible) • Simplify numeric concepts (e.g. use numbers instead of percentages) • Frame instructions effectively (use illustrative anecdotes, drawings, pictures, table or graphs) • Confirm understanding by using the ‘teach-back’ method (ask patients to repeat instructions) • Ask a second person (e.g. nurse, family member) to repeat the main messages • Pay attention to non-verbal communication by the patient (e.g. poor eye contact) • Make patients feel comfortable about asking questions

©2019 Global Initiative for Asthma, available from www.ginasthma.org, reprinted with permission [3]

population, and it should be used in combination with in-person consultations. Overall, regular follow-up appointments are important to review control, adjust treatment, review agreed asthma action plans and encourage patient–HCP dialogue.

To implement all the above strategies, good communication skills are required by the HCP. The 2019 GINA report suggests possible communication strategies (Table 3) [3]. Further education is needed to support HCPs, especially those who are not specialised in asthma.

CONCLUSIONS

We believe that improving dialogue between people with asthma and HCPs will improve our chances of success with asthma management. To achieve good asthma control, it is important to align on shared goals at the outset of treatment, taking into consideration the beliefs and experiences of people with asthma. It is vital that patients and HCPs discuss the importance of both current control and reducing future risk. Regular review should include discussion of treatment goals and any concerns, needs and priorities that patients may have, ensuring a

greater involvement of patients in the shared written action plan.

ACKNOWLEDGEMENTS

Funding. Boehringer Ingelheim provided financial support for the medical writing assistance and reviewed the manuscript for factual accuracy only. They also funded the journal’s Rapid Service and Open Access Fees.

Medical Writing, Editorial and Other Assistance. Medical writing assistance, in the form of the preparation and revision of the draft manuscript, was supported financially by Boehringer Ingelheim and provided by Helen Moore, PhD, of MediTech Media, under the authors’ conceptual direction and based on feedback from the authors.

Authorship. Both named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work as a whole and have given their approval for this version to be published. Both

authors take full responsibility for the scope, direction, content of, and editorial decisions relating to the manuscript, were involved at all stages of development, and have approved the submitted manuscript.

Disclosures. Kevin Gruffydd-Jones has spoken on behalf of and worked as a consultant for AstraZeneca, Boehringer Ingelheim, Chiesi, GlaxoSmithKline, Mundipharma, Napp, Novartis and Pfizer. Kjeld Hansen has spoken on behalf of and worked as a consultant for Boehringer Ingelheim, the European Lung Foundation and GlaxoSmithKline.

Compliance with Ethics Guidelines. This article is based on previously conducted studies and does not contain any studies with human participants or animals performed by any of the authors.

Data Availability. Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Open Access. This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits any non-commercial use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

REFERENCES

- Global Burden of Disease 2016 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet*. 2017;390(10100):1211–59.
- Bousquet J, Khaltaev N. Global surveillance, prevention and control of chronic respiratory diseases: a comprehensive approach. Geneva: World Health Organization; 2007.
- Global Initiative for Asthma (GINA). Global strategy for asthma management and prevention (2019 report); 2019. <https://ginasthma.org/wp-content/uploads/2019/06/GINA-2019-main-report-June-2019-wms.pdf>. Accessed September 16, 2019.
- Demoly P, Annunziata K, Gubba E, Adamek L. Repeated cross-sectional survey of patient-reported asthma control in Europe in the past 5 years. *Eur Respir Rev*. 2012;21(123):66–74.
- Lee LK, Obi E, Paknis B, Kavati A, Chipps B. Asthma control and disease burden in patients with asthma and allergic comorbidities. *J Asthma*. 2018;55(2):208–19.
- Price D, Fletcher M, van der Molen T. Asthma control and management in 8,000 European patients: the REcognise Asthma and Link to Symptoms and Experience (REALISE) survey. *NPJ Prim Care Respir Med*. 2014;24:14009.
- Wilson SR, Strub P, Buist AS, et al. Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *Am J Respir Crit Care Med*. 2010;181(6):566–77.
- Kew KM, Malik P, Aniruddhan K, Normansell R. Shared decision-making for people with asthma. *Cochrane Database Syst Rev*. 2017;10:CD012330.
- Sastre J, Fabbri LM, Price D, et al. Insights, attitudes, and perceptions about asthma and its treatment: a multinational survey of patients from Europe and Canada. *World Allergy Organ J*. 2016;9:13.
- Adams RJ, Wilson DH, Taylor AW, et al. Psychological factors and asthma quality of life: a population based study. *Thorax*. 2004;59(11):930–5.
- Chapman KR, Boulet LP, Rea RM, Franssen E. Suboptimal asthma control: prevalence, detection and consequences in general practice. *Eur Respir J*. 2008;31(2):320–5.
- British Thoracic Society. SIGN 158. British guideline on the management of asthma, 2019. <https://www.brit-thoracic.org.uk/quality-improvement/guidelines/asthma/>. Accessed September 16, 2019.
- Haughney J, Barnes G, Partridge M, Cleland J. The Living & Breathing Study: a study of patients' views of asthma and its treatment. *Prim Care Respir J*. 2004;13(1):28–35.
- Cochrane GM, Horne R, Chanez P. Compliance in asthma. *Respir Med*. 1999;93(11):763–9.
- Royal College of Physicians. Why asthma still kills: the National Review of Asthma Deaths (NRAD); 2015. <https://www.rcplondon.ac.uk/projects/>

- [outputs/why-asthma-still-kills](#). Accessed September 16, 2019.
16. Cooper V, Metcalf L, Versnel J, Upton J, Walker S, Horne R. Patient-reported side effects, concerns and adherence to corticosteroid treatment for asthma, and comparison with physician estimates of side-effect prevalence: a UK-wide, cross-sectional study. *NPJ Prim Care Respir Med*. 2015;25:15026.
 17. Gibson PG, Powell H, Coughlan J, et al. Self-management education and regular practitioner review for adults with asthma. *Cochrane Database Syst Rev*. 2002;1:CD001117.
 18. Chapman KR, Hinds D, Piazza P, et al. Physician perspectives on the burden and management of asthma in six countries: the Global Asthma Physician Survey (GAPS). *BMC Pulm Med*. 2017;17(1):153.
 19. Gruffydd-Jones K, Hollinghurst S, Ward S, Taylor G. Targeted routine asthma care in general practice using telephone triage. *Br J Gen Pract*. 2005;55(521):918–23.
 20. Chongmelaxme B, Lee S, Dhippayom T, Saokaew S, Chaiyakunapruk N, Dilokthornsakul P. The effects of telemedicine on asthma control and patients' quality of life in adults: a systematic review and meta-analysis. *J Allergy Clin Immunol Pract*. 2019;7(1):199–216.e11.
 21. Partridge MR, Hill SR. Enhancing care for people with asthma: the role of communication, education, training and self-management. 1998 World Asthma Meeting Education and Delivery of Care Working Group. *Eur Respir J*. 2000;16(2):333–48.
 22. Maguire P, Pitceathly C. Key communication skills and how to acquire them. *BMJ*. 2002;325(7366):697–700.
 23. Rosas-Salazar C, Apter AJ, Canino G, Celedon JC. Health literacy and asthma. *J Allergy Clin Immunol*. 2012;129(4):935–42.