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Clinician perspectives on a culturally adapted patient decision aid concerning maintenance therapy for asthma

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ABSTRACT

Background and Objective: Patients with persistent asthma often show poor adherence to inhaled corticosteroids (ICS). Shared decision-making can improve adherence rates in this population. Patient decision aids (PDAs) are tools to facilitate shared decision-making. To date, only one PDA, developed in a Canadian French-speaking population, exists for patients considering ICS maintenance therapy. This PDA has been culturally adapted in this study to contextualize to the needs of multi-ethnic Asian patients in Singapore. This study explored the views of local clinicians on the content, design and implementation of this newly-adapted PDA.

Methods: 24 clinicians, who were purposively sampled from polyclinics and a tertiary institution, were interviewed on the content, design and implementation of the PDA. The interviews were audio-recorded, transcribed and analyzed via thematic analysis.

Results: Clinicians generally accepted the design of the PDA. They suggested for the target users to be patients on Step 2 of GINA guidelines and the number of options to be reduced from four to two (do nothing or start inhaled corticosteroids). Moreover, they supported including a list of values for patients to select from given that Asian patients often do not articulate their values readily. The addition of more visual aids, the production of multilingual Asian editions and the involvement of nurses to administer the PDA was also suggested.

Conclusion: The PDA was culturally-adapted with local clinicians' perspectives to target multi-ethnic Asian patients with persistent asthma (Step 2 GINA guidelines). The main changes include a list of values and addition of visual aids.

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Introduction

Asthma is a prevalent chronic inflammatory respiratory disease that affects about 339 million people worldwide (1). To reduce airway inflammation, international guidelines recommend the use of inhaled corticosteroids (ICS). However, poor adherence to ICS can be as high as 32% to 56% (2–4). Poor adherence is correlated with patients' misunderstanding and concerns about asthma medications (5), which are often not elicited nor adequately addressed by their physicians. The latter infrequently involve patients in choosing their asthma treatment options (6) as many physicians have still not adopted shared decision-making (SDM) as part of their routine practice (7).

Barriers to involving patients in decision-making include physicians' perceptions of a lack of suitable information designed specifically to support patient involvement (8–9) and the difficulty in presenting the

numerical risk in an understandable manner to patients (10). These barriers hinder the conduct of SDM in clinical practice (11).

SDM is a process by which health decisions are discussed and made jointly by the patient and their healthcare provider, taking into account the best-available evidence and the patients' unique values and preferences (12). Studies have reported that clinicians who adopt SDM achieve better patient degrees of satisfaction with the decision made (13), greater rates of patient involvement in their treatment (14) and improved medication adherence and clinical outcomes (15). SDM can be facilitated by knowledge translation tools, such as a patient decision aid (PDA), which presents evidence in a clear, concise and user-friendly format to aid decision making (16). In contrast with conventional educational materials, a PDA can reduce decisional conflict of patients, enable patients to recognize the values-sensitive nature of the

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decision and clarify the value they place on the benefits and harms. In addition, PDAs can provide structured guidance in the steps of decision making and communication with family and clinicians (14,17).

The development of a PDA involves a substantial amount of resources, in terms of time, logistical costs and manpower (18). Adapting a PDA can save on these resources. However, a PDA needs to be adapted to the cultural setting that it is intended for, in order to meet the needs of the target population. Chenel et al. (19) described four phases in the cultural adaptation process of PDAs: exploration, adaptation to the new cultural context, lab testing the preliminary version and field testing. This study focused on the exploration and adaptation phases of a PDA on ICS.

Singapore is an urbanized island state located in Southeast Asia whose population consists of multi-ethnic Asians (i.e. Chinese, Malay and Indians). The prevalence of asthma in Singapore is about 10.5% among adults aged 18 to 69 years (20). English is the most common language spoken in Singapore (21) and is usually used in local clinical practice.

Currently, from the Ottawa Hospital Research Institute Decision Aid Library Inventory, only a French-language PDA on ICS has been developed (22–23). This French decision aid on ICS, developed in Canadian French-speaking patients with asthma, was translated to English. Its target audience was patients, aged 18 to 65 years, suffering from persistent asthma, and prescribed ICS as a regular controller treatment (24–26). However, this PDA was not developed in a multi-ethnic Asian context and terms used in this PDA may be foreign to patients in Singapore. Furthermore, the pattern of asthma medication prescription in Singapore has been heavily influenced by the doctors' medical training and acquisition of asthma-related information, as well as, costs related to differential subsidies in the consultation fees and drugs between public clinics and private clinics in the local primary healthcare system (27).

The clinicians' perspectives on the PDA would contribute toward the action cycle of the Knowledge to Action (KTA) framework, by contextualizing content of the original patient decision aid developed by the University of Laval to the Asian healthcare environment in Singapore. Engaging the stakeholders, such as the clinicians, is a crucial component of the action cycle (28). Their feedback on the PDA would contextualize the content to ease its implementation during consultations with local patients. Therefore, we propose to interview clinicians on this PDA to culturally-adapt it for local patients. This study aimed to culturally adapt an existing PDA for patients considering taking ICS to manage asthma while

integrating clinician perspectives on design, content, and plan of implementation in a refined PDA.

Methods

Development of the PDA prototype

We have adapted the PDA on ICS developed by University of Laval in Canada (26). The PDA by University of Laval was designed according to the 4-step structure of the Ottawa Personal Decision Guide (OPDG), which incorporated the principles of the ODSF: the PDA serves to 1) clarify the decision to commence or resume ICS therapy, 2) explore the decision by comparing and weighing the risks and benefits of this maintenance treatment, 3) identify the decisional needs and 4) guide its implementation in clinical practice. This PDA satisfies all of the criteria of the International Patient Decision Aid Standards, which is an internationally-accepted criteria to guide the development and assess the quality of decision aids (29). The target audience is patients with mild, moderate or severe asthma aged 18–65 years old.

With reference to the original PDA by the University of Laval, we have designed our PDA prototype. Our prototype was delivered via an 18-page, colour-printed B5-size booklet. The ODSF framework calls for the inclusion of four essential elements in a PDA, which are introducing the decision; describing benefits, risks and probabilities; clarifying and communicating values; and clarifying unresolved needs and next steps. These essential elements have been incorporated in this PDA prototype. The first six sections guide decision-making. A brief description of asthma and its management is followed by the current treatment options, which is similar to the French version. Then, a table lists the merits of each treatment option and its associated risks. In the section on 'What is important to you?', known patient values and preferences are listed for easy referencing. Thereafter, the patient completes a knowledge test about the options and the SURE test to elicit unresolved needs (30). This test was also present in the French PDA. The SURE test is the screening version of the Decisional Conflict Scale and includes modifiable factors contributing to decisional conflict, such as feeling uninformed and unsupported (31). The last section 'What is your choice?' allows the patient to indicate his or her choice after completing the PDA.

Study design

A qualitative research design was employed to deep dive into the subjective views of clinicians on the

content, design and plan of implementation of the newly designed PDA prototype.

Conceptual framework

The Ottawa Decision Support Framework (ODSF), which emphasizes the provision of interventions to support decision-making so as to prepare the patient and clinician alike to make and implement a medical decision, often in the context of treatment selection (32), underpins the basis of this qualitative research study (33). This study leveraged upon the ODSF to understand the perspectives of the clinicians in using a decision aid to support their patients with persistent asthma in choosing ICS as maintenance therapy.

Study site

The study was conducted at the Bedok Polyclinic, a public primary care clinic in the eastern region of Singapore that is an accredited training center for family medicine (FM). The polyclinic physicians include FM faculty members and trainers, family physicians with postgraduate qualifications, medical officers and FM residents or trainees. Its 25 physicians and 32 primary care nurses serve approximately 1,000 multi-ethnic Asian residents daily during office hours. The polyclinic was managing about 1,500 patients with asthma in 2019.

Study population

The primary target participants were primary care professionals who had declared that they had previously managed patients with asthma. Both senior and junior polyclinic physicians were purposively recruited as the future utility of the PDA prototype might vary depending on the level and years of FM training of the clinician administering it together with their experiences in managing asthma in primary care. Senior family physicians from the institution steering workgroup on asthma were also deliberately recruited as they were considered opinion leaders poised to spearhead and enhance asthma care across all polyclinics in the institution. In addition, both senior and junior asthma-trained nurses at the study site were recruited for involvement in this study. These nurses routinely counsel patients with asthma and will be a major group of future users of the PDA. A pulmonologist from a tertiary hospital was also invited to provide feedback on the PDA from a specialist's perspective.

Recruitment procedure

The chosen clinicians were invited by email. Those who expressed interest in participating in the study were emailed a hard copy of the PDA two weeks prior to the date of their interview. At the same time, they were given a participant information sheet to understand the study rationale and protocol prior to the interview. After queries were addressed on the day of the interview, the participants provided written informed consent before the commencement of their interview.

Topic guide

The topic guide contained questions to explore participants' views on the content and perceived utility of the PDA in general practice. It also specifically sought to collect their views on the design of the PDA in terms of its flow of ideas, understandability and mode of delivery.

Interviews

One-to-one in-depth interviews (IDIs) were conducted initially to assess the scope of the topic guide. Focus-group discussions (FGDs) involving five to seven participants were subsequently carried out. The FGDs allowed for the exchange and deliberation of views of the various participants. The interviews were conducted by investigator, Z.L.F., who is a family physician with a Master's degree in medicine (FM) and trained in qualitative research. A co-investigator was present alongside the interviewer to take field notes during the interviews. Each interview was conducted in a quiet room at the study site to ensure privacy. The participants were addressed by their assigned study identification label during the interviews and each session lasted between 40 min (for IDIs) and 70 min (for FGDs). All sessions were audio-recorded and later transcribed verbatim by either the study team member, N. J. Y. X. or a professional transcriber with reference to the field notes.

Data coding

The transcripts were proof-read and audited by one investigator (Z. L. F.). Separately, N. S. H. A. is an asthma nurse counselor and nursing trainer. Upon familiarization with the transcripts for the first two IDIs, Z. L. F. and N. S. H. A. independently coded the data. Any discrepancy was resolved by discussion and consensus on the coding framework was attained.

The coding framework helped to guide the coding of subsequent interviews. New codes that emerged from subsequent interviews were added to the coding framework following the agreement of both investigators (34).

Data analysis

The codes were reviewed repeatedly and themes were constructed, using the research question and conceptual framework as guides. The interviews were terminated when no new theme was identified. Ultimately, data saturation (35) was achieved after six IDIs and three FGDs.

Ethics approval

The study was approved by the SingHealth Centralized Institutional Review Board (approval no. 2018/3105).

Results

A total of 24 participants, which included 12 physicians, 11 nurses and a pharmacist aged between 26 to 73 years, were interviewed. 6 participants were interviewed one-on-one. The first focus group had 6 participants ($n=6$), the second focus group had 5 participants ($n=5$) and the third focus group had 7 participants ($n=7$). Their profiles are presented in Table 1.

The results are presented according to the content, design and perceived mode of implementation of the PDA prototype.

Content

Adequacy of information

Participants felt that the information on asthma as a long-term medical condition, the importance of ICS

maintenance therapy, the benefits and side effects of medications and patients' values were adequately covered in the PDA prototype. They found the whole PDA to be useful in facilitating the counseling of patients.

Actually, the whole document is very useful. I wouldn't say it covers everything about asthma education but [it] drives home the key messages that we are trying to educate our patients with. The inhaled steroids reducing the airway inflammation is something we try to (tell) the patients and I think it tackles the most important part here.

D1, FM physician with postgraduate qualifications

I personally think it's sufficient since it's going to be used by a layman. It's written in simple language and easy to understand – [it's] easy to counsel them on what is this condition about as well. I think there's nothing much that needs to be added to it.

D5, FM resident/trainee

Informed patient decision

Participants opined that the PDA in its current form enables the patient to make the decision to commence ICS maintenance therapy.

The decision to be made is clear. More importantly, it is helping the patients to make the 'right' decision to start ICS.

D12, FM physician, senior management position in the polyclinic

Just like blood pressure and diabetes...to show them that the medicine (for asthma) is required as a long-term treatment.

P1, pharmacist, polyclinic

Presentation of choices of therapy

Participants disagreed with listing the medications Montelukast and Omalizumab as alternative options to ICS. These medications have specific indications in the step-up approach in asthma treatment. It was felt

Table 1. Demographic characteristics of the participants.

	Demographic profiles	Participants ($n=24$)
Gender	Male	7
	Female	17
Age (years)	Less than 35	8
	35 and above	16
Physicians	Pulmonologist	1
	FM physician - Senior Management	1
	FM physicians - Members of Respiratory Workgroup	2
	Other FM physicians with post-graduate qualifications	2
	FM residents/trainees	6
Nurses	Asthma nurse counselor from tertiary hospital	1
	Polyclinic asthma nurse counselors	10
Pharmacist Member of Institution Workgroup on	Asthma	1
Ethnicity	Chinese	18
	Malay	4
	Indian	2

that their prescription should not be decided by the patients but instead recommended by physicians after the assessment of the former's asthma status.

Yes, [options should be presented according to the] clinical indication, so I wouldn't compare it side by side. You are going to end up confusing the patient. For example, can I take this and not take that?...ICS is really a gold standard of treatment of asthma. By comparing it, for example, to Montelukast or Omalizumab, it's not a direct comparison. Omalizumab is in Step 5 – an add-on therapy if steroids don't work. If you look across clinical studies, no one has actually compared ICS vs. Omalizumab. Most of the time, patients have failed ICS, which, thankfully, is a minority that they add on Omalizumab.

D2, pulmonologist

Participants suggested the removal of 'Montelukast' and 'Omalizumab' as these medications were not the focus of this PDA and could lead to confusion.

Montelukast and injection should be taken out...it would be less confusing because you are not going to be starting them on these two.

D4, FM resident/trainee

If you list it in that way, it means that they can choose whatever options that they prefer, but, in fact, the real treatment...depends on their severity of asthma and the physician will recommend accordingly. So, maybe you can take away options apart from ICS and ask them to discuss with their physician about the best treatment choice for them.

D10, FM physician, member of the institution steering workgroup on asthma

Sufficient information on side effects of ICS

Participants commented that patients with asthma were mostly concerned about the side effects of ICS; however, they felt that the PDA covered patients' concerns comprehensively.

They believe this [ICS] is bad...I will acknowledge their fear; then, I will reassure them. Look at the oral steroid tablet, it is in milligrams. The inhalers [ICS] are in micrograms. So, [they are] actually very safe, even safe for kids.

N2, asthma nurse counsellor, tertiary hospital

We do have patients who are worried about the side effects, I think you have hit the nail on the head. Most of the reasons are these listed here [in the PDA].

D2, pulmonologist

Usefulness of eliciting patients' values section

Participants believed that it was useful to include a list of possible values for patients to choose from in

the PDA because Asian patients are generally more conservative and may not articulate their values and preferences readily.

Locally, we are just not very open to talking about what we feel [or] what we think.

N2, asthma nurse counsellor, tertiary hospital

Detecting decisional conflict in patients when making a decision

Participants supported the use of the SURE test in the PDA prototype to detect decisional conflict in patients.

Do you need more support? These four questions identify decisional conflict and, if you circle 'yes' to any one or more of the options, there is decisional conflict. Yeah, [it's] good to put this in.

D6, FM resident/trainee

Multilingual PDA

Participants suggested that the PDA could be made available in the major languages in Singapore so as to cater to the needs of the multi-ethnic population in Singapore.

[Considering] patients who cannot speak English, it's difficult for [them]. I [suggest] both Mandarin and Malay [versions].

D3, FM resident/trainee

Language can be a challenge. [I suggest] to translate to the major languages in the local context.

N3, asthma nurse counsellor, polyclinic

Design

Understandability and readability

Participants commented that the language used in the PDA prototype was easily understood.

It is actually trying to deliver the message in...layman's term[s] and trying to look at [the situation] from the patient's perspective as well.

D1, FM physician with postgraduate qualifications

The language and words are ok [and] easy to understand.

N1, asthma nurse counsellor, polyclinic

Presentation and flow

Participants accepted the font, font size and flow of the PDA prototype.

Yes, I think it flows very well.

D1, FM physician with postgraduate qualifications

I think the font size [is] okay; the colour [is] okay.

P1, pharmacist working in the polyclinic

Importance of visual aids

Participants advocated for the use of visual aids such as diagrams to illustrate concepts of the disease or pictures of different ICS inhalers and cartoons. The use of visual aids was deemed to increase the appeal of the PDA to patients.

I felt that maybe [it] can have more diagrams, such as “narrowed [airways]” and “produce mucus”. I mean, when we were learning in medical school, they have diagrams showing “edematous” and “inflammation”. If there’s more visual aids, more pictures, more diagrams, it attracts people to read it. I was thinking back on all those other brochures and pamphlets – they tend to have cartoons [and] it’s easy [for patients] to understand.

D8, FM resident/trainee

Paper and digital formats

Participants differed in their preferences for printed and digitized copies. A hard paper copy was preferred by some due to greater ease of distribution to patients, whereas the digital format was deemed to possibly better capture the attention of younger patients.

If you want to hand [it] out to people, then, definitely, [a] hard copy is better.

D7, FM resident/trainee

We [can] put a QR code there and let the patients scan. Of course, usually, it will be used by those younger patients. I think most of the phones can scan QR codes and just a scan will lead you to the link.

D10, FM physician, member of the institution steering workgroup on asthma

Implementation

Setting of PDA administration

Participants had mixed views regarding the optimal timing of PDA introduction to patients. Some suggested delivering it before the physician consultation, while others preferred offering it after the consultation.

Before the consultation, they have these reading materials before they see the doctor, they can go straight to ask[ing] the physician questions they may have to clarify their doubts.

D1, FM physician with postgraduate qualifications

[I suggest] post-consultation, as the nurse counsellor can emphasize the concepts [which were] brought up by the physician during the consult.

D12, FM physician, senior management position in the polyclinic

Most suitable healthcare professional to administer the PDA

Participants perceived that nurses were suited to deliver the PDA given their longer interaction time and rapport with patients.

... Because the nurses have the rapport with patients, we can spend more time to go through this [PDA] with them.

N2, asthma nurse counsellor, tertiary hospital

[I suggest] an asthma nurse in the polyclinic. Doctors can broach the subject, but we cannot afford to go through the whole booklet in our doctors’ consult – we can just direct them [the patients] to the nurses, where they can slowly educate them.

D8, FM resident/trainee

Discussion

Clinicians generally viewed the content and design of the PDA prototype favorably. In particular, the participants noted the clearly-defined step-by-step approach for medical decision-making, adequate information conveyed on asthma as a chronic condition, the relevance of ICS maintenance therapy, and the benefits and side effects of asthma medications.

During the interviews, the participants highlighted the usefulness of eliciting values and preferences from patients. They discussed that Asian patients tended to be more conservative and less forthcoming in describing their preferences to clinicians. Asian values and culture focus on collectivist behavior such that Asians have a greater tendency to conform to authority instead of emphasizing their individual autonomy (36). In this context, doctors represent the authority of medical knowledge and respect for their opinions by patients is valued in Asian culture (37). Therefore, Asian patients tend not to verbalize their preferences and values readily. Furthermore, Asian patients with chronic medical conditions have been shown to report poorer patient–provider communication and lower degrees of confidence in engaging in medical decisions relative to patients in Europe or North America (38). Chinese patients were also more likely to leave the consultation with unanswered questions and were less likely to request additional information (39). This PDA

serves as a handy tool for the clinician to overcome this cultural barrier by facilitating a discussion with Asian patients in which values and preferences about asthma maintenance therapy can surface to enable mutual understanding.

Participants also recommended the development of multilingual versions of the PDA to enhance its accessibility and utility by the multi-ethnic Asian population in Singapore. In response, editions of the PDA in major local languages (Mandarin, Malay and Tamil) will be created during the next stage of development.

According to the Ottawa Health Research Institute, an ideal PDA should present all therapeutic options (40); therefore, options of 'do nothing (being on a reliever only)', 'ICS', 'Montelukast' and 'Omalizumab' were included in the PDA prototype ([Online Appendix 1](#)). However, participants opposed the inclusion of these as options as these medications have specific clinical indications and should not be chosen for use based on patient preference. For example, Montelukast is considered second-line to ICS in the treatment of persistent asthma for adults in the Global Initiative for Asthma (GINA) guidelines and is used as an add-on therapy for step 2 of the GINA stepwise approach to the treatment of patients with concomitant allergic rhinitis. Separately, Omalizumab is usually recommended for patients with severe allergic asthma in step 5 of the GINA guidelines (41). Both medications were thus removed in the revised PDA ([Online Appendix 2](#)).

Participants also suggested the addition of more visual aids to the PDA; as such, it has been revised to include illustrations of a normal bronchus and another with features of airway inflammation (e.g. edema, secretions and smooth muscle hypertrophy of its wall). Different ICS inhalers available in Singapore will be featured for ease of recognition by patients. Frequent use of pictograms illustrating key points in PDAs has been shown to result in higher rates of patient-perceived usefulness and satisfaction with the PDA (42). According to the Patient Education Materials Assessment Tool (PEMAT), a systematic method designed to evaluate the understandability and actionability of patient education materials, a patient's understanding of the content is facilitated by the use of visual aids (43).

Notably, the design of our PDA prototype also adheres to other principles from PEMAT such as using an active voice; using informative headers and breaking information into sections; and using common, everyday language. Several PDAs on chronic diseases, such as for choosing renal replacement therapy in

end-stage renal failure and dementia, have also shown good readability as reported by patients through the use of simple language (44). The use of common language and clear explanations of medical jargon in this PDA have enhanced its readability based on participants' feedback.

Opinions on the timing for the introduction of the PDA to patients were divided amongst the participants. Various studies (45,46) showed that administering the PDA prior to physician consultation resulted in lower decisional conflict and better knowledge among patients. The French PDA on ICS was also field-tested among patients before the physician consultation and found to be acceptable by patients and physicians.

The participants also suggested that nurses would be the best choice of healthcare professional to administer the PDA for patients given time constraints during a local primary care consultation. According to a systematic review by Stacey et al., a consultation performed involving a PDA can take, on average, 2–3 min longer than a routine consultation. As the typical local primary care physician consultation is usually confined to 10 min (47), it may not be possible to effectively accommodate the use of a PDA during the consultation. As nurses' sessions are usually longer than physician consultations, nurses may therefore be better poised to administer the PDA. Furthermore, patients are more likely to receive counseling when they visit nurses than when seeing primary care physicians (48). Team-based care involving both physicians and nurses can be explored to leverage the merits of both professions in chronic disease care. In addition, the PDA could potentially be scaled up for use in the tertiary setting in the future.

Strengths and limitations

The strength of this study was the creation of a culturally-adapted PDA prototype on maintenance ICS therapy through incorporating the views of local clinicians in Singapore. Cultural adaptation, the process of adjusting health messages to the intended patient group by incorporating their cultural heritage and language to enhance understanding (49–50), was leveraged to create a PDA prototype that was contextualized to local practice. A qualitative research design enables deep diving into the views of clinicians on the PDA. The perspectives of the PDA from the clinicians were subjective, perceptual and varied due to their contexts. However, feedback on the PDA was

only sought from clinicians in this study. Patients' views, which may differ, will be sought when the PDA is implemented in the next phase of the study, which will aim to assess their understanding of the PDA content and quality of decision-making when clinicians use it for SDM in three settings: before, during and after their consultation. This next stage of investigation is expected to provide insight into the optimal implementation of the PDA.

The present study is also limited by the perspectives gathered from clinicians practising in public healthcare institutions. Considering the views of general practitioners in private practice is also important for exploring the utility of the PDA in their setting. As such, their views will be sought when the implementation of the PDA is expanded to other clinical practices.

Conclusion

Incorporating the perspectives of clinicians on a culturally-adapted English-language PDA prototype on maintenance ICS therapy led to its enhancement. It is hoped that, with this tool, patients and physicians can focus on initiating ICS through shared decision-making. Other classes of asthma medications will be removed in the revised version of the PDA. The latest PDA edition will next be introduced to patients and its effect on improving the quality of decision-making and adherence after its initiation will be further evaluated in a subsequent trial.

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Declaration of interest

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Data availability statement

Qualitative data are not available due to a clause in the SingHealth Centralized Institutional Review Board

approval. Please refer to the [online appendices](#) for the PDA from University of Laval, PDA prototype and its revised version.

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SHOULD I START INHALED
STEROIDS (ICS)?

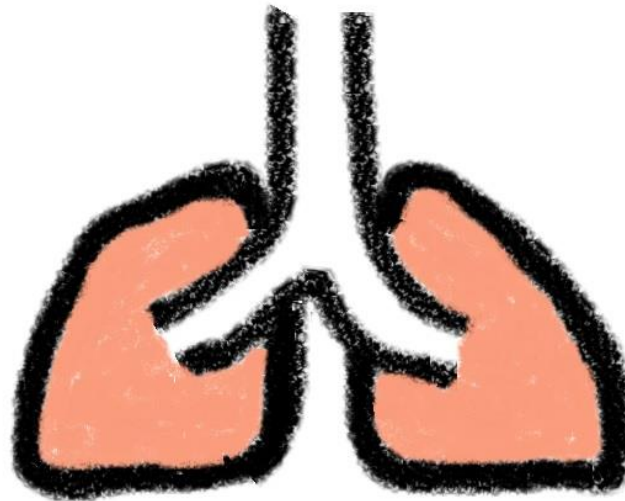
What is Asthma?



Asthma is a long-term airway disease. The airways can become swollen, narrowed and produce mucous, after your contact with substances which you are sensitive to (allergens). Sometimes there is no obvious reason for the airway swelling.

The swollen airways causes you to be out of breath and cough out phlegm badly. It can be dangerous to your life too.

There is no medicine to stop the swelling permanently, but there are ways to control it.



What is Asthma?



Using **inhaler** is one way to control it. They allow the medicine to reach the airways directly and hence the amount needed to treat is tiny.

Inhalers can be divided into those that help to reduce the airways from swelling (controller) and decreases phlegm, so that air can enter the airways and you can breathe normally with little phlegm

Another type of inhaler can help to open up the airways over short period of time. It allows you to breathe easier, but does not help with the airway swelling and phlegm.

Repeated swelling will lead to hardening of the airways, so that they cannot go back to their original size and the amount of air entering is reduced. You may become breathless even at rest.

Another group of medicine is taken **by mouth**. One of them is **Montelukast**, which also reduces the swelling of airways but the effect is mild and may not work for some patients with asthma.

A newer group of medicine is given **by injection**. One of them is **Omalizumab**, which reduces the level of allergy in people, and hence reduces the swelling of airways.

Controller Medicine: Inhaled Steroids (ICS)



In people with sensitive airways, when they take a breath, some things in the air, such as dust, pollen and tobacco smoke (allergens), can trigger their airways to become narrow.

Inhaled steroids are medicines that can be sprayed and breathed in through the mouth into lungs. They prevent the airways from becoming narrow.

Inhaled steroids in asthma treatment are different from steroid in body-building.

Compared to steroid to be taken by mouth, inhaled steroid is tiny in amount because it can be directly delivered to the airways. It will have less side effects to the rest of the body. They can therefore be used daily and safely, as asthma is a life-long condition.

What happens when you are having an asthma attack?



You might:

1. Cough
2. Produce Phlegm
3. Wheeze
4. Become breathless

Is your asthma controlled?

You can use a set of questions to check if your asthma is under control.

A locally accepted set of questions is the **Asthma Control Test**.

Asthma Control Test

The following test can help people with asthma (12 years or older) assess their asthma control. Please circle the appropriate score for each question. There are FIVE questions in total.

You can calculate your total Asthma Control Test score by adding up the numbers for each of your responses. Be sure to review your results with your doctor or nurse.

QUESTION 1

During the past 4 weeks, how often did your asthma prevent you from getting as much done at work, school or home?

1 All of the time	2 Most of the time	3 Some of the time	4 A little of the time	5 None of the time	☐
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QUESTION 2

During the past 4 weeks, how often have you had shortness of breath?

1 More than once a day	2 Once a day	3 3-6 times a week	4 Once or 2x/week	5 Not at all	☐
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QUESTION 3

During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest lightness or pain) wake you up at night or earlier than usual in the morning?

1 4 or more times/week	2 2-3 nights/week	3 Once a week	4 Once or twice	5 Not at all	☐
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QUESTION 4

During the past 4 weeks, how often have you used your rescue inhaler or nebuliser medication (such as Salbutamol)?

1 3 or more times a day	2 1 or 2 times/day	3 2-3 times a week	4 Once a week or less	5 Not at all	☐
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QUESTION 5

How would you rate your asthma control during the past 4 weeks?

1 Not controlled	2 Poorly controlled	3 Somewhat controlled	4 Well controlled	5 Completely controlled	☐
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TOTAL SCORE ☐

SCORE OF 25 - Congratulations! You have **total control** of your asthma.

SCORE OF 20-24 - On Target. Your asthma may be **well controlled** but not totally controlled.

SCORE OF LESS THAN 20 - Off Target. Your asthma may **not be controlled**.

What will you be like when you have good asthma control?



You can

1. Exercise without feeling breathless
2. Travel
3. Be free from cough

What happens if your asthma is not controlled in the long run?



Your airways might become hardened and lungs become permanently damaged. How good are your airways can be measured by a **Lung Function Test**.

Eventually, you may also develop heart failure if your airways and lungs are damaged.

What are your concerns?



Concerns	Things you may need to know
I am afraid that inhaled steroids are expensive.	There are several types of inhaled steroids that are available in polyclinics, such as Beclomethasone and Fluticasone. They are subsidised. A canister usually holds 200 puffs, which can be used for about 2.5 months (for 2 puffs/day).
I am afraid of being “addicted” to inhaled steroids and have to use them for a lifetime.	You have a choice. However, upon stopping, your asthma will less likely to be controlled. Poorer asthma control can affect your lifestyle, such as doing sports activities.
I think using inhaled steroids is inconvenient.	If using once a day, it can be taken at home. It only takes a few minutes.
I am afraid of side effects: 1. Fungal infection of throat (white clumps on the throat) 2. Broken bone (fracture) 3. Cataract (blur vision/loss of vision due to opaque eye lens) 4. Bruising/thinning of skin	(1) Fungal infection of throat were reported in less than 10% of patients treated with inhaled steroids. This can be prevented by gargling your mouth after using inhaled steroids. (2) No significant difference in risk of broken bone and bone thickness between patients who use inhaled steroids and those who do not use (3) No significant difference in risk of getting cataracts in those who use inhaled steroids (4) No significant difference in risk of bruising of skin in those who use inhaled steroids

What are your choices to gain good control of asthma?



1. No change
2. Take controller medicine (inhaled steroids)
3. Take Montelukast (tablet)
4. Take Omalizumab (injection), if your body shows strong allergic marker

What are the pros and cons of the treatment options?



Treatment	Asthma complications	Asthma symptoms/Reliever Use	Lung Function	Quality of Life	Side Effects	Cost
No change	May develop complications, higher rates of hospitalisation, mortality	Will remain the same or get worse	No change or decrease	Will remain the same or get worse	No immediate side effect of no change in treatment	No added cost now, potential for higher health cost in the future
Start Inhaled Steroids	6 out of 10 will not have asthma attack	Will improve, reduce use of relievers by 0.4 to 2.3 puffs per day	Increase by about 0.1 to 0.5 litres (about 20% of total)	Improve according to Asthma Quality of Life Questionnaire (AQLQ)	Fungal throat infection (<10%), which can be prevented by gargling mouth after use of inhaler	About \$5- \$38* per canister, depending on brand and strength. Each canister can last for about 2 months depending on dose.
Start oral medicine, Montelukast	Reduce risk of asthma attack but less effective than inhaled steroids	Will improve, but less effective than inhaled steroids	Increase (but less effective than inhaled steroids)	Improve according to Asthma Quality of Life Questionnaire (AQLQ)	Headache (≥2%), diarrhoea (≥2%), anxiety, depression, abnormal dreams (<1%)	About \$3.50* per 10mg pill for Singulair brand, usually taken daily
Start injection, Omalizumab	8 out of 10 will not have asthma attack	Will improve, reduce use of relievers by 0.3 to 0.6 puffs, usually used in patients who were already taking inhaled steroids	Small increase by about 67 millilitres	Improve according to Asthma Quality of Life Questionnaire (AQLQ)	Headache (6-12%) Injection site reaction (45%), including bleeding, bruising, redness and swelling	About \$540 to \$1000* per month depending on the dose *Figures correct at the time of print.

Quiz Time



1. Which treatment option increases how well your lung works the most?
2. Which treatment option improves asthma symptoms the most?
3. Which treatment is the most cost-effective?

The answer is **inhaled steroid**.

What is important to you?



Tick those that apply to you

- ☐ I want to avoid admission to hospital
- ☐ I want to avoid going to A&E
- ☐ I want to avoid missing work/school
- ☐ I want to avoid taking strong steroid (oral steroid)
- ☐ I want to avoid causing damage to lungs

What is important to you?



Tick those that apply to you

- ☐ I want to take cold drinks
- ☐ I want to exercise
- ☐ I want to travel
- ☐ I want to go out with friends
- ☐ I want to chat over the phone without feeling breathless

Summary of Your Concerns

- ☐ I want to avoid admission to hospital
- ☐ I want to avoid going to A&E
- ☐ I want to avoid missing work/school
- ☐ I want to avoid taking strong steroid (oral steroid)
- ☐ I want to avoid causing damage to lungs
- ☐ I want to take cold drinks
- ☐ I want to exercise
- ☐ I want to travel
- ☐ I want to go out with friends
- ☐ I want to chat over the phone without feeling breathless

Do you need more support?



Please circle the correct option

Do you think you know enough about each treatment option to make a choice?

Y/N

Do you know the pros and cons of each treatment option?

Y/N

Are you clear about which pros and cons are most important to you?

Y/N

Do you have enough support and advice from your doctor/nurse to make a choice?

Y/N

What is your choice?

Yes, I am ready

If you are ready to make a decision, which choice do you prefer?

- ☐ Do nothing
- ☐ Start Inhaled Steroids
- ☐ Start oral medicine, Montelukast
- ☐ Start injection, Omalizumab

No, I am not ready

We respect your decision.

We encourage you to continue to discuss with your healthcare providers.

THIS DECISION AID IS NOT MEANT TO REPLACE THE CONSULTATION. WHATEVER YOU DECIDE, PLEASE DISCUSS YOUR OPINION(S) WITH YOUR DOCTOR/NURSE.

AS CIRCUMSTANCES MAY EVOLVE, YOU SHOULD REVIEW YOUR DECISION PERIODICALLY WITH YOUR HEALTHCARE PROVIDERS.

THANK YOU FOR USING THIS BOOKLET.
WE HOPE YOU FOUND IT HELPFUL.



SHOULD I START INHALED CORTICOSTEROIDS (ICS)?

This booklet is for **adults** who have been diagnosed with **asthma** and told by their doctors to use an inhaler **daily**.

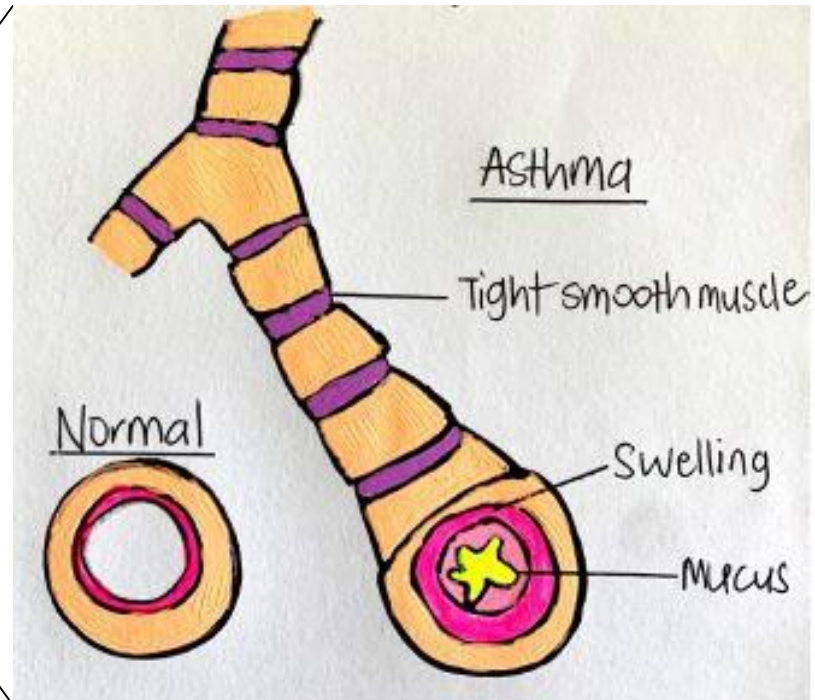
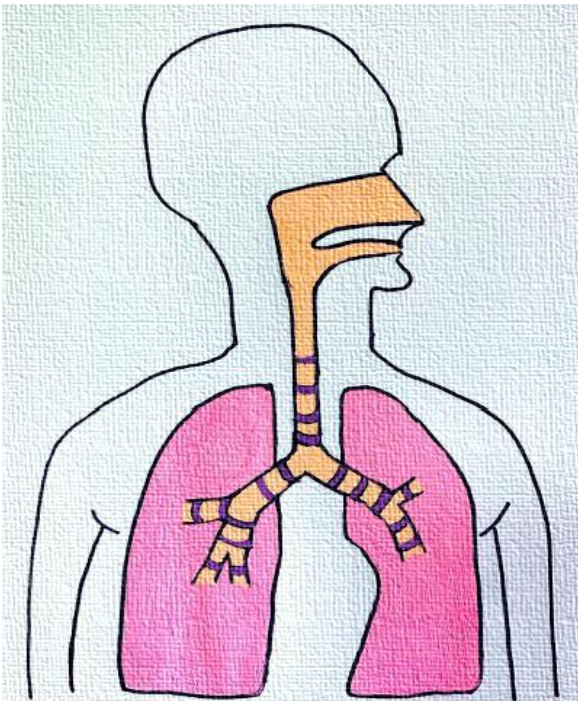
What is Asthma?



Asthma is a long-term airway disease affecting many people in the world. When people with asthma, like yourself, come into contact with substances they are sensitive to (allergens), they can develop an asthma flare-up/attack. During the asthma attack, the airways become swollen, narrowed and filled with mucus.

The swollen airways can cause you to be out of breath and cough out phlegm badly. It can be dangerous to your life too.

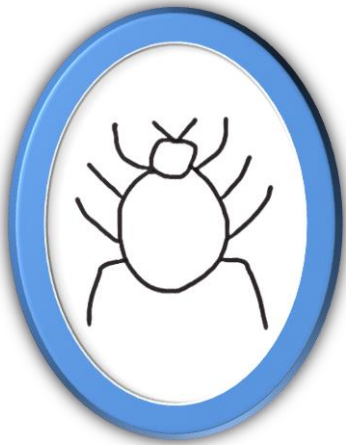
There is no medicine to stop the swelling permanently, but there are ways to control it.



What is Asthma?



Some things in the environment, such as dust mites, moulds and tobacco smoke (allergens) can trigger your airways to become narrow.



Dust mite



Moulds



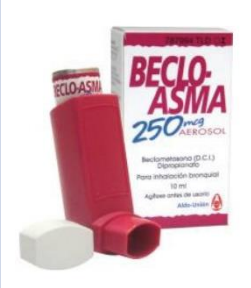
Tobacco smoke

Controller Medicine: Inhaled Steroids (ICS)



Using **inhaler** is one way to control it. They allow the medicine to reach the airways directly.

Types of Inhalers

Function	Reliever	Controller
Reduce the swelling of airways	X	✓
Decrease phlegm	X	✓
Example		

Controller Medicine: Inhaled Steroids (ICS)



Inhaled steroids are medicines that can be sprayed and breathed in through the mouth into lungs. They prevent the airways from becoming narrow.

Compared to steroid that is taken by mouth, inhaled steroid is tiny in amount and it can be directly delivered to the airways. It causes less side effects to the rest of the body. Therefore, it can be used daily and safely.

What happens when you are having an asthma attack?



You might:

1. Cough
2. Produce phlegm
3. Wheeze
4. Become breathless

Are your symptoms controlled?



GINA Assessment of Asthma Control

In the past 4 weeks, have you had: Please tick “Yes” or “No”		Yes	No	Level of Asthma Symptom Control		
				Well Controlled	Partly Controlled	Uncontrolled
1	Daytime asthma symptoms more than twice/week?			None of these	1-2 of these	3-4 of these
2	Any night waking due to asthma?					
3	Reliever needed for symptoms more than twice/week*?					
4	Any activity limitation due to asthma?					

* Excludes reliever taken before exercise.

What will you be like when you have good asthma control?



You can

1. Exercise without feeling breathless
2. Travel
3. Go to work/school
4. Be free from cough, phlegm, shortness of breath
5. Prevent hospital stay

What are your concerns?



Concerns	Things you may need to know
I am afraid that inhaled steroids are expensive.	There are several types of inhaled steroids that are available, such as Beclomethasone and Fluticasone. A canister usually holds 200 puffs, which can be used for about 2.5 months (for 2 puffs/day).
I am afraid of being “addicted” to inhaled steroids and have to use them for a lifetime.	Upon stopping, your asthma will less likely to be controlled. Poorer asthma control can affect your lifestyle, such as doing sports activities.
I think using inhaled steroids is inconvenient.	If using once a day, it can be taken at home. It only takes a few minutes.
I am afraid of side effects: 1. Fungal infection of throat (white clumps on the throat) 2. Broken bone (fracture) 3. Cataract (blur vision/loss of vision due to opaque eye lens) 4. Bruising/thinning of skin	(1) Fungal infection of throat were reported in less than 10% of patients treated with inhaled steroids. This can be prevented by gargling your mouth after using. (2) No significant difference in risk of broken bone and bone thickness between patients who use inhaled steroids and those who do not use (3) No significant difference in risk of getting cataracts in those who use inhaled steroids (4) No significant difference in risk of bruising of skin in those who use inhaled steroids

What are your choices to gain good control of asthma?



1. No change
2. Take controller medicine (inhaled steroids)
3. Talk to your doctor about other options

What are the pros and cons of the treatment options?



Options	Asthma complications	Asthma symptoms/ Reliever Use	Side Effects	Cost
No change	May develop complications, higher rates of hospitalisation and death	Will remain the same or get worse	No immediate side effect of no change in treatment	No added cost now, potential for higher health cost in the future
Start Inhaled Steroids	6 out of 10 will not have asthma attack	Will improve, reduce use of relievers by 0.4 to 2.3 puffs per day	Fungal throat infection (<10%), which can be prevented by gargling mouth after use of inhaler	Depends on brand and strength. Each canister can last for about 2 months depending on dose.

What is important to you?



Tick those that apply to you

- ☐ I want to avoid admission to hospital
- ☐ I want to avoid going to A&E
- ☐ I want to avoid missing work/school
- ☐ I want to avoid taking strong steroid (oral steroid)
- ☐ I want to avoid causing damage to lungs

What is important to you?



Tick those that apply to you

- ☐ I want to take cold drinks
- ☐ I want to exercise
- ☐ I want to travel
- ☐ I want to go out with friends
- ☐ I want to chat over the phone without feeling breathless

Summary of Your Values

- ☐ I want to avoid admission to hospital
- ☐ I want to avoid going to A&E
- ☐ I want to avoid missing work/school
- ☐ I want to avoid taking strong steroid (oral steroid)
- ☐ I want to avoid causing damage to lungs

- ☐ I want to take cold drinks
- ☐ I want to exercise
- ☐ I want to travel
- ☐ I want to go out with friends
- ☐ I want to chat over the phone without feeling breathless

Others: _____

Most important value(s): _____

Do you need more support?



Please circle the correct option

Do you think you know enough about each treatment option to make a choice?

Y/N

Do you know the pros and cons of each treatment option?

Y/N

Are you clear about which pros and cons are most important to you?

Y/N

Do you have enough support and advice from your doctor/nurse to make a choice?

Y/N

What is your choice?

Yes, I am ready

If you are ready to make a decision, which choice do you prefer?

- ☐ Do nothing
- ☐ Start Inhaled Steroids
- ☐ Talk to your doctor about other options

No, I am not ready

We respect your decision.

We encourage you to continue to discuss with your healthcare providers.

THIS DECISION AID IS NOT MEANT TO REPLACE THE CONSULTATION. WHATEVER YOU DECIDE, PLEASE DISCUSS YOUR OPINION(S) WITH YOUR DOCTOR/NURSE.

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Last updated: 30 April 2020

References



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WHAT ARE MY OPTIONS REGARDING INHALED CORTICOSTEROIDS USE TO IMPROVE ASTHMA CONTROL?



Qvar^{MD}



Alvesco^{MD}



Pulmicort^{MD}



Flovent^{MD}
Flovent Diskus^{MD}



Asmanex^{MD}

A Four-Step Decision Aid

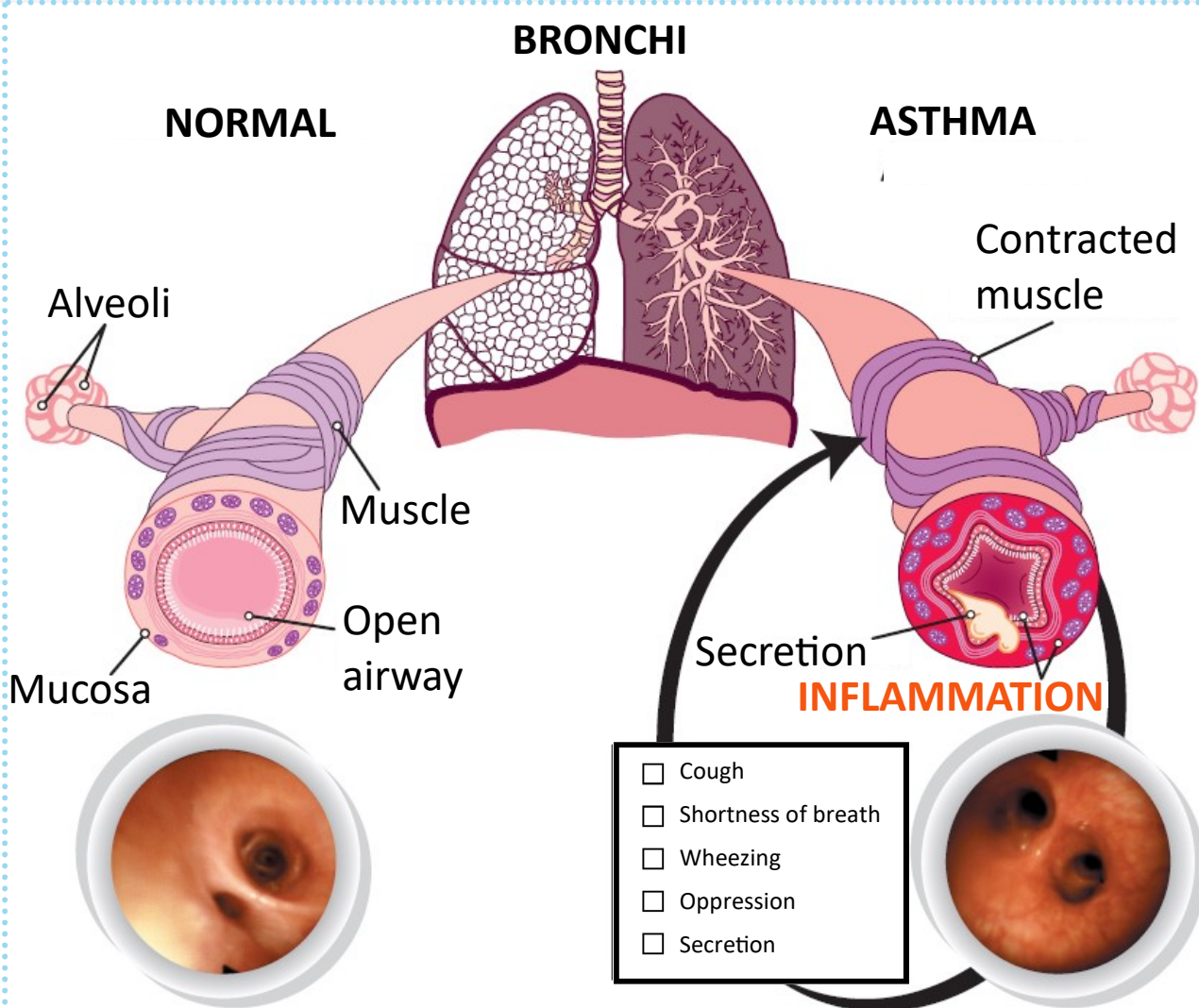
This decision aid is for me if:

- ♦ I am an adult aged between 18 to 65;
- ♦ I received a mild, moderate, or severe asthma diagnosis from my doctor;
- ♦ Asthma is not controlled if I only take my rescue medicine (Airomir^{MD}, Ventolin^{MD}, Bricanyl^{MD}, etc.);
- ♦ My doctor has recommended the regular intake of one of the inhalers shown above to treat asthma.

STEP 1: CLARIFY THE DECISION THAT I HAVE TO MAKE

What is asthma?

It is a chronic inflammatory disease that affects my bronchi.



Asthma cannot be cured. However, some measures can be implemented in order to prevent changes in the structure of my bronchi and so that I can reach the main criteria in asthma control^[1] which are:

- ♦ Have symptoms less than 4 days/week;
- ♦ Have symptoms less than 1 night/week;
- ♦ Do normal physical activities;
- ♦ Use my rescue medicine less than 4 doses/week.

What is the content of my inhaler?

This inhaler contains a **maintenance medication** used for long-term control of asthma.

- ♦ This maintenance medication is used to **reduce the inflammation** of my bronchi.
- ♦ This maintenance medication starts working **12 to 48 hours** after the beginning of treatment.
- ♦ This maintenance medication has a **slow and gradual effect**.
- ♦ **To be effective**, the inhaler must be taken regularly, **every day**, even in the absence of symptoms.

What are my choices^[1]?

- ♦ Use the inhaler;
- ♦ Not to use the inhaler & discuss with my healthcare provider the other measures that could be implemented to treat the inflammation of my bronchi and improve the control of asthma.

STEP 2: COMPARE AND WEIGH THE PROS AND CONS

The pros.

Are there any benefits in using the inhaler?

When compared with taking a placebo medication (dummy medication), the inhaler containing a maintenance medication...



Improves :

- ◆ Quality of life^{*}
- ◆ Lung function[†] (degree of bronchi opening)



Decreases :

- ◆ Asthma symptoms[†]
- ◆ Use of rescue medicine[†]
- ◆ Hospitalizations or emergency medical visits[†]
- ◆ Episodes of asthma control deterioration, characterized by an increase in symptoms and may require cortisone tablets intake[†]

... in patients with mild, moderate, and severe asthma^[2].

^{*} High-quality evidence^[2]

[†] Moderate-quality evidence^[2]

The cons.

Are there any risks associated with using this inhaler?

When compared with taking a placebo medication (dummy medication), the inhaler containing a maintenance medication...



Increases the likelihood to see appearing:

- ♦ Thrush (white patches in the mouth caused by a fungus)
- ♦ Hoarse voice (husky)
- ♦ Sore throat*

... in patients with mild, moderate, and severe asthma^[2,3,4].

* If it appears, this effect disappears after taking a few doses.

How can I reduce the possibility that these effects appear?

- 
- ♦ I use a spacing chamber if my inhaler is a metered-dose inhaler.
 - ♦ With the help of my health care provider, I make sure that my inhalation technique is adequate.
 - ♦ I rinse my mouth with water after inhaling my medicine.

Some myths are associated with the use of this inhaler.

These are the facts.

The use of this inhaler:

- ♦ Is not fattening^[2];

- ♦ Does not lose its effectiveness in the long term^[5];

- ♦ Is not addictive^[6];

- ♦ Does not cure asthma, but helps control asthma^[2].
Currently, no measure succeeds in curing asthma.

Weigh the pros and cons.

What is most important to me?

To find out, I indicate the importance I give to each of the following statements, by filling in the corresponding circle.

1 means "it is very unimportant to me";

2 means "it is rather important to me";

3 means "it is very important to me".

a. Not being hospitalized.

b. Reduce asthma symptoms.

c. Reduce the use of rescue medication.

d. Avoid having to take cortisone tablets.

e. Prevent the emergence of thrush.

g. Improve my life quality.

i. Avoid emergency medical visit.

f. Maintain or improve my lung function.

h. Avoid having a hoarse voice.

j. Other:

At this point, which decision seems to be the most satisfying for me?

To find out, I write here below how many times, on the previous page, I filled:

♦ A purple arrow:  ____ time;

♦ An orange arrow:  ____ time;

♦ A blue arrow:  ____ time.

I check the box that applies:

If the number of purple arrows is the highest...
...I will take the inhaler. ☐

If the number of orange arrows is the highest...
...I will not take the inhaler. ☐

♦ In all other situations...
....I am unsure. ☐

STEP 3: WHAT DO I NEED TO MAKE A DECISION?

I check the box that applies to my answer.

	Yes	No
<u>S</u>ure of myself		
Do I feel sure about the best choice for me?	☐	☐
<u>U</u>nderstand information		
Do I know the benefits and risks of each option?	☐	☐
<u>R</u>isk-benefit ratio		
Am I clear about which benefits and risks matter most to me?	☐	☐
<u>E</u>ncouragement		
Do I have enough support to make my choice?	☐	☐

The SURE test© 2008 O'Connor & Légaré^[7]

STEP 4: PLANNING THE NEXT STEPS ACCORDING TO MY NEEDS

I check the box that applies to my answer.

To improve asthma control...

♦ I do not know if I will take the inhaler. I am unsure. ☐

♦ I write why here below.

♦ I will take the inhaler. ☐

♦ I will not take the inhaler. ☐

TO CONCLUDE, HERE IS A SUMMARY OF MEASURES THAT IMPROVE ASTHMA CONTROL.

To improve asthma control, I have to:



Medication

- ♦ Adequately take my medication against asthma;



Cold Influenza

- ♦ Wash my hands regularly to avoid contracting microorganisms responsible for respiratory infections (e.g. common cold) or influenza;
- ♦ Get a vaccination against influenza each year;



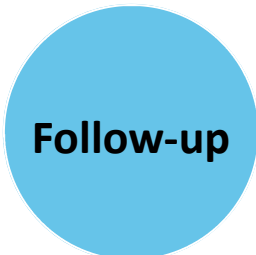
Allergens

- ♦ Avoid being in the presence of substances to which I am allergic (allergens);



Tobacco

- ♦ Stop smoking;
- ♦ Avoid being exposed to tobacco smoke;



Follow-up

- ♦ Have a regular monitoring of asthma by my health care provider;
- ♦ Having my inhalation technique checked by my health care provider;



Action plan

- ♦ Assess asthma control on a regular basis;
- ♦ Follow my action plan recommendations when asthma worsens.

WHAT ARE MY OPTIONS REGARDING INHALED CORTICOSTEROIDS USE TO IMPROVE ASTHMA CONTROL?

A Four-Step Decision Aid

References

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© 2014. Planned update of the tool in 2016.

The format is based on the *Ottawa Personal Decision Guide* © O'Connor, Stacey, Jacobsen, 2004 and on the *International Patient Decision Aid Standards*, 2005.

The information presented in this tool are not intended to replace advices or prescriptions from a health care provider, but rather to improve the communication between the latter and the patient and to help decision-making based on evidence and values.

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Whatever the choice made by the patient, neither the authors nor the Laval University, nor AllerGen NCE Inc. do not win or lose anything financially.

Topic Guide for In-depth Interview and Focus Group Discussion

Content

1. How useful is the PDA in guiding you on providing information of inhaled corticosteroids (ICS) to your patients?
 - a. Which segment is useful? Why?
 - b. Which segment is not useful? Why?
2. How useful is the PDA in identifying the values of patients?
3. How does knowing the values of patients affect the treatment chosen?
4. How useful is the PDA in guiding patients to make a decision on using ICS?
 - a. Which segment is useful? Why?
 - b. Which segment is not useful? Why?

Design

5. What are your views on the design of the PDA?
 - a. Sequence and flow of the segments
 - b. Font size and font type
 - c. Use of visual aid
 - d. Is the PDA easily understandable by patients?
6. What are your views on digitalising the PDA?

Method of delivery

7. How will you use the PDA in your setting?
 - a. Should the PDA be used during consultation? Why?
 - b. How feasible do you think it will be to use the PDA during consultation? Why?
 - c. Who should be administering the PDA? Is it the doctor or the nurse or both? Why?