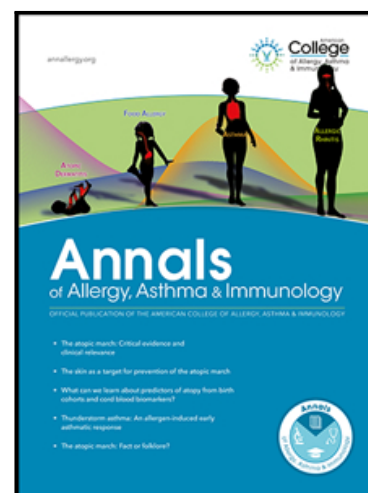


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Key messages

- Shared decision making (SDM) is playing an increasing role in healthcare decisions
- Benefits and barriers to SDM are well documented and are applicable to allergy practice
- SDM has been shown to improve adherence and outcomes for asthma
- Patient decision aids to be used in SDM have been developed for allergen immunotherapy, severe asthma, and atopic dermatitis.

Shared Decision Making for the Allergist

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Keywords: Shared decision making; asthma; allergy; atopic dermatitis

Abbreviations: AIT, allergen immunotherapy; IOM, Institute of Medicine; SCIT, subcutaneous immunotherapy; SDM, shared decision making; SHARE; Seek Help Assess Reach Evaluate; SLIT, sublingual immunotherapy.

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Introduction

In the age of personalized medicine, patients are playing a greater role in their treatment decisions. The internet has allowed patients to better educate themselves about their health and come prepared to office visits with questions and opinions. In a survey of 300 patients who attended an allergy clinic, 53% indicated they searched online for information on allergy before their consultation.¹ In consideration of the informed patient and increasing patient empowerment in healthcare decisions, personalized medicine cannot be implemented without shared decision making (SDM) between patients and healthcare providers.

Ethical, practical, economic, and psychological imperatives exist for implementation of quality SDM. SDM is advocated by a number of healthcare-related organizations including the National Institutes of Health, US Preventive Services Task Force, the American Medical Association, the American College of Critical Care, and the American Academy of Pediatrics.² Indeed, the importance and benefits of SDM have become well recognized such that SDM is a prerequisite by Medicare and Medicaid for certain preventive screenings and medical procedures.³⁻⁵ Although there is currently no requirement for SDM specifically mandated before payer reimbursement for allergy management, there is an emphasis from payers to motivate change in healthcare provider behaviors to include the “voice” of the patient.⁶

SDM is particularly important for chronic diseases which often require long-term and potentially complicated or intensive treatments. Adherence to these treatments can be driven by patient characteristics and preferences which cannot be fully explored without SDM. SDM is also important when there is not a clear best choice for disease management.⁷ Chronic diseases

seen by allergists such as allergic rhinitis, asthma, rhinosinusitis, atopic dermatitis, chronic spontaneous urticaria, food allergy, and eosinophilic esophagitis are reasonable targets for SDM. Until recently, there have unfortunately been few SDM tools available to the allergist. The purpose of this review is to educate the allergy healthcare provider about how SDM works and provide practical advice and allergist-specific SDM resources.

What is SDM?

In a 2001 landmark report, SDM was promoted by the Institute of Medicine (IOM) as part of the strategy to improve the quality of health care in the United States.⁸ The IOM recommended that healthcare should be customized based on the patient's needs and values, the patient should be given adequate knowledge and control to make decisions that affect his/her health, patients and healthcare providers should communicate and share information, and patients should receive information that allows them to make informed decisions.⁸ To this end, SDM is the joint involvement of patients and healthcare providers in making healthcare decisions that are informed by the best available evidence in regards to possible options, potential benefits and harms, and that consider patient preferences and values.⁹ SDM ensures patients get no more and no less of the care they need and want.

In SDM both the healthcare provider and patients are sources of information, bringing different, but equally important, forms of expertise to the decision-making process (**Figure 1**). In a survey of patients' perceptions of decision making, one patient summed up SDM this way, "The doctor has skills but we know our body and what we are".¹⁰ However, not all patients are comfortable being actively involved in decision making and some may become anxious about this responsibility.¹¹ Thus, as the first step, the allergy healthcare provider may need to explain the importance of SDM to the patient and then assess the patient's desire to be involved.¹¹ The

level of the patient's activation and participation in the decision making can in itself be part of SDM.¹²

To help facilitate SDM there are many different tools and patient decision aids which have been developed. For information on allergy-related diseases that may be beneficial during SDM discussions, helpful resources for both the healthcare provider and patient are available through organizations such as the American Academy of Allergy Asthma & Immunology and the American College of Allergy, Asthma, & Immunology.^{13, 14} In addition, patient decision aids are designed to provide balanced, evidence-based information and clarify personal values in a way that helps the patient make difficult healthcare decisions.¹⁵ The patient decision aids may be utilized with a healthcare provider or, in some cases, independently by the patient.¹⁵ Information in the patient decision aid should include a description of the disease or problem, the decision that needs to be made, a balanced presentation of the available options for the presented decision, as well as each option's benefits and harms (with outcome probabilities), and also what happens if no action is taken.^{16, 17} In addition, the decision aid should help patients imagine the effects of the options and provide a step-by-step method to making a decision.¹⁶ Furthermore, a good patient decision aid should:

- Use up-to-date resources of the highest quality and possibly be certified^{18, 19}
- Be patient-friendly and engaging so as to not overwhelm the patient
- Begin with the premise that the information and content need to be considered in the context of an individual's experience and preferences
- Be available in many languages and consider cultural sensitivities
- Include real patient stories and experiences

- Provide feedback on patient experience-knowledge gain, levels of confidence and satisfaction

A list of some of the available online resources to access patient decision aids for various diseases is in **Table 1**.

In order to be successful, SDM needs to be done well. To this end, the allergy healthcare provider should also be aware of what SDM is not (**Table 2**). For example, SDM is not a 60-second discussion during a visit. Rather, SDM should encompass the entire visit, with the visit planned around SDM. Furthermore, SDM does not have a beginning and end; the consequences are ongoing (particularly in a chronic disease such as asthma). In addition, SDM is not interchangeable with informed consent, in which patients are educated on options and then asked if they agree to treatments or procedures.²⁰ SDM is also not simply providing patients educational materials.

Benefits of SDM

Numerous benefits of SDM have been observed (**Table 3**). Patients who use decision aids have improved breadth and depth of knowledge and feel better informed about decision options.^{21, 22} In a systematic review of 105 studies, decision aids were also shown to increase patients' accuracy of risk perception and reduce the number of patients who were undecided about optional choices.²² Clinically-related benefits of SDM include ability of patients to manage disease, improved medication adherence, and better outcomes.²³⁻²⁶ In a randomized controlled trial of adults with poorly controlled asthma, patients who participated in SDM had significantly better adherence to their controller medication regimens after 1 year, significantly better symptom scores and lung function, and had nearly twice the odds of having no asthma control problems when compared with standard care.²⁴ In a randomized controlled trial of a SDM patient portal, parents of children with asthma reported the portal made it easier to manage their child's

asthma and increased awareness of the importance of asthma management compared with standard care.²⁵ Parents who used the SDM portal also reported receiving more controller medications, fewer prescriptions for oral corticosteroids, a trend toward fewer missed school days by their children in the previous month, and better improvement from baseline in frequency of asthma flares when compared with standard care.²⁵ In addition, prospective matched cohort studies found that use of SDM for children with asthma significantly reduced the proportion of patients experiencing an asthma exacerbation and significantly delayed the time to asthma exacerbation compared with usual care.^{26, 27}

Patients involved in SDM often choose less invasive options, and decision aids have been found to reduce the rates of elective treatments/procedures and screenings.^{22, 28} In addition, healthcare resource use and costs are reduced when SDM and decision aids are implemented, including a reduction in asthma-related hospitalizations, emergency department visits, and doctor's visits.^{24, 25, 28, 29}

Barriers to SDM

Despite the demonstrated benefits of SDM, research shows that it has been challenging to implement.³⁰⁻³² In fact, when the US Centers for Medicare & Medicaid Services considered testing a specific approach to integrate SDM in clinical practice the program was cancelled due to lack of interest by Accountable Care Organizations.³³ Many barriers to SDM implementation have been observed and documented. One of the main barriers is the perception by healthcare providers that SDM will require too much time.^{30, 31, 34, 35} In an environment where fee-for-service payment systems do not include time spent for SDM, healthcare providers likely give priority to paid services.³⁶ However, a review of studies showed that the median consultation time only increased 2.6 minutes when a patient decision aid was used.²² Another major barrier is the perception by healthcare providers that SDM is already being accomplished because they

currently involve patients in decisions.^{30, 37} Current office practice should be carefully reviewed to determine if SDM is truly being conducted.³⁰ There are also perceptions by healthcare providers that patients want physicians to make decisions for them or that factual information is too complicated for patients.^{30, 35} In reality, most patients want input on their healthcare decisions and if SDM is conducted properly, patients will then have enough information to make a decision.^{22, 38} Healthcare providers may also find SDM difficult to fit into their clinical systems and pathways, particularly with a lack of leadership and implementation strategy.^{31, 34}

In addition to barriers by healthcare providers in implementing SDM, patient barriers also exist. In a review of 44 studies, one of the common patient barriers was workflow, as indicated by patient requests for nurses to help explain information, gather information on patient preferences, and convey the preferences to the physician.³⁹ Time may also be a barrier if patients feel they are taking up too much of the healthcare providers' time or if they have not had enough time to adjust to the shock of a diagnosis before being asked to participate in SDM.³⁹ Another barrier is the patients' belief that they do not have enough information to make a decision.³⁹ Improved access to patient decision aids may ameliorate this barrier.

What does SDM look like?

From the healthcare provider's perspective, SDM can vary based on consulting style. However, a style that corresponds with SDM is characterized by the absence of orders and interruptions, by the avoidance of medical jargon, and by the use of dialog with open-ended questions.^{40, 41} Good clinical communication skills, including building a rapport with the patient and attentive listening, need to be the foundation of SDM.^{42, 43}

Different approaches to the SDM process have been proposed. The 3-talk model recommends SDM in 3 steps comprised of the team talk, the option talk, and the decision talk

(Figure 2).^{42, 44} In the team talk, the healthcare provider lets the patient know that options related to the needed decision are available and that the patient's preferences are important in the decision-making process. The team talk can be conducted face-to-face or by other means of communication (i.e., email, letter, telephone call). In the option talk, the various options are listed, described, and compared with regard to benefits, harms, and the patient's preferences. This information needs to be presented, without medical jargon, in a way the patient can understand. In the decision talk, the healthcare provider guides the patient to form preferences and move toward a decision based on those preferences. More time to consider the decision can be offered to the patient if necessary. During the SDM dialog the healthcare provider and patient should be paying close attention to each other and thinking carefully about the various options. The dialog itself may be dynamic, without necessarily moving in a linear fashion from benefits, to harms, to preferences, to decision, etc.⁴⁴ It should also be emphasized to the patient that once a decision is made, it does not preclude any of the other options or the option to change their choice in the future.

Another proposed SDM approach is the 5-step SHARE model (Seek Help Assess Reach Evaluate) developed by the Agency for Healthcare Research and Quality.⁴⁵ The principles behind the SHARE model are similar to the 3-talk model. Based on the principles of the 3-talk and SHARE models, the authors have developed a flow-chart that suggests a potential SDM process during an allergy visit (**Figure 3**). Some patients will want to know what the healthcare provider would do and may even wonder why they are being asked for their input. In situations where multiple clinically appropriate options exist (i.e., choices among biologics for asthma with an eosinophilic phenotype), the provider should explain that there is little to no evidence to lean the decision in any particular direction, so it comes down to the patients' beliefs and preferences.

The healthcare provider involved in SDM does not necessarily need to be a physician. Nurse practitioners, physician assistants, and nurses can play a large role in the SDM process, such as explaining the need for SDM, providing patient support, providing literature and reviewing with the patient disease and option information, as well as determining patient preferences.^{31, 34} However, the physician should interact with the patient at some point to address specific medical considerations and/or questions.

Once a decision has been reached using the SDM process the decision needs to be implemented. Documentation is also an important part of the SDM process because it provides justification and rationale for why a particular management decision was made.³¹ Furthermore, documentation will help guide any subsequent healthcare provider who sees the patient at a follow-up visit. Follow-up visits should be scheduled to evaluate efficacy of the therapeutic intervention (when applicable), how the patient is progressing, review the decisions made in the previous visit, assess patient satisfaction, and determine if the initial decision needs to be reassessed.

SDM for allergy healthcare providers

Many of the conditions treated by allergists, such as allergic rhinitis, asthma, and atopic dermatitis, have a significant impact on patients' quality of life.⁴⁶⁻⁴⁸ Poor control of these conditions leaves patients feeling anxious or unsatisfied and in the case of asthma, may even be life-threatening.^{46, 49, 50} It is well known that many patients with atopic diseases are not adherent to their treatments.^{51, 52} Furthermore, patients often assume and feel their atopic disease is not able to be effectively managed^{46, 48, 49} Indeed, as discussed previously, SDM and decision aids have been shown to improve medication adherence and outcomes for asthma,²⁴⁻²⁷ although to date there is little published evidence on the impact of SDM on other atopic diseases. SDM is an

opportunity to emphasize adherence to medication and other therapeutic modalities and to determine behaviors that may improve adherence, which in turn will lead to better disease control and improved patient satisfaction. Allergy healthcare providers should review charts to identify patients with poor outcomes who may benefit from SDM, such as consistently poor Rhinitis Control Assessment Test or Asthma Control Test scores.

The allergy healthcare provider encounters many situations in which SDM may be useful. AIT to treat allergic rhinitis provides an excellent example of the utility of SDM since AIT options have very different implications for patients. Let us consider a hypothetical case study:

A 22-year old man who works as a landscaper is allergic to temperate grasses and experiences problematic symptoms in the late spring and early summer. He has been treating his allergy symptoms for many years with an oral antihistamine and an intranasal corticosteroid without satisfactory control. During a regular follow-up visit the patient mentions he read on the internet that allergy shots may help reduce his allergy symptoms.

First, a decision needs to be made as to whether AIT is right for the patient. Secondly, a decision between subcutaneous immunotherapy (SCIT) and sublingual immunotherapy (SLIT)-tablets needs to be made, as both options are efficacious.⁵³⁻⁵⁶ Therefore, the below questions need to be considered:

- Are the patient's symptoms well controlled with avoidance behaviors and pharmacotherapy?
- Is there an interest by the patient in modifying disease with AIT and potentially improving outcomes and reducing pharmacotherapy use?
- Is the patient willing to be adherent to 3-5 years of AIT?
- Does the patient understand the financial cost associated with AIT?
- Is there a preference for sublingual versus subcutaneous administration?

- Does the patient prefer regular office visits 2-4 times a month or daily at-home administration?
- Does the patient understand the potential risks including side effects of SCIT and SLIT?

In this case study, a patient decision aid would be useful for SDM. There have been 3 AIT patient decision aids developed (**Table 4**). Two of the patient decision aids were developed by Healthwise, Inc and are designed to help the patient decide if he/she should receive SCIT for environmental allergies or insect venom allergy.^{57, 58} Another similar decision aid developed by Nemours' Center for Healthcare Delivery Science is designed to help parents decide if their child should receive SCIT for environmental allergies.⁵⁹ In addition, the American College of Allergy, Asthma, and Immunology and Allergy & Asthma Network have designed a tool to help the patient decide whether pharmacotherapy and avoidance procedures alone are sufficient or whether the addition of SCIT or SLIT-tablet is the more appropriate management modality of his/her allergic rhinitis (<http://allergytherapy.acaai.org>).⁶⁰ SLIT-drops are not an option on this decision aid since no aqueous SLIT product is currently approved by the US Food and Drug Administration.

One patient decision aid for asthma has been developed with the intent of helping the patient decide which inhaled corticosteroid is the best choice for him/her (**Table 4**).⁶¹ In a randomized controlled trial of 51 patients with asthma, the use of the inhaled corticosteroid decision aid along with educational intervention significantly improved decisional conflict scores and asthma control from baseline, although there was no significant difference in these measures compared with patients receiving educational intervention alone.⁶² A patient decision aid for the treatment of severe asthma was launched in 2018⁶³ and a decision aid for atopic dermatitis is under development and should be available by 2019.

Implementing SDM in allergy practice

The numerous barriers to SDM can make implementation challenging. Initially, interactive skills workshops that include clinical scenarios with role-playing may help allergy providers differentiate SDM from current practice and improve understanding of the SDM process.³⁰ A collaborative, whole-team approach with a dedicated clinical lead will help to motivate and sustain implementation and make sure the process fits into the team's priorities and clinical demands.³⁰ In addition to the healthcare team, patients also need to be prepared to participate in SDM by raising awareness through distribution of posters and videos.³⁰ The need for SDM can be reinforced to patients through educational directives.

Support, delivery, and increased patient adoption of patient decision aids are key to implementing effective SDM. Ideas to improve patient access to decision aids include offering the decision aid in an accessible format and adding drop-down options in electronic medical record patient portals. Credibility of the patient decision aid can be reinforced to the patient through posters and pamphlets, especially if these have the endorsement of a medical specialty society. In addition, patient incentives can be offered to those who use the decision aids and demonstrate knowledge (ie, options, harms, benefits) that was presented in the aid. For more information on implementing SDM into everyday practice, the agencies and healthcare sites that provide patient decision aids also provide practical guidance (**Table 1**). We encourage allergists to publish their experience with implementing SDM into their practice.

Conclusion

Shared decision making is a process by which patients and healthcare providers join together to choose the best treatment option for the patient. Allergy healthcare providers should work with their patients on treatment decisions which align with their preferences and values as this can

improve adherence and lead to better outcomes. Several SDM tools are now available for atopic diseases.

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Figure Legends

Figure 1. Shared expertise of healthcare providers and patients leading to shared decision making.

Figure 2. 3-talk model of shared decision making. Reproduced from Elwyn et al.⁴⁰ Permission to reuse is not required based on open access license of the article.

Figure 3. Suggested SDM process for the allergy healthcare provider.

Table 1. Online resources for patient decision aids and SDM implementation.*

Organization	Patient Decision Aids Link	SDM Implementation Link
Massachusetts General Hospital: Health Decision Sciences Center	https://mghdecisionsciences.org/tools-training/decision-worksheets/	https://mghdecisionsciences.org/tools-training/
Agency for Healthcare Research and Quality	https://effectivehealthcare.ahrq.gov/search?f%5B0%5D=field_product_type%3Adcision_aid	https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html
Ottawa Hospital Research Institute	https://decisionaid.ohri.ca/	https://decisionaid.ohri.ca/implement.html
Mayo Clinic SDM National Resource Center	https://shareddecisions.mayoclinic.org/decision-aid-information/decision-aids-for-chronic-disease/	https://shareddecisions.mayoclinic.org/resources/sharing-with-others/
Healthwise	https://www.healthwise.net/cochrane/decisionaid/Content/StdDocument.aspx?DOCHWID=share	https://www.healthwise.org/resources/infographic/8-steps-to-shared-decision-making-success.aspx

SDM, shared decision making.

*All links last accessed July 6, 2018.

Table 2. Description of what SDM is and is not.

SDM is ...	SDM is not...
A distinct process	A vague concept of simply interacting with patients in decision making
A collaborative effort between patients and healthcare providers	Under the sole control of the patient or healthcare provider
An ongoing discussion throughout the course of the provider/patient relationship	A one-time discussion
A process encompassing the entire visit	A 60 second conversation during the course of the visit
Sharing and discussing information	Providing educational materials not geared to a specific decision Providing educational materials that advise people to choose one option over another Educational materials designed to promote adherence with a recommended option Outlining the pros and cons of the options to the patient Informed consent
SDM, shared decision making.	

Table 3. Observed benefits of patient decision aids and SDM.

Psychological Benefits	Clinically-related Benefits	Healthcare Resource Benefits
Improved patient knowledge ^{21, 22}	Improved adherence to medication ^{24, 64}	Reduced healthcare resource utilization ^{25, 28, 29}
Increased risk perceptions by patient ²²	Resulted in better outcomes ^{24, 25}	Reduced healthcare costs ^{28, 29}
Resulted in more active patient involvement ²²		Reduced rates of elective treatments/screenings ²²
Reduced patient indecision ²²		Reduced rate of invasive options ^{22, 28}
Improved patient//provider communication ²²		
Helped patients arrive at decisions consistent with their values ²²		
Improved patient satisfaction ²²		
SDM, shared decision making.		

Table 4. Patient decision aids for the allergy healthcare provider.

Condition	Decision	Resource	Format
Allergic rhinitis/asthma	Should I take allergy shots? ⁵⁷	https://www.healthwise.net/cochrane/decisionaid/Content/StdDocument.aspx?DOCHWID=aa69795	Internet, paper
Allergic rhinitis	Should my child get allergy shots? ⁵⁹	https://www.nemours.org/content/dam/nemours/wwwv2/filebox/research/Environmental%20Allergies%20Decision%20Aid.pdf	Internet, paper, PDF
Allergic rhinitis	Should I treat my allergies with immunotherapy? ⁶⁰	http://allergytherapy.acaai.org	Internet
Insect venom allergy	Should I take shots for insect sting allergies? ⁵⁸	https://www.healthwise.net/cochrane/decisionaid/Content/StdDocument.aspx?DOCHWID=rt1299	Web, paper
Asthma	Choice of inhaled corticosteroid ⁶¹	Gagne ME, Legare F, Moisan J, Boulet LP. Development of a patient decision aid on inhaled corticosteroids use for adults with asthma. <i>J Asthma</i> . 2016;53(9):964-974.	Paper
Severe asthma	What is the best treatment option for my severe asthma? ⁶³	http://severeastmatreatments.chestnet.org/	Internet