



## Review

## Shared decision making in allergic rhinitis

## An approach to the patient

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## Key Messages

- Shared decision making improves adherence, and improved outcomes follow.
- Patients consult various sources for disease state information; we need to ensure that allergists provide high-quality information.
- Helping patients make more informed choices improves satisfaction with their care.
- Shared decision making is an ongoing process that meets the variable needs of the patient over time.

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## ABSTRACT

**Objective:** To review what is known about the importance of shared decision making (SDM) in allergic rhinitis.  
**Data Sources:** MEDLINE and PubMed database searches for SDM, patient preferences, patient motivation with mobile apps, over-the-counter medications, adherence, complementary and alternative therapies, nasal steroids, and immunotherapy.

**Study Selections:** No articles directly dealt with the effects of SDM on outcomes in allergic rhinitis. Thus, of the 77 articles produced by these searches, 41 were selected based on the information relevant to evaluating the need for SDM in these patients.

**Results:** Poorly controlled allergic rhinitis continues to be associated with substantial morbidity. Complicating the effective control of the disease is the tendency of patients to self-manage using information from a variety of sources other than health care providers. Although direct evidence in allergic rhinitis is lacking, controlled trials have found the benefits of SDM in improving adherence and outcomes in at least 50 other disease states. Thus, this review explores the aspects of the disease that are complicated by poor adherence, establishing the case for the need for widespread use of SDM techniques.

**Conclusion:** Patients are confronted with a complex array of treatment options for allergic rhinitis, and a consistent SDM approach can better equip them to make the requisite care decisions needed to achieve optimal control. Furthermore, improving patient education through SDM provides a framework that enables long-term adherence for maximal outcomes.

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## Introduction

Physicians have always been responsible for pointing out treatment options to their patients. Unfortunately, paternalism in past medical practice narrowed the range of treatments discussed

and often ignored a discussion of risks of adverse outcomes. The era of personalized medicine discourages such paternalism. Although a discussion of the risks and benefits of various treatment options has already become more commonplace, true shared decision making (SDM) requires an exhaustive presentation of the risks and benefits of all relevant therapeutic options.

Shared decision making is a 2-way, interactive discussion in which the physician helps guide the patient to carefully weigh these risks and benefits in the context of their own beliefs and preferences.<sup>1</sup> Ideally, this discussion makes use of written, visual, or multimedia decisional aids that help bridge any barriers because of

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inadequate health literacy. A main goal of SDM is to improve adherence, which consists of the following 3 domains: (1) concordance, in which the physician and patient explore the available therapeutic options and agree on a treatment plan that best serves all needs; (2) compliance, in which the patient follows this agreed-on treatment plan on a day-to-day basis; and (3) persistence, which is continuing to actively comply with this plan for the recommended duration of treatment.<sup>2</sup> Persistence is of paramount importance in chronic diseases, such as allergic rhinitis, underscoring the need for the SDM process to be active and ongoing, adjusting to the varying needs of the patient over time. This discussion of SDM for rhinitis therapeutic options assumes that appropriate testing and counseling for relevant allergen avoidance strategies have already taken place and that other causes of rhinitis have already been excluded, especially in elderly patients.<sup>3</sup>

### Current Status of SDM in Allergic Rhinitis

There are no published randomized controlled trials that evaluated the effectiveness of SDM in allergic rhinitis, although 2 decision-making tools for allergic rhinitis treatment, 1 published online by the American College of Allergy, Asthma and Immunology (ACAAI)<sup>4</sup> and the other by the Nemours Children's Clinic,<sup>5</sup> are now available. However, we can infer the importance of SDM in allergic rhinitis from the findings of a Cochrane review of 105 articles that evaluated decisional aids for 50 different treatment and prevention tools across multiple disease states. This analysis found that independent of disease state and compared with usual care, the use of patient decision tools in a SDM format increased patients' knowledge of the disease state, improved the accuracy of their perception of risk, helped patients clarify their values, improved the congruence between the chosen option and their values, and helped patients feel that they were more in control of their decision.<sup>6</sup> Especially relevant to allergic rhinitis in general and allergen immunotherapy (AIT) in particular, the improved communication between a physician and a patient that develops during the SDM process substantially addresses many of the well-characterized barriers to adherence with the prescribed treatment regimen.<sup>7</sup>

### Need for SDM in Allergic Rhinitis

The burden of allergic rhinitis is well-known and considerable.<sup>8</sup> People often attempt to self-manage their rhinitis and do a poor job or are simply nonadherent with effective prescribed therapeutic regimens.<sup>9</sup> Uncontrolled rhinosinusitis has an important impact on quality of life, leading to disrupted sleep, poor school or work performance, suboptimal athletic performance, recurrent sinus infections, and the development or worsening of asthma. Previously, only limited survey data were available to indicate that compliance with medical therapy is generally low. However, emerging technologies, such as symptom and medication use monitoring by mobile technologies, as used in the Mobile Airways Sentinel Network (MASK) study,<sup>9</sup> are now providing real-world data that verify that compliance is low. It is incumbent on the allergist to take advantage of all available means to reverse these trends to improve outcomes. However, a substantial barrier to adherence in allergic rhinitis (ie, consistent medication use) stems from the fact that symptoms vary widely from week to week or month to month. Patients tend to adapt their therapy to the level they believe they need to minimize what is perceived to be unnecessary medication use.<sup>2</sup> The effect of SDM in other disease states to increase patient understanding of their disease and improve adherence to therapy provides the basis to assert that greater effort at the use of SDM by the allergist when treating patients with allergic rhinitis needs to be expended as a matter of routine. Important topics for further investigation include whether these known effects of SDM can translate to improved outcomes in

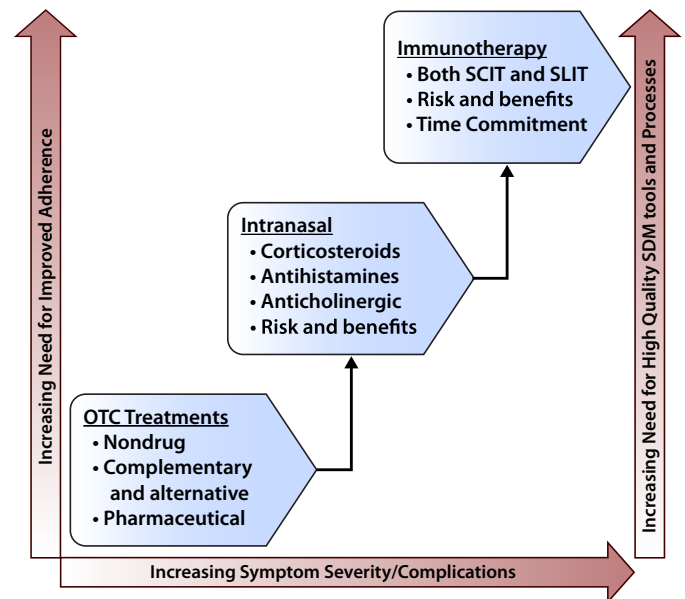


**Figure 1.** Adherence to rhinitis medications is low and is associated with adverse outcomes; thus, the more severe the disease, the higher the potential for adverse outcomes, the more therapy is required to control the inflammation, and therefore the greater the need to promote adherence to the agreed-on treatment regimen. OTC, over-the-counter; SCIT, subcutaneous immunotherapy; SDM, shared decision making; SLIT, sublingual immunotherapy.

allergic rhinitis and whether the SDM process can be used in a cost-effective manner. Options for this include billing based on time spent in educational discussion with the patient or minimizing the face-to-face time by having the patient complete online SDM tools, such as those indicated above, to allow a targeted discussion focused on questions the patient may have (Fig 1).

### Therapeutic Domains Amenable to SDM

#### Self-management with over-the-counter medications

Despite the effect of allergic rhinitis on quality of life, some patients believe that it can be self-managed<sup>10</sup>; at least two-thirds of patients with allergic rhinitis attempt self-management before seeking professional care,<sup>11,12</sup> with up to 80% believing that they need minimal to no guidance from a health care professional to manage their disease.<sup>12</sup> This belief is facilitated by the move toward self-management by regulatory agencies, which have brought several useful, previously prescribed, over-the-counter (OTC) medications in recent years. Both this belief in the effectiveness of self-management and the increased availability of powerful medications used without physician supervision contribute to the burden of the disease. Other than through community outreach activities, it is difficult for the allergist to have a meaningful impact on patients who do not come to the office, but it is equally true that patients who see an allergist may not follow-up and return to self-management after satisfying their desire to determine the substance to which they are allergic. One survey found that most patients had not discussed their rhinitis with a health care professional in the previous year, with half reporting that they had not seen their health care practitioner in the past 2 years.<sup>12</sup> Thus, it becomes incumbent on the allergist to use the SDM process at the initial patient visit to ensure that patients are adequately educated on their disease state. If they decide to self-manage with OTC medications, they need to understand the red flags that indicate the potential for adverse outcomes and seek expert assistance in their care to prevent them. Of course, the main intent is that engaging in

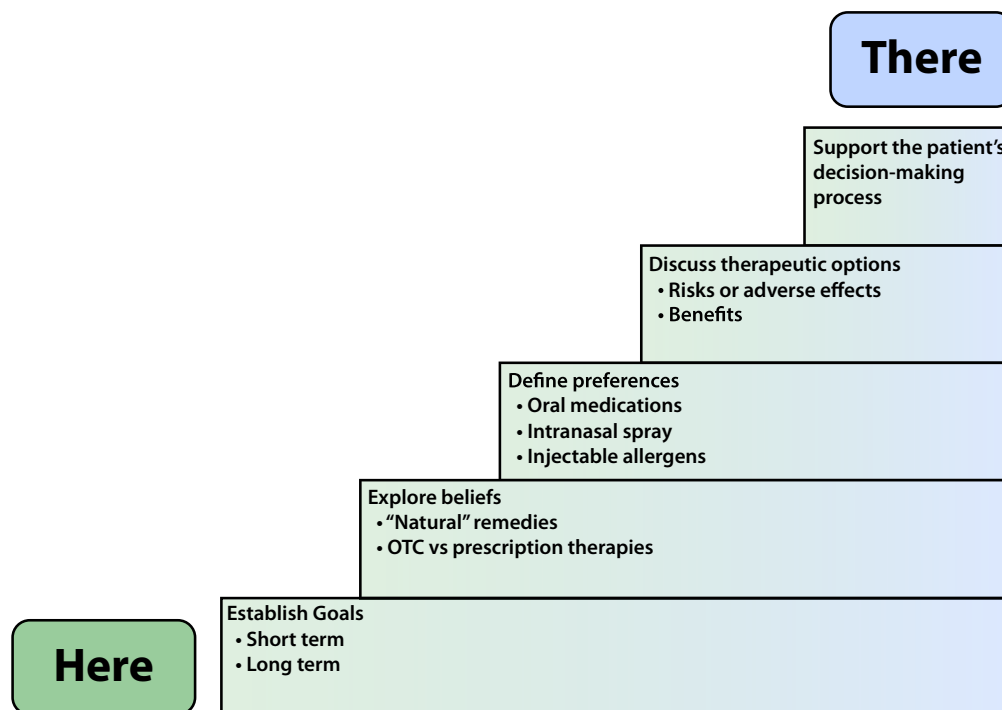


**Figure 2.** A stepwise approach to help the clinicians operationalize the shared decision-making process into their workflow. OTC, over-the-counter.

the SDM process will build the recognition of the need for active disease management in conjunction with the allergist. However, if patients opt to return to self-management, a better understanding of their disease and its treatment will not only improve their ability to self-manage but also increase the likelihood that they will again seek assistance well before experiencing serious complications, assuming that their self-care will likely result in inadequate control of the  $T_H2$  inflammation. Expert opinion in phases 3 and 4 of the Allergic Rhinitis and Its Impact on Asthma (ARIA) study recognized the increasing role of self-medication in allergic rhinitis and advocated SDM as an essential method to engage the patient to improve their decision making.<sup>13</sup>

A small Australian study provided intriguing insights into the approach that patients with allergic rhinitis take toward seeking information about their disease state and recommendations for treatment. The authors evaluated the allergic rhinitis network, which includes the sources that patients use for information about their disease and help with treatment decisions. Roles were identified for 17 different sources, with each patient using up to 11 different resources. The median was 5 resources or alters; the greater the effect of the disease on the patient’s quality of life, the more resources for information were sought and the more likely they were to seek advice from health care practitioners.<sup>14</sup> The following 5 categories of information were identified: diagnosis; medication prescription, supply, and administration; medication recommendation; information about allergic rhinitis; and emotional support.<sup>15</sup> Notable among the findings were that family, friends, pharmacists, and the patient’s own previous experiences were influential in choosing OTC medications, underscoring the need to address OTC options in any SDM discussion. The role of the pharmacist in patient education about the disease and proper use of medications should not be neglected.<sup>16</sup> In addition, 1 small survey of patients choosing OTC medications in the pharmacy found that those interacting with the pharmacist were more likely to have rhinitis symptoms that were affecting daily activities or at least 1 other aspect of quality of life.<sup>17</sup> Regarding this frontline role of the pharmacist,<sup>18</sup> education to ensure that pharmacists make treatment suggestions to patients choosing OTC

therapeutic options that are consistent with current guidelines<sup>19</sup> should be encouraged.

Patients also tend to explore complementary and alternative treatments. A basic tenet of SDM is to take into consideration the patient’s beliefs and preferences, so the allergist must be prepared to discuss these options when the patient expresses an interest in them.<sup>20</sup> For example, acupuncture may be effective in treating allergic rhinitis, but its cost-benefit ratio makes it less cost-effective than many other treatment options.<sup>21</sup> Mention can be made in an SDM tool of the use of vitamin D, butterbur, and capsaicin, all of which have been reported to be effective in allergic rhinitis<sup>20</sup> in addition to advice to carefully evaluate the efficacy of each to decide whether their use should be continued. A recent Cochrane review<sup>22</sup> found that although there is low-grade evidence for the use of saline irrigation, its safety profile indicates that it has a place in SDM discussions as an adjunct to another pharmacotherapy.

#### *Supervised Management With Primarily Intranasal Medications*

Topical therapy now includes both OTC and prescription medications. Some intranasal corticosteroid sprays are available both OTC and by prescription. Topical antihistamines and ipratropium remain available only by prescription in the United States. It is well-known that a variety of sensory attributes affect patient preferences when using intranasal corticosteroids, including spray volume or force,<sup>23</sup> running down the back of the throat,<sup>24</sup> odor, taste,<sup>25</sup> and delivery (aqueous vs aerosol).<sup>26</sup> Furthermore, nearly half of patients have serious concerns about intranasal corticosteroids, such as systemic adverse effects, habituation, and nosebleeds.<sup>11</sup> This is an area well-suited to an SDM discussion because a review of multiple studies regarding the safety, perceptions, and efficacy of intranasal corticosteroids revealed that there is no evidence of clear-cut superiority of any one over another and that the variety of patient perceptions justifies the role for both aqueous and aerosol formulations.<sup>27</sup> Inclusion of these aspects of therapy in the SDM discussion mitigates any surprises once a patient purchases a topical agent and starts to use it. Building one’s approach to SDM regarding prescription

medications is best served by using high-quality evidence, particularly guideline consensus documents based on Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) analysis. For example, the recent evidence-based GRADE document on the treatment of allergic rhinitis recommends that both intranasal corticosteroids and intranasal antihistamines be used concurrently, with high-quality evidence supporting the efficacy of this approach.<sup>28</sup> Whenever possible, high-quality data and guideline recommendations should be explained to patients to increase their trust in the recommendation and improve the likelihood of remaining adherent to therapy.

Unfortunately, an unavoidable aspect of modern pharmacotherapy is formulary coverage and affordability. The adage that “even the best medication won’t work if the patient doesn’t take it” applies equally to whether a particular medication is affordable to the patient by formulary or self-pay. Each allergist must determine whether their third-party payer climate is such that all prescription options are presented to the patient with the intent to pursue prior authorization if the patient chooses a poorly or noncovered option or if the discussion focuses on options known to be affordable to the patient based on prior experience with the local payers.

Of particular importance in an SDM discussion of intranasal medications is the role and risks of intranasal decongestants because patients continue to self-medicate even while under the care of a physician. Topical decongestants used in conjunction with intranasal corticosteroids may be safe and beneficial,<sup>29</sup> but a survey-based evaluation of the use of intranasal decongestants found that more than half of the patients overused them, even though 80% admitted that they had been counseled on limiting the duration of use.<sup>30</sup> Disclosing this information can help reveal to the patient that the frustration they have with the persistence of their disease is common and can emphasize the need to remain engaged in the entire SDM process that can span multiple office visits during multiple years as the disease state and our tools to treat it evolve.

### Allergen Immunotherapy

Management of chronic disorders using long-term therapies, such as AIT for allergic rhinitis, demands deliberate attention to the long term; unlike OTC or prescription medications, the patient will not be able to evaluate efficacy for symptom control in a matter of days or weeks and change to another option if control is suboptimal. Successful AIT requires excellent listening skills, building rapport with the patient, and careful evaluation of buy-in on the part of the patient to maximize the likelihood that the patient will adhere to therapy in the long term. Shared decision making builds on this framework by providing a comprehensive guideline for choosing treatments in the context of the patient’s goals.<sup>31</sup>

A significant difference in the SDM process with patients considering AIT compared with pharmacotherapy alone is addressing the long term. Patients considering pharmacotherapy are concerned about the benefits and adverse effects of medications in the short term. Thus, SDM discussions need to address long-term risks and benefits, such as the tendency for AIT to prevent further sensitizations or the development of asthma.<sup>32</sup>

A major new development for AIT in the United States since 2014 has been the first approvals of sublingual immunotherapy (SLIT) by the US Food and Drug Administration. Some thought that the ease and safety of SLIT would mean the end for subcutaneous immunotherapy (SCIT), especially once the efficacy of single-allergen SLIT had been found in polysensitized patients. However, patients still often choose SCIT over SLIT whether polysensitized or not<sup>33</sup> and maintain a high level of adherence to the prescribed regimen.<sup>34</sup> Regardless of whether SCIT or SLIT was chosen, the use of SDM to engage patients in the decision as to which modality to pursue improved adherence, and the dropout from therapy was

halved during the 6 months of the treatment.<sup>35</sup> Factors improving adherence include greater patient education to understand the therapy and choice of convenient dosing schedules, such as a pre-seasonal schedule when indicated<sup>36</sup> (Fig 2).

### Conclusion

For clinicians developing their approach to SDM discussions, the 48 recommendations within the 2010 revision of the ARIA guidelines provide excellent talking points with a wide variety of the patient types typically seen by the allergist. Additional comments are provided on values and preferences because they relate to AIT, prescription medications, OTC medications, and complementary and alternative therapies.<sup>37</sup> The summary statements in the US immunotherapy practice parameters provide additional evidence-based talking points for both SCIT<sup>38</sup> and SLIT.<sup>39</sup> The aforementioned tools developed and published by the ACAAI<sup>4</sup> and Nemours Children’s Clinic<sup>5</sup> are valuable resources to engage the patient and augment the in-person discussion of options, risks, and benefits.

Once the patient’s therapeutic decisions have been made, the focus turns to adherence with the agreed-on treatment plan to maximize outcomes. Techniques for this have been previously described, including continuing to build a relationship with the patient, focusing on listening, continuing to provide information as needed, continuing to collaborate on the treatment plan, and following up with the patient on a regular basis.<sup>40</sup>

Finally, it is important to reemphasize that SDM is not a single conversation; it is a process that extends throughout multiple patient visits over time and evolves and adapts to the needs of the patient. An essential element relevant to that evolution is the use of health-related smartphone apps that monitor disease severity and medication use and empower the patient to better participate in their treatment discussions and provide data to inform and refine future treatment decisions.<sup>41</sup>

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