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# The future of allergic rhinitis management: A partnership between healthcare professionals and patients

Biljana Cvetkovski, PhD[a,1]*, Danielle Muscat, PhD[b,1], Jean Bousquet, MD, PhD[c], Martha Cabrera, PhD[d], Rachel House, PhD[a], Gregory Katsoulotos, MBBS, PhD[e], Olga Lourenco, PhD[f], Nikolaos Papadopoulos, MD, PhD[g], David B. Price, MD[h], Janet Rimmer, MD[i], Dermot Ryan, MB BCh BAO[j], Pete Smith, MBBS, PhD[k], Kwok Yan, MBBS, MD[l] and Sinthia Bosnic-Anticevich, PhD[a]

## ABSTRACT

Allergic rhinitis (AR) is a chronic respiratory condition that internationally continues to be burdensome and impacts quality of life. Despite availability of medicines and guidelines for healthcare providers for the optimal management of AR, optimisation of its management in the community continues to be elusive. The reasons for this are multi-faceted and include both environmental and healthcare related factors. One factor that we can no longer ignore is that AR management is no longer limited to the domain of healthcare provider and that people with AR make their own choices when choosing how to manage their condition, without seeking advice from a health care provider. We must build a bridge between healthcare provider knowledge and guidelines and patient decision-making. With this commentary, we propose that a shared decision-making approach between healthcare professionals and people with AR be developed and promoted, with a focus on patient health literacy. As custodians of AR knowledge, we have a responsibility to ensure it is accessible to those that matter most–the people with AR.

## THE GLOBAL BURDEN OF ALLERGIC RHINITIS

Allergic rhinitis (AR) is a chronic, upper respiratory condition which currently affects 10–40% of the world's population and is increasing in prevalence;[1–4] yet optimal control of this disease remains elusive.[5–7] Many factors contribute to the poor control of AR, including undertreatment or inappropriate treatment,[8–14] whether it be the result of suboptimal diagnosis, confusion between allergic and non-allergic rhinitis, or patients' perceptions of their illness.[15,16] Studies have shown that patients often treat themselves according to symptoms irrespective of healthcare provider (HCP) recommendations[17] and often do not even mention the condition to their general practitioners (GPs), evidenced through the under recording of AR in GP medical records.[18] In fact, 70% of people with AR self-manage without consulting a HCP, primarily basing their treatment decisions on their own perceptions of medication effectiveness, gathered through experience, experimentation, and historic medical recommendations, rather than regular or recent HCP review.[13,16,19,20] Moreover, misguided perceptions of treatment effectiveness[7] and poor

[a]Woolcock Institute of Medical Research, Australia.
*Corresponding author. E-mail: biljana.cvetkovski@woolcock.org.au
[1] Danielle Muscat and Biljana Cvetkovski are co-first authors.
Full list of author information is available at the end of the article
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treatment adherence were also identified in a real-life study using the MASK-air app in around 7000 patients with AR which showed that adherence to AR treatment is under 10%.[21] It is within this pattern of patient behaviour that HCPs are trying to implement treatment guidelines [7,20,22-24] and are clearly failing to do it.[7,20] Therefore, when it comes to AR management, it may be time to take a different approach.

## THE ROLE OF AR GUIDELINES AND PATIENT SELF-MANAGEMENT

The management of other chronic respiratory diseases such as asthma is supported by clear guidelines targeting the role of HCPs, especially pharmacists, GPs, and specialists, as well as tools and frameworks aimed at supporting patient self-management.[25,26] These guidelines dually recognise the role of HCPs and patients in the management of these conditions.[27] This is in stark contrast to the scenario for managing AR.

Although the Allergic Rhinitis and Impact on Asthma (ARIA) guidelines have over many years tried to generate new knowledge and develop clinical pathways for the management of AR, they solely focus on HCPs, save for noting that the first step in managing rhinitis symptoms for a patient is "self care" (Fig. 1). When it comes to patient self-management of AR, patients are left to their own strategies, primarily based on their personal experiences.[28,29] In effect, this provides a disconnect between the patient and the HCP, and behaviours that do not align with treatment guidelines.[30]

## A SOLUTION FOR AR MANAGEMENT IN A SHARED DECISION-MAKING APPROACH

Shared decision-making is a process in which HCPs and patients work together to select tests, treatments, management or support packages based on clinical evidence and the patient's values and informed preferences.[31] Although shared decision-making models differ to some extent, many prominent models distinguish 4 key

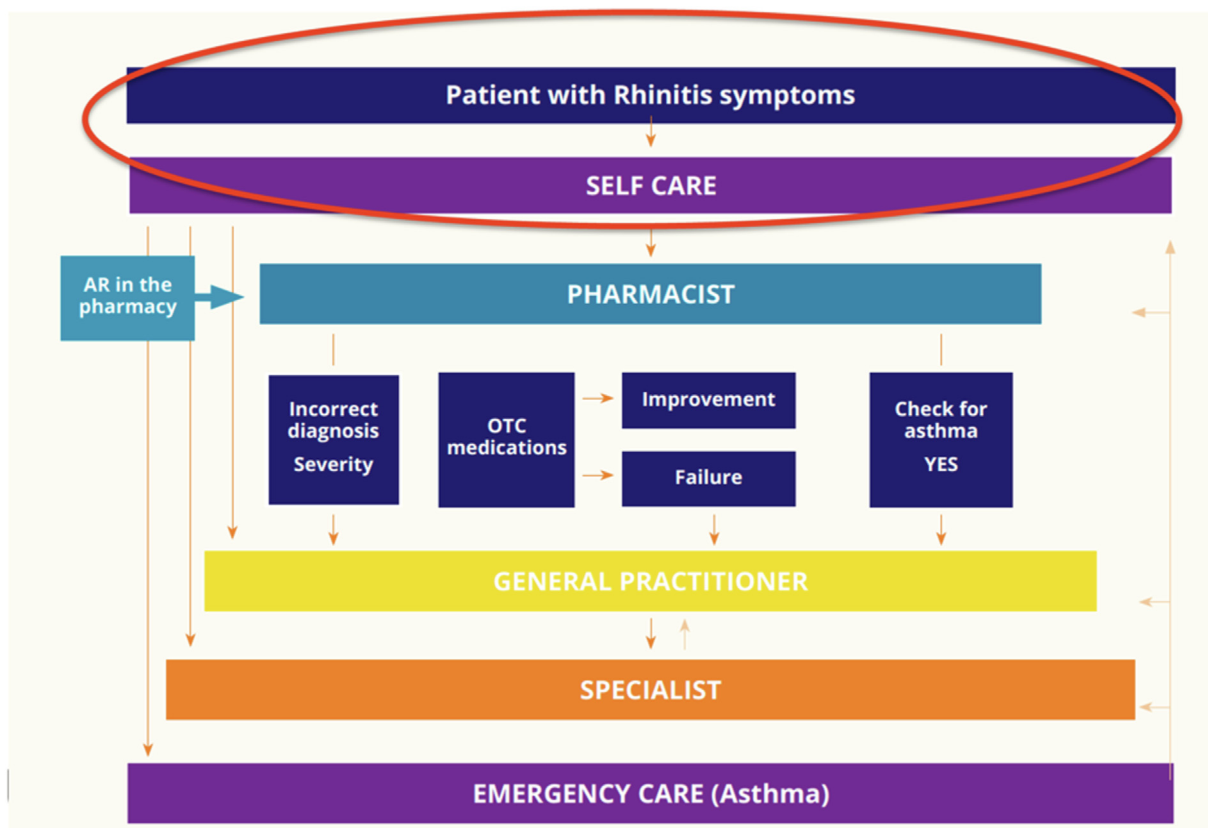


**Fig. 1** ARIA integrated care pathways for rhinitis and asthma multimorbidity.

elements: 1) fostering choice awareness, 2) discussing relevant options and corresponding benefits and harms, 3) discussing patients' values and preferences, and 4) making the final decision.[32] At its core, shared decision-making is about bringing together evidence about different treatment options and a patient-centred perspective to make optimal treatment decisions.[33]

In the context of AR, a shared approach to decision-making appears a promising way to overcome some of the current impediments to optimal decision-making by creating a forum for patients to better understand the evidence related to different treatment options, while still incorporating their values, preferences and past experiences into the final treatment choice. As a midpoint between "paternalistic" and "consumerist" models of clinical decision making, a shared decision-making approach seeks to recognise the autonomy and responsibility of both HCPs *and* patients.[31] Therefore, to facilitate shared decision-making, it is necessary to map required actions for both providers and patients.

*How do we move towards shared decision making in AR? – Required actions for healthcare professionals*

**Action 1: Promote a shared decision-making approach**. AR management has currently well and truly left the realm of HCP oversight and is in the hands of the people with AR. It is important to bridge this gap between people with AR and their HCPs and to reconnect the them through shared decision-making. One way to facilitate this may be through the development and implementation of clinical practice guidelines which include explicit recommendations for shared decision-making, as has been increasingly done in other clinical contexts.[34] Such recommendations would serve as an explicit prompt for clinicians to engage with their patients. Incorporating shared decision-making into medical education for different HCPs also presents an immediate opportunity to raise awareness of this approach in the context of AR and to build HCP skills.[35]

A challenging aspect that must be addressed is the relative role of each HCP within the ARIA integrated care pathways (Fig. 1). To deliver shared decision-making, a joint or at least parallel effort of different disciplines is needed as this will not happen automatically. Interprofessional education (IPE) with health care providers has been shown to improve attitudes towards each other's disciplines and improve patient care.[36] In the context of AR management will facilitate understanding of each other's speciality and skillset and the opportunity to interact with people with AR where a collaborative approach can further support the patient. While traditional IPE has not included the patient, in the context of AR management it would be a grand oversight not to include the perspective of people with AR within the educational content.[37,38]

**Action 2: Support evidence-based practices**. Continued efforts are needed to increase our pathophysiological and clinical understanding of the disease and its treatments[39] and to ensure that HCPs are aware of treatment options and existing guidelines for AR management given that perception of AR severity in primary care is poor.[40] HCPs are under enormous pressure and need to be equipped to practice evidence-based medicine, rather than relying on their own experience.

**Action 3: Facilitate patient-centred care and communication**. As shown in Fig. 2, shared decision-making requires patients to be at the centre of care. To achieve this in AR, HCPs must be able to communicate evidence-based information about AR including the nature of the condition, treatment benefits, risks, and alternatives in a way in which patients understand, using patient-centred communication.[35] Thankfully, several resources already exist to support this. Simple communication strategies, such as the use of Teachback where HCPs ask patients to repeat back the information that they have provided in their own words, are increasingly backed by evidence and are supported by open-access training resources (see, for example, Teachback.org).[41] Ensuring that written information is developed using health literacy principles – including attention to the grade reading level of text and with consumer review – are also more achievable than ever through digital tools (eg, the SHeLL Editor) and processes and risk communication guidelines now exist to support the presentation of numerical probabilities.[42-44]

As well as providing evidence-based information, HCPs must also recognise the critical role that factors have in forming AR plans of care, including the past experiences of patients, their priorities, and the particulars of their situation, such as comorbidities, existing burdens of illness and treatment, social support, and personal capacity to safely enact the care plan.[34] Without engaging patients meaningfully, evidence may poorly translate into practice and improved outcomes.[35] HCPs must fully appreciate the daily experiences and treatment of AR patients, which can increasingly be facilitated through mobile health tools.[45]

*But it "takes two to tango" - Health literacy and the power of the patient*

Encouraging shared decision-making among clinicians is unlikely to be sufficient to achieve active patient participation in decision-making about AR treatment and management. This is particularly true given the evidence suggesting that many patients rely on their own experience or advice from past healthcare encounters to select treatment options, rather than consulting with GPs or pharmacists about the changing nature of evidence;[13,16] shared decision-making within clinical encounters is not possible if the encounters are not initiated by patients in the first place.

Recent conceptual models of shared decision-making acknowledge the need to engage patients in solutions to enable this model of care, particularly by emphasizing the importance of health literacy (See Fig. 2).[46] Although numerous definitions of health literacy exist, almost all definitions in common use have the same core elements describing the personal skills and environmental conditions that enable individuals to obtain, understand, and use information to make decisions and take actions that will have an impact on health status.[46,47] To successfully share in decision-making within consultations patients need health literacy skills to communicate effectively, to obtain, understand, and share information with health professionals (including, for example, alternative options, risks, benefits, and uncertainties related to new AR treatment regimens). Patients also need the cognitive and social skills to express personal values, preferences, and past experiences (which we know heavily impact on AR treatment decision making), and to contextualize and critically evaluate information to make a decision which aligns with these values and preferences.[46]

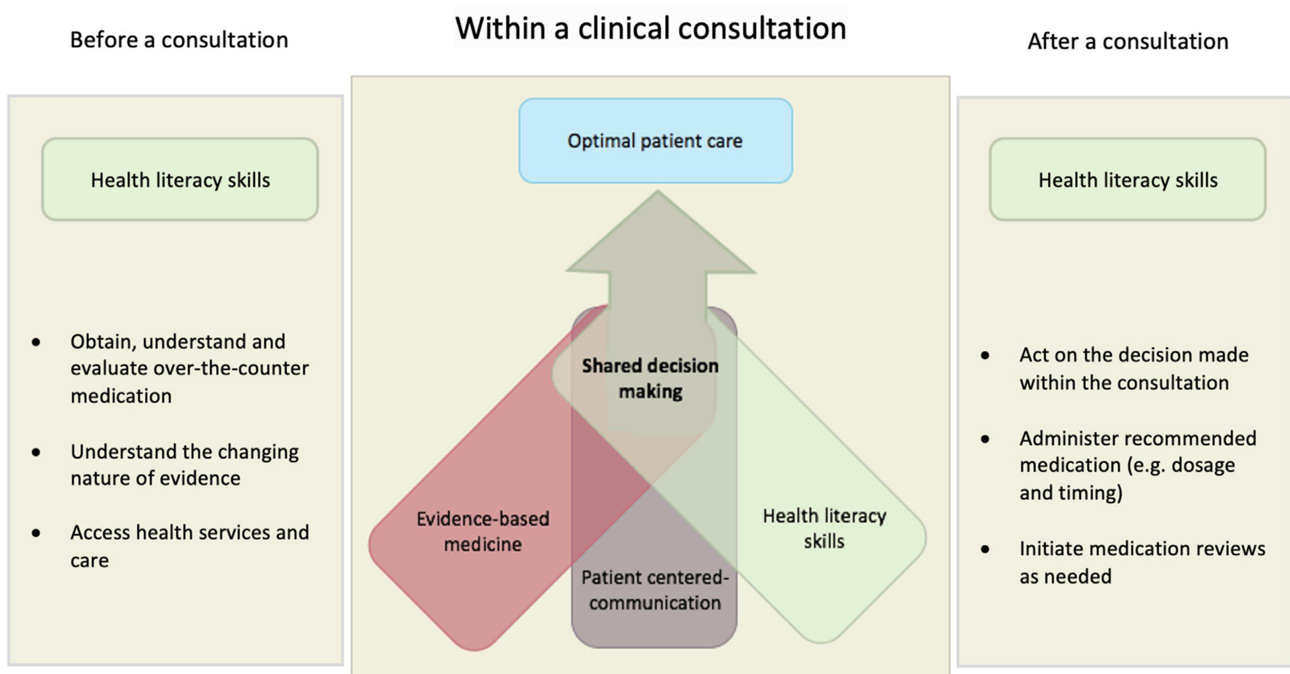


**Fig. 2** Revised model of shared decision making in the context of allergic rhinitis.

In the context of AR, health literacy is also required to enable shared decision-making even prior to the consultation. Patients need, for example, to be able to understand the nature of their condition, obtain and think critically about information related to over-the-counter medications, appreciate the changing nature of evidence (ie, medications prescribed years prior may no longer be gold standard), and to access health services and care in order to optimise the management of their AR. Following the consultation, health literacy skills will, for example, enable patients to act on the decision made within the consultation, administer the chosen medication, and initiate medication reviews as needed.

**Action 4: Understand and support health literacy**. Given this, we must concurrently take actions to understand and support health literacy among AR patients. Although structured education and communication have long been proposed as avenues for developing health literacy online platforms and applications as well as new forms of media open up a range of new opportunities for targeted communication – including to encourage help-seeking from HCPs when symptoms arise.[48] Additionally, mobile phone applications such as MASK-Air®, which aim to monitor, evaluate, and review the management of AR to support patient communication with their HCPs[49,50] can also be expanded to include evidence based information for patients about the risks and benefits of different AR treatments and to better encourage self-management through actionable content. Tools must also necessarily be developed with the health literacy principles outlined earlier and with tailoring to accommodate different health literacy levels.[51] The responsibility lies not with the patient but with the health system and providers to take action at all levels to support health literacy.

## CONCLUSION

In considering ways in which AR management can be improved in the future, it is first essential to continue to increase our pathophysiological and clinical understanding of the disease and its treatments (eg, the evolving phenotyping/classification of AR of Lemonnier et al and Papadopoulos et al)[39,52] and to make use of the technological advances which are increasingly part of clinical practice. However, it is also critical to acknowledge the failings of our approach to date, in that current AR management only addresses evidence-based medicine practices with minimal to no regards for the potential of a shared decision-making AR model (Fig. 2). There have been few research or practice developments related to fundamental patient-related factors of health literacy and communication,[53] which is in stark contrast to other chronic diseases such as asthma, which have invested in patient centred-communication[54-58] and health literacy[59-61] to develop shared decision making tools to optimize disease management.[62] Equipping HCPs with patient centred communication tools, an understanding of AR health literacy in conjunction with evidence-based guidelines and shared decision-making aids, will elevate their preparedness to manage AR substantially and work towards improving clinical outcomes. Not only will shared decision-making empower people with AR when collaborating with their HCP on their AR management but it has also been shown to address clinical inertia among HCP and therefore improve the implementation of the guidelines in the primary care setting.[63] With both the HCP and patient equipped to manage AR, we will see change in the AR management landscape.

### Abbreviations

AR, Allergic Rhinitis; ARIA, Allergic Rhinitis and Impact on Asthma; GP, General Practitioner; HCP, Health Care Provider; MACVIA, Contre les MAladies Chroniques pour un VIeillissement Actif; MASK, (MACVIA ARIA Sentinel NetworK)

### Author details

[a]Woolcock Institute of Medical Research, Australia. [b]The University of Sydney, Australia. [c]University Hospital Centre of Montpellier, France. [d]Los Madroños Hospital, Spain. [e]The University of Notre Dame Australia and The University of Technology, Australia [f]University of Beira Interior, Portugal. [g]Athens Area Pediatrics, Greece [h]Observational and Pragmatic Research Institute, UK. [i]St Vincent's Hospital Sydney, Australia. [j]University of Aberdeen Academic Primary Care Research Group, UK. [k]Griffith University - Gold Coast Campus, Australia. [l]Royal Prince Alfred Hospital, Australia.

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