



The respiratory allergy patient's healthcare journey: An international qualitative survey employing an ethnographic approach

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ABSTRACT

Respiratory allergy (RA), one of the most prevalent global chronic diseases, is often suboptimally managed by both patients and healthcare professionals (HCPs). This qualitative survey investigated the RA healthcare journey from the patient perspective to better understand the challenges faced at key stages and the unmet needs for potential improvements in physician-patient relationship, shared decision-making and patient quality of life outcomes.

The survey employed an ethnographic approach consisting of getting rid of any preconceived ideas and adopting an attitude of listening and empathy devoid of any prejudices. It involved 105 participants distributed across 3 countries (France, Germany, and Italy) who took part in a 2-h interview. All were diagnosed with intermittent or persistent RA and were at different stages of the journey/treatment (without treatment, antihistamine, undergoing Allergen Immunotherapy [AIT], completed AIT, reluctant to AIT, or discontinued AIT). Regional differences and variations related to medical subspecialties are considered, offering a comprehensive and nuanced perspective on RA management at an international level.

The examination of a complex and lengthy journey revealed 4 key stages and explored the corresponding emotional experiences. Physician-patient communication, clinical and emotional support and timing are found to be crucial factors in treatment choice, adherence and the psychological impact of the journey. Additionally, the data collected identified 4 distinct profiles related to AIT, based on their approach to managing RA and their level of access to treatment information: the "skeptical", the "skittish", the "determined", and the "convinced". This patient stratification can help physicians tailor their strategies and adopt more personalized approaches.

Keywords: Healthcare journey, Emotional experience, AIT treatment, Patient adherence, Qualitative methods

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<http://doi.org/10.1016/j.waojou.2025.101111>

Received 28 April 2025; Received in revised form 25 July 2025; Accepted 9 August 2025

Online publication date 9 October 2025

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INTRODUCTION

Respiratory allergies (RA) can severely impact quality of life, leading to compromised school attendance, strained family relationships, and hindered social skill development.¹ Inadequate management of allergic rhinitis, particularly nasal obstruction, can result in facial malformations, sleep disorders, including apnea, and orthodontic issues. These complications, coupled with the resulting levels of disability, premature mortality, reduced productivity in adults, and impaired academic performance, contribute to significant economic repercussions for both individuals and society.² The journey of patients with allergy can begin at any age, though it is most commonly diagnosed in childhood. Adult allergic patients tend to adopt a self-management approach towards their condition, mainly consisting on avoiding triggers, using various treatments, and eventually seeking professional advice.¹ They often perceive their symptoms as normal or trivial and simply rely on over-the-counter (OTC) medications. In this context, pharmacists serve as the initial, crucial point of contact for early disease management, as they are trusted healthcare professionals (HCPs) who can recommend appropriate OTC treatments.³ Patients who do visit general practitioners or specialists typically present with moderate to severe rhinitis.⁴

Allergy diagnosis in a medical or specialist setting is followed by the development of a therapeutic plan based on the severity and impact of symptoms, the presence of comorbidities, and the availability of therapeutic options.⁴ The treatment is complex due to the heterogeneous nature of IgE-mediated allergic diseases, which vary in clinical presentation and sensitization patterns. In order to be effective, treatment strategies must be personalized, ranging from primary prevention to targeted pharmacotherapy aimed at managing specific organ symptoms.² First-line treatment for mild respiratory allergies typically targets symptom alleviation and involves antihistamines, leukotriene receptor antagonists, nasal decongestants and avoidance measures.⁵

For moderate-to-severe patients who seek an alternative to symptomatic medication or for whom conventional treatments are ineffective, allergen

immunotherapy (AIT) is recommended.⁴⁻⁶ AIT lowers inflammatory responses and allergic reactions by gradually inducing tolerance to specific allergens through mechanisms such as altering allergen-specific IgE and IgG levels, generating blocking antibodies, and promoting regulatory immune cell subsets. Indeed, unlike traditional pharmacotherapy, which focuses on managing symptoms, the disease-modifying effect of AIT aims at long-term remission, prevention of disease progression, a lower risk of developing new sensitizations or conditions like asthma, and a reduced reliance on pharmacotherapy.⁷⁻¹⁰ AIT's effectiveness relies on a precise diagnosis and an individualized approach based on the selection of a tailored allergen composition which addresses the patient's unique IgE spectrum.^{2,4}

Although the exact mechanisms of AIT are not fully understood, randomized controlled trials and meta-analyses have demonstrated its efficacy and safety⁸ as well as its valuable preventive role, especially in pediatric populations, in lowering the likelihood of transitioning from allergic rhinitis to asthma.¹⁰ However, achieving these long-term benefits requires sustained adherence to treatment, as multi-season or multi-year administration is needed for durable effects.¹¹ EAACI (European Academy of Allergy and Clinical Immunology) guidelines recommend a treatment duration of at least 3 years.⁶ Unfortunately, therapy discontinuation after 1 or 2 years of therapy is common, as shown by multiple European studies.^{12,13}

Multiple factors are known to influence adherence to treatment, which often declines over time. These include patient education, effective communication between HCPs and patients, consistent support from physicians throughout the treatment journey, and the patient's perceived efficacy of the treatment. Additionally, reimbursement policies complicate adherence, as inadequate coverage for AIT can result in higher dropout rates, particularly in regions where insurance support is limited.⁸ Other important factors, such as age, socioeconomic status, overall health, and disease severity, also significantly affect adherence.⁸

Despite advances in the treatment of allergic diseases, particularly with AIT, there remain

substantial unmet needs throughout the journey of allergic patients. This survey examines the healthcare journey of RA patients through an international qualitative survey employing an ethnographic approach. The research identifies key stages, challenges, and unmet needs encountered along the journey. Additionally, it delves into the emotional experiences of patients to better understand the psychological impact of RA on their quality of life. Finally, the survey highlights 4 distinct patient profiles based on their knowledge, practices, and approaches to managing RA.

METHODS

This survey employed a qualitative methodology incorporating an ethnographic approach to gain a comprehensive understanding of the healthcare journey of patients with RA.

An expert committee, composed of 4 specialists in the management of RA patients practicing in the 3 countries surveyed (2 in France, 1 in Germany, 1 in Italy) validated the patient recruitment screener and participated in a dedicated session aimed at developing hypothesis trees to structure and guide the qualitative research process.¹⁴ This methodology offers a systematic framework for exhaustively mapping all existing hypotheses, and available knowledge related to the topic under investigation, whether derived from literature, clinical practice, or stakeholder discourse. In line with ethnographic traditions, the hypothesis tree is not only a tool for structuring inquiry but also a reflexive instrument that allows researchers to identify and surface their own and others' preconceptions prior to data collection. Treating these preconceptions as objects of study rather than implicit assumptions enabled the research team to develop interview guides that remained open and exploratory.

The fieldwork consisted in a 2-h semi-structured interview during which the personal representation of RA, the effect on quality of life, the stages of the care pathway and their experiences were discussed. The analysis delved into the detailed narratives to extract themes, patterns, and nuances about the perceptions and experiences related to RA treatment and management. For further exploration, participants

completed a 30-min homework assignment, which focused on the personal description of the condition and its effect on quality of life. It allowed patients to express themselves in a different format, and a short collection of medical appointment history and experience enabled completeness of data on this key part of our research. Thematic analysis was performed to process this data on personal experience of RA and the healthcare journey.

All RA patients contacted for this survey were recruited through a standardized process designed to ensure fully informed and voluntary participation. Initially, each participant received an information letter outlining the context and purpose of the project. This was followed by a detailed consent form specifying the survey objectives, the intended use of the data collected, the approximate duration of the interview, the researchers' obligation to maintain confidentiality, and participants' rights, including the right to withdraw at any time and the right to request the erasure of their personal data in accordance with GDPR regulations. Prior to each interview, participants were also provided with a brief verbal disclaimer summarizing these points, and consent was confirmed explicitly before proceeding. All data were anonymized and securely stored, and no personally identifiable information was used in the analysis or reporting.

RESULTS

Participants' characteristics

The survey included a total of 105 participants from three different countries: Germany (DE), France (FR), and Italy (IT), with each country contributing with 35 participants. The demographic composition of the participants was diverse, including 57 women and 48 men. The age distribution was also varied, with 27 individuals being younger than 18 years old and 78 individuals aged 18 years or older.

Among the participants, 64 individuals experienced intermittent RA, characterized by periods of remission and flare-ups, while 41 individuals had persistent RA, with continuous symptoms. The survey explored the participants' experience with AIT: out of 23 participants undergoing AIT, 19

were receiving sublingual immunotherapy (SLIT) and 4 were receiving subcutaneous immunotherapy (SCIT). Additionally, 36 participants had already completed AIT, with 25 having undergone SLIT and 11 having undergone SCIT. The survey also included 16 participants who had discontinued AIT, with 10 having stopped SLIT and 6 having stopped SCIT. Furthermore, 30 participants were identified as being reluctant to undergo AIT.

Allergic patients downplay their condition despite its impact on their lives

Overall, participants tended to minimize the severity of RA, whether due to ignorance or denial, even after years of living with the illness and despite its strong and sometimes overwhelming impact on their lives. They described RAs primarily in terms of discomfort and symptoms they experienced. Words like “uncomfortable,” “suffering,” and “difficult” were used to define their condition, often associating the allergy with sensations that mirrored their symptoms, such as “tingling” and “tickling.” Their feelings towards allergy were overwhelmingly negative, ranging from “irritation” to “rage.” Only 14 out of 105 patients referred to RA as a chronic disease.

Many held on to the belief or hope that their symptoms would lessen over time or that the condition would eventually resolve on its own (without treatment). The banalization of the allergy, with terms such as “hay fever”, was strong. However, patients shared the major impact the RA has on their social life or on their quality of life, leading to restricted, or even cancelled outings, impossibility to physically work in environments where the allergen is present, etc. Nevertheless, they expressed a strong belief that their pathology is less severe in comparison to others, such as diabetes, cancer, or serious pediatric diseases. Yet, patients who had received information about chronic asthma or who had experienced it themselves perceived RA as potentially serious or capable of worsening. These situations prompted them to actively seek therapeutic solutions.

Patient journey: Challenges and patient emotions

Fieldwork revealed key stages of the RA care pathway

First signs

Participants reported that their RA began with a feeling of discomfort and symptoms such as coughing, a cold or itching. These recurring events initially led them to self-medicate. Some said they had used OTC medicines without advice, while others (5/105) had borrowed from other family members or friends who had experienced similar health problems. The persistence or intermittent recurrence of symptoms has prompted patients to turn to HCPs. Most patients said that they first turned to primary care professionals (GPs or paediatricians) because of their accessibility. These non-specialist healthcare providers played a crucial role in the early stages of RA.

First non-specialist consultation(s)

Patients have reported that primary care professionals usually make a preliminary assessment of the patient's condition and often make a pre-diagnosis of RA based on the symptoms presented. They may suggest an initial treatment plan, which may include OTC medication, prescription of symptomatic treatments or alternative solutions such as allergen avoidance strategies. Initially, all patients reported that symptomatic RA treatments offered them a rapid improvement in quality of life (QoL), making daily activities easier to manage. They reported the use on demand of easily accessible, OTC treatments, offering patients flexibility.

However, relief was often temporary, and the underlying disease process untreated. 70/105 patients felt a reduction in effectiveness of these treatments over time. Due to the complexity and variability of RA symptoms, these initial treatments often led to poly-medication and avoidance strategies (forced cessation of activities/hobbies) to reduce symptoms, with a possible impact on the patient's emotional journey.

He'd like to spend more time with friends and cousins. Sometimes there are lots of outdoor activities and he can only do 10-15 minutes.

And you must tell him "Stop, you're going home". Or when we're having a barbecue in the garden, he can't sit next to the trees. It's frustrating for him and it saddens me.

When I discovered I was allergic to rabbits, I avoided going to friends' houses who had this pet.

When the initial treatment plan did not lead to significant improvement, the GP's role extended to referring the patient to a specialist, such as an allergist, otolaryngologist (ENT), dermatologist, or pulmonologist. However, the referral process was not always timely or straightforward. The duration of this non-specialized phase of care varied considerably, from as little as one (1) month to as long as ten (10) years. Missed or delayed referrals resulted in 44/105 patients experiencing "fatigue" and/or "frustration". They reported repeatedly consulting primary care providers with "little" or "no relief".

Additionally, even when they were referred to a specialist, patients had to wait an average waiting time of 3.3 months for an appointment, although this could vary widely, ranging from 1 to 8 months due to referral and appointment difficulties.

During this waiting period, patients reported feeling a mix of emotions. Firstly, a sense of relief when they got an appointment with a specialist. However, this relief was accompanied by a feeling of impatience and hope for effective care to treat their symptoms and improve their quality of life. The length of the waiting period accentuated these emotions, making the consultation with a specialist a highly anticipated and emotionally charged event.

The steps related to first consultation(s) with a non-specialist are illustrated in Fig. 1.

Specialist consultations

Almost all patients (102/105) said that they had received a diagnosis during their first consultation with the specialist: anamnesis, skin tests and sometimes spirometry. They were relieved and satisfied to receive an accurate diagnosis.

However, despite these positive feelings, most of them have not expressed the full story of their care and the impact on their QoL since the onset of RA. This has led specialists to favor symptomatic over curative treatment.

When AIT has been mentioned at the first consultation (as reported by 26 out of 105 patients), patients tended to react with hope and

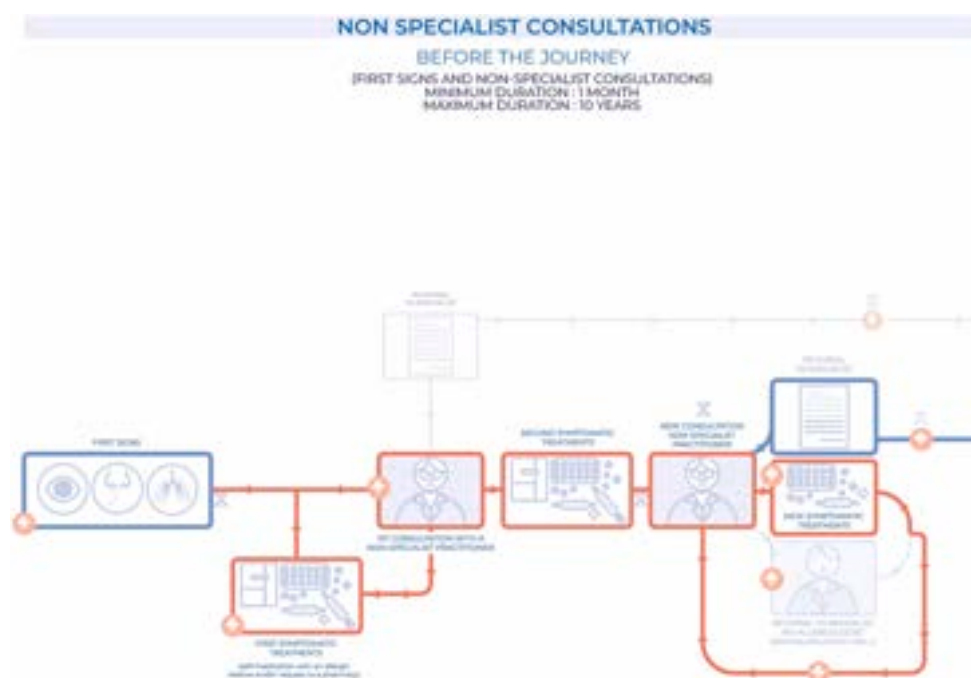


Fig. 1 Illustration of the RA patient's healthcare journey: Non-specialist consultation(s). Note: Key stages that most surveyed patients have gone through are highlighted. Red highlights indicate the stages where a patient's progress may slow down or come to a halt.

enthusiasm, seeing it as a new and promising option. Unfortunately, AIT was often mentioned by the specialist after 2 years/seasons and after the failure of some symptomatic treatments. Disappointment was reported by 44 out of 105 patients, who doubted the value of maintaining a specialist care, particularly considering the challenges involved, such as travel, financial burdens, and long waiting times. Some patients left the pathway before a curative solution was proposed or even mentioned and returned to self-medication to manage their condition. Some patients, especially those with more determined profiles, chose to persist and schedule a follow-up appointment, hoping for a better outcome. However, if, after 2 years, they were again offered a new symptomatic treatment after an initial failure, without a clear explanation for the recommendation, feelings of “frustration” and “disillusionment” emerged.

This growing disappointment increased the risk of patients disengaging from specialist care. 32 patients abandoned the specialize care pathway, reverting either to non-specialist care or self-medication as a means of managing their illness.

The steps of the journey involving diagnosis, first specialist consultations and AIT initiation are represented in Fig. 2.

AIT initiation and long-term journey

75/105 patients were initiated on AIT, accompanied and supervised by the specialist or their assistant. Patients generally noticed the first effects of AIT after about 6 months, with significant progress during the first and second years. The positive and consistent results during this period have been key drivers of good compliance. However, any periods of stagnation, or decline in treatment efficacy often caused patients to question the effectiveness of AIT. A total of 16/75 patients stopped AIT before the end of their treatment. 7 patients justified this discontinuation because of lack of efficacy, 3 because of side effects, 3 because of the time required to take the treatment (2/3 were on SCIT galenic), 2/16 because of the cost of the treatment (both were Italian), and finally, 1 patient stopped AIT because of lack of follow-up by his specialist.

Bi-annual or annual follow-up consultations were described by the majority of patients as moments that either reinforced their adherence to AIT or accelerated its cessation. Of the 75 patients in our survey, 34 said they felt unsupported by their specialist. The reasons given by patients to explain this lack of support were varied: the emotional disconnect with their specialist, the limited time available for each consultation, which discouraged patients from talking about their

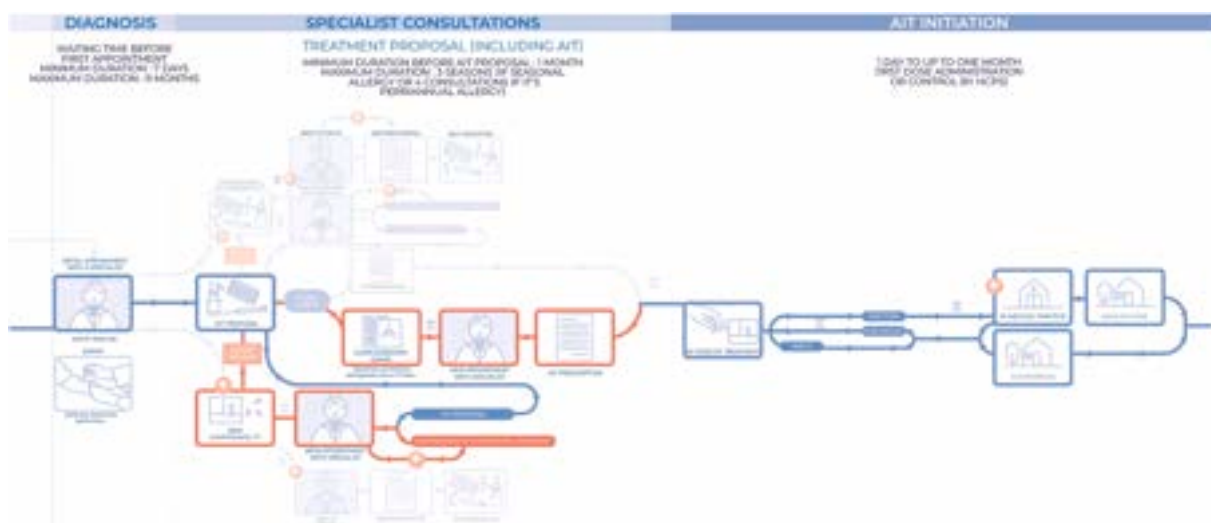


Fig. 2 Illustration of the RA patient's healthcare journey: Diagnosis, specialist consultations and AIT initiation. Note: Key stages that most surveyed patients have gone through are highlighted. Red highlights indicate the stages where a patient's progress may slow down or come to a halt.

problems, and external factors, such as the retirement or end of activity of their specialist.

The duration of treatment was sometimes cited by patients as an argument for either avoiding treatment or taking time to reflect. When the treatment period initially announced by the specialist was extended, patients often felt misunderstood, especially if they lacked adequate support from their specialist. This scenario significantly increased the risk of non-adherence: out of the 16 patients who experienced this situation, 5 stopped their treatment before the date indicated by the specialist.

The last follow-up AIT consultation marked the end of medical care with that specialist, who prescribed a symptomatic treatment as an “emergency plan.” Some patients were worried about the resurgence of symptoms and the possibility of returning to a restricted life. This ending was sometimes experienced as abrupt, leaving patients feeling lost. Many returned to their frontline GP, even though they had not been advised to do so, largely due to the GP’s availability.

The emblematic steps of the AIT treatment follow-up are highlighted in Fig. 3.

AIT as disease-modifying treatment - patient experience

AIT awareness

When AIT is not presented clearly and accurately, patients may experience confusion and uncertainty, making it difficult for them to fully understand and appreciate the potential benefits of this treatment.

Healthcare providers often leave it to the patient to express their willingness to engage in treatment, which can be an emotionally difficult experience. Among the surveyed patients, some reported feeling ‘isolated’ when faced with the decision to accept or refuse AIT. This decision-making process could have a significant impact on the emotional state of the patient, who had to face up to their doubts and hopes about the treatment.

She (editor’s note: the specialist) was very singular and very expeditious, there was no room where one could be curious, she explained what she wanted to explain.

Conversely, people who had received strong support from their care professional (and/or their family and friends) began the AIT experience with serenity and confidence in this solution.

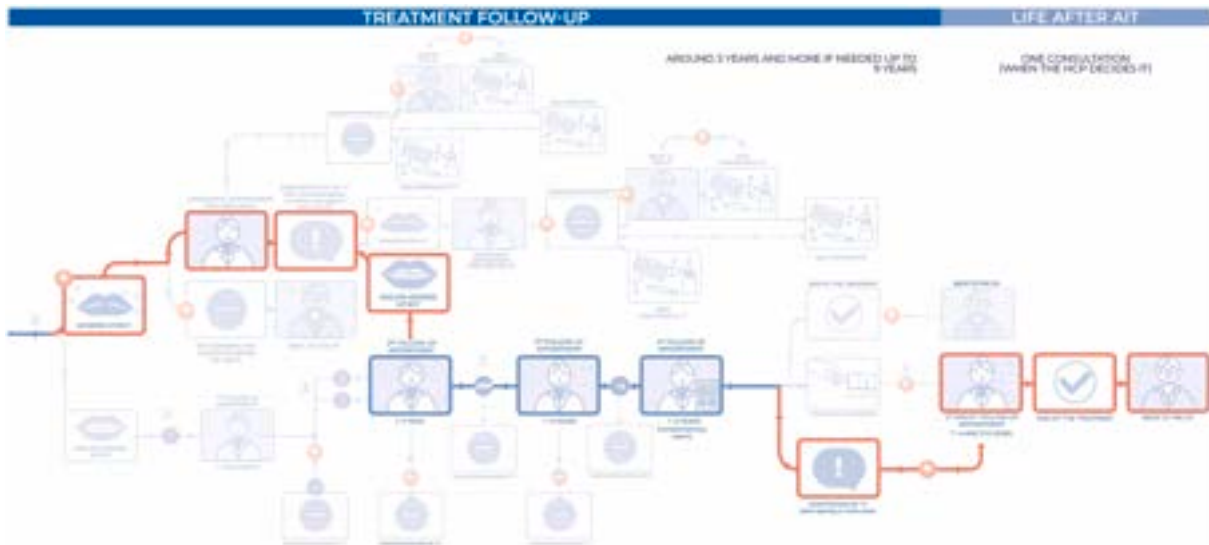


Fig. 3 Illustration of the RA patient’s healthcare journey: AIT treatment follow-up. Note: Key stages that most surveyed patients have gone through are highlighted. Red highlights indicate the stages where a patient’s progress may slow down or come to a halt.

My doctor gave me some flyers as well. I looked up things on the internet, on health pages, on specialist pages. Then it happened a coworker of mine is doing this therapy as well, and we communicated a lot about the procedure, how it's going for him, how he's doing on it. That really helped me a lot in deciding to go for it with a clear conscience.

Nonetheless, acceptance of AIT was high, with 80.8% of patients responding positively to the offer.

Knowledge of galenic formulations and impact on daily treatment

The decision about what formulation to use was usually not a fully shared decision-making process between the patient and healthcare provider. However, patients did not report being bothered by this lack of involvement. Some patients said they were aware of other formulations (SCIT, liquid formulations, tablets), but did not ask their HCP if they were eligible.

Patients reported various experiences with their daily routine while on treatment, depending on the formulation, as detailed in [Table 1](#).

Patient profiles

The semi-structured questionnaire submitted to patients explored key aspects about their relation with medical care and their understanding of treatment options, particularly the extent of their knowledge about AIT. The analysis of these 2 themes revealed significant differences in responses, which were correlated with the representation of emblematic therapeutic journeys.

Relation/goal with medical care

Patients' attitudes toward medical care varied widely. 45/105 patients expressed a preference for simplicity in their medical care. These individuals prioritized quick results and favored treatments that were easily accessible and not too demanding in terms of time or effort. For these patients, the convenience and ease of the treatment process were of paramount importance ([Table 2](#)).

In contrast, 60/105 patients were more exacting concerning their personal medical care. These

individuals had higher expectations for their treatment, seeking detailed, personalized care plans, and were more involved in the decision-making process. They valued thoroughness and were willing to invest more time and effort into their treatment, often seeking out specialists and complex care regimens that they believed would best address their condition ([Table 2](#)).

Extent of patient knowledge (access to information on AIT)

The extent of patient knowledge regarding AIT varied significantly across the survey population. 61/105 patients had access to AIT information, either through previous exposure to at least 1 AIT formulation, such as subcutaneous injections, tablets, or liquids, or by actively seeking out information on their own. These patients were generally more informed and often sought feedback from others or conducted their own research to better understand their treatment options ([Table 2](#)).

On the other hand, a significant portion of patients (44/105) had either no or only partial access to AIT information. These individuals often did not know where to find reliable information about their treatment options and relied heavily on their healthcare providers to guide them. Some trusted their referent to provide them with all necessary information and to make the best decisions regarding their treatment ([Table 2](#)).

The cross-referencing of these data led to the identification of 4 distinct patient profiles ([Fig. 4](#)), 2 of them, with a positive experience with AIT, 2 others, with a negative or incomplete experience or no experience with AIT.

Skittish (35/105)

The "Skittish" patient prioritized rapid relief and easy access to treatment, often opting for symptomatic solutions that could be obtained directly from pharmacies without the need for long-term treatment or regular medical follow-up ([Table 3](#)). "Skittish" patients were confident in their choice. They received moderate information about AIT due to limited support from frontline healthcare providers. Their conviction to use it is currently very weak. This profile was at risk of adopting skeptical stance with regard to the condition and

	SLIT TABLET	SLIT LIQUID	SCIT
Advantages	<ul style="list-style-type: none">• Treatment close to antihistamines or other “common” treatments traditionally taken in case of classical infections• Simple to store• Easy access to supply (at the pharmacy)	<ul style="list-style-type: none">• Personalized dosing of medication and the affiliated service (preparation time/ order/reception at home)• Easy to use (autonomy for older children/ teenagers/adults)• Feeling of better efficiency by the product’s action which “directly penetrates the body”, vs a treatment needing to be ingested	<ul style="list-style-type: none">• Not a daily treatment• Strengthening the relationship HCPs/ assistants
Verbatim	<i>It’s a simple solution. She takes it by herself at home. She has better self-control over when to take it.</i>	<i>Yes, for me it was customized, it was meant for me at that time (...) she must have selected the good stuff to stop my birch tree allergy, my allergy to dog and cat hair ...</i>	<i>As it was fortnightly, it was always the same day so ... it was easy to remember.</i>
Disadvantages	<ul style="list-style-type: none">• Having to keep it under the tongue for some time• Less refund• Less perceived as “personalized treatment”	<ul style="list-style-type: none">• Needs a cool storage	<ul style="list-style-type: none">• Regular trips• Appointment making• Needle phobia
Verbatim	<i>Regarding therapy, it could have been better in terms of cost. I’m not saying it shouldn’t be paid for, but it should be more affordable (...) There’s a difference, there are nuances between free and costing over 100 euros. So, I would make it a bit more acceptable. I don’t have the feeling that it was personalized because this information leaflet we’ve received, I think it’s for everyone.</i>	<i>“It is difficult if you are traveling for several hours by car, plane, or railway. Or it is difficult if you are camping and don’t necessarily have a fridge.”</i>	<i>For me as a student it would be easier if I also had a doctor in my hometown where I can do the therapy in order to be a bit more flexible in terms of the location. I was afraid of the injection (...) In winter it is never a problem for me going to the hospital, but during the summer I get annoyed everytime.</i>

Table 1. Patient feedback on different treatment galenics.

treatment. Key areas of information that could have helped them transition to AIT included: raising awareness about the risks of chronic disease, the dangers of long-term corticosteroid

use, and the misuse of symptomatic treatments. Providing encouraging data on the efficacy of AIT, along with information on its different formulations (liquids and tablets) and the relative ease

Relation/goal with medical care		Access to information on AIT	
Simplicity of the medical care	Exacting on their medical care	Access to information on AIT	No or partial access to information on AIT
Definitely something that's fast and easy and with great efficiency. That would be optimal for me. Something with little effort to put into but with a big impact in the end.	I googled everything, trying to find out why and how it was happening and, most importantly, how to get rid of it. I wanted to see a specialist to cure and treat this problem.	He told me that it exists, that desensitization treatments last 3 years and he explained it really well. He told me everything and gave us some time to think, he said 'I leave you to do some research on your own, and then you can come back.	Yeah, I did the whole breath-test and everything, and she asked me if I'd like to do immunotherapy, she talked about it a little bit. We brushed over the subject. I never went back.

Table 2. Selection of verbatims illustrating the position regarding the relation of medical care and access to information on AIT.

of AIT compared to their current treatment, could have improved their interest with more sustainable options.

Skeptic (10/105)

The “Skeptical” patient chose the treatment based on personal experience, largely because of previous disappointment with prescriptions from frontline doctors (Table 3). “Skeptical” patients opted for the least restrictive solution, as they believed the results were uncertain. Emotionally, this patient profile did not experience any significant benefits from the treatment.

Their conviction toward AIT was extremely low, with only partial accessibility to AIT, as they were

outside of a structured care pathway. This profile carried the risk of remaining skeptical about their condition and treatment. These patients appeared to need more information about the chronic nature of the disease, access to specialist care, and the benefits of AIT. Providing information on the ease and advantages of AIT, as well as sharing patient testimonials and building trust in their specialist, could have helped shift their perspective.

Determined (34/105)

The “Determined” patient selected their current treatment based on the goal of restoring QoL and achieving long-term life objectives (Table 3). They sought a solution that would provide lasting benefits. These patients were not or not

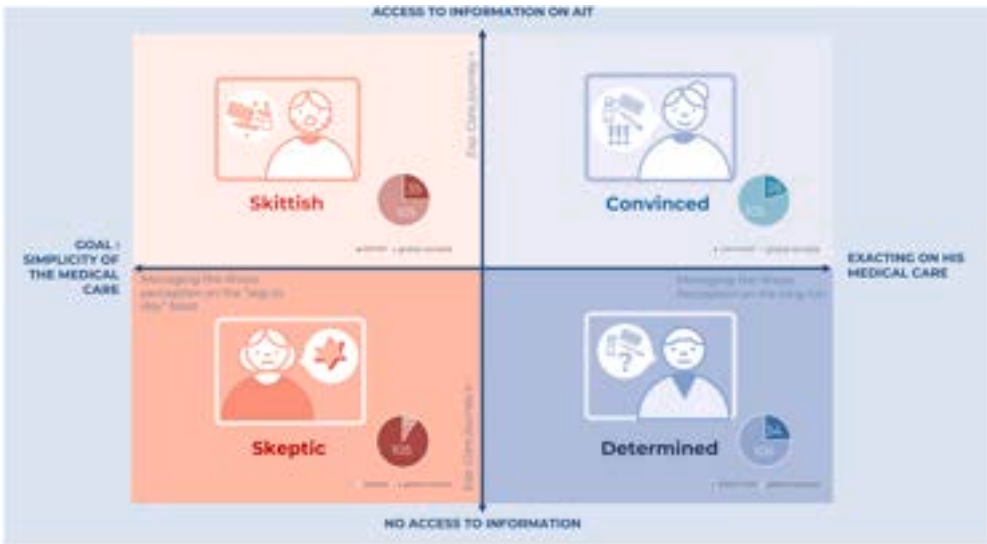


Fig. 4 Emblematic patient’ profiles defined according to their position on the 2 axes.

Patient Profile	Selection of verbatims
Skittish	<i>I'm comfortable with it (ndlr: antihistamine TTx), especially because it's an easy therapy, it's also easy to take, and it's convenient when you're on the move or traveling. The important thing is to carry the blister, eye drops, the antihistamine, and remember to take the medication every morning or evening, depending on your routine. AIT still is some medication, and I don't necessarily want to, if I can't see the use, I don't see why I should take it (...) it's obvious, I don't want to put pills in my body for no reason.</i>
Skeptical	<i>To be honest, it's too time consuming. From what I know about it is that you have to go there quite often, you have to wait a long time, it drags out over a long period of time. That's what scares me away. And then it's not even guaranteed that it will help. (...) Due to the fact that I got very little information about it, I wasn't really motivated to take another look at it. I don't really have a fixed plan. I just take cetirizine daily when I feel unwell. Evastel when I feel really bad. And Loratadine from time to time, when I know that I need to be fit mentally and I can't work with fatigue. I try to counteract that with Lorano.</i>
Determined	<i>I want a cat one day. I can't spend my entire life on Zyrtec. There must be a way to get rid of this allergy, somehow, and they told me, well, I had to, I mean I already knew that it existed, I learned about desensitization on the internet. Obviously, I went there with that idea in the back of my mind. My goal for that doctor's consultation was to get desensitization. That much was clear because I had spoken to people who knew about the products.</i>
Convinced	<i>He told me it's a treatment that can last up to 3 years. At the moment, I feel like it flies by because it has almost been 6 months now and I think we have very benefic effects and it's really not restrictive (...) the allergist had said it has rather good efficiency rates, 80%. And I can see that we are not well informed, because for most of the population, it's (Ed. 'the RA') something quite banal, but no it's not, it can destroy your entire life.</i>

Table 3. Selection of verbatims illustrating the different patient profiles.

immediately supported in this research. They had to demonstrate self-sacrifice and autonomy in their search for a solution. Their proactivity resulted in accessibility, so their level of adherence was very high. Recurrence of symptoms could lead them to become skeptical. To support their transition to AIT, they needed comprehensive information, including access to “pro AIT” experts. Additionally, reassurance and information about the process of stopping AIT treatment were crucial to maintaining their commitment and avoiding potential skepticism.

Convinced (26/105)

The “Convinced” patient (Table 3), elected to pursue the recommended course of treatment, with a particular emphasis on the expeditious achievement of a cure. They sought to avoid any unnecessary delays and to find a solution that

would effectively resolve their condition. The patients in question experienced a relatively straightforward and uneventful course of treatment, which allowed them to live with a sense of calm and tranquility. From the outset of the AIT process, they were furnished with comprehensive information and granted prompt access to the relevant specialist. The provision of information and support was crucial for maintaining the patient’s commitment to the treatment.

DISCUSSION

This ethnographic survey closely examined the healthcare journey of allergic patients to identify the ongoing challenges many patients face in finding lasting relief from allergy symptoms. It is well established that consistent, high-quality care is crucial at every stage of a patient’s journey, from

initial diagnosis to long-term management, with an emphasis on adapting to the patient’s evolving needs over time.¹ A critical aspect of this process is effective patient education and communication between HCPs and patients. In the early stages, patients with limited awareness of their condition often resort to OTC solutions and downplay their symptoms, avoiding medical support and fearing social stigmatization. As symptoms persist or recur, patients tend to seek professional care, and education becomes pivotal in enhancing adherence to treatment. Research shows that well-informed patients are more likely to stay committed to their therapy, with adherence improving significantly when there are at least 4 check-ups per year.⁸

The findings from this survey align with these insights, underscoring that regular, well-timed visits, combined with adequate clinical and emotional support, play a vital role in improving treatment adherence—particularly in the context of AIT, which has a long treatment course. Among the 75 surveyed patients who underwent AIT, nearly 50% reported feeling unsupported by their

specialists, which was a common reason for therapy discontinuation. Moreover, 30% of patients who discontinued AIT cited both a lack of perceived support and the unexpected extension of therapy as key factors in their decision to stop. This highlights a significant gap in the physician-patient relationship, where insufficient patient engagement and low health literacy critically impact treatment adherence.³

Communication breakdowns occur at multiple stages of the patient journey, with patients often failing to fully share their experiences. This lack of information makes it harder for physicians to recommend the most appropriate solutions, such as timely AIT proposals. Delayed AIT recommendations may reduce patient openness to this treatment option, while limited communication about the therapy’s potential, expected efficacy over time, and post-treatment expectations can hinder the success of the therapeutic process (Table 4).

Effective communication is crucial, especially during the decision-making process for AIT

Contributors	Barriers
	Limited awareness of symptoms initially leads to reliance on OTC solutions and avoidance of medical care.
	Social stigmatization discourages patients from seeking timely medical help.
	Shortages of allergy specialists and insufficient training among HCPs lead to poor patient-centered care.
Regular, well-timed visits and clinical/emotional support improve adherence.	Communication breakdowns reduce effective sharing of patient experiences and hinder tailored treatment.
Strong patient-specialist relationships enhance trust and adherence.	Poor communication about AIT duration, benefits, and post-treatment expectations hinders adherence.
Timely decision-making supports better clinical outcomes.	Delayed AIT recommendations reduce patient openness to treatment.
AIT’s unique and potentially curative nature offers hope for long-term relief.	The late introduction of AIT and its lack of attention to the potential for efficiency creates feelings of pressure and uncertainty.
SLIT offers a safer, more convenient self-administered alternative.	SCIT requires frequent clinic visits, presenting logistical challenges.
	Fragmented healthcare pathways delay referrals to specialists, causing patient frustration and fatigue.

Table 4. Factors which contribute or hinder an overall positive healthcare journey.

initiation—a pivotal moment for allergic patients. A lack of focus on AIT's unique and potentially curative aspects can result in patients feeling pressured, rather than informed and confident in their choice. Furthermore, the selection of the appropriate AIT formulation significantly influences the patient's treatment experience. The route of administration, whether subcutaneous (SCIT) or sublingual (SLIT), plays a key role in adherence, convenience, and overall quality of life. Adherence rates vary between SCIT and SLIT, ranging from 23% to 89% for SCIT and 64%–95% for SLIT.⁸ Non-adherence is a challenge for both forms, driven by factors such as time commitments and perceived inconvenience.¹¹ SCIT, which requires regular clinic visits due to the risk of systemic allergic reactions, presents logistical challenges for patients.⁷ SLIT, while safer and self-administered at home, demands daily commitment, which some patients struggle to maintain. Adverse effects, the lengthy duration of treatment, and frequent applications further contribute to non-adherence, particularly for SCIT.^{7,8} Thus, it is essential to provide patients with detailed information to help them make informed decisions about the administration route that best fits their lifestyle and preferences (Table 4).

Timely decision-making also plays a crucial role in the clinical pathway of allergic patients. While GPs and pediatricians are often the first point of contact due to their accessibility, delays in referring patients to specialists, combined with long wait times for appointments, lead to frustration and fatigue—an issue highlighted by approximately half of the surveyed patients. A key challenge in the patient journey is the shortage of allergy specialists, compounded by insufficient training among healthcare providers and poor communication between different stakeholders. This fragmentation is worsened by the absence of a universal best-practice model or clearly defined guidelines for integrated care, making cohesive, patient-centered management difficult to achieve.¹

The different patient profiles identified in this survey, based on their relationship with medical care and their awareness of AIT, highlight the diverse expectations and attitudes toward allergic

disease management. These profiles underscore the importance of tailoring healthcare approaches to the specific needs and preferences of each patient. Given the critical role of adherence in the success of AIT, recognizing the patient type allows physicians to offer personalized care and adjust management strategies to improve outcomes. This personalized approach includes delivering information in a way that resonates with the patient and appropriate reassurance, increasing the likelihood of AIT adoption and continued commitment to the treatment, even during periods of discouragement due to perceived low efficacy (Table 4).

Furthermore, the emotional journey of allergic patients may cause them to shift between different profiles over time, emphasizing the importance of regular check-ups to monitor progress and adapt care accordingly along with personalized communication.

The distribution of patients for each patient profile is indicated, along with other descriptive statistics, but it cannot be assumed to represent the broader RA patient population in France, Germany, and Italy, as the sample size only allows for limited statistical inference. Second, all interviews were conducted via video conferencing, which may have introduced a selection bias by favoring participants who are comfortable with digital technologies. This potentially affected the diversity of experiences captured, particularly regarding access to information.

Furthermore, it is important to acknowledge that the differences between national healthcare systems of the 3 countries (eg, access to specialists, reimbursement policies) may have shaped certain patient experiences and expectations. However, these systemic variations do not undermine the soundness of the identified patient profiles, which emerge consistently across the respondents of the 3 countries. Additionally, while these countries represent a diversity of healthcare models within Europe, the findings may not be generalizable to patients in countries with significantly different healthcare infrastructures, cultural attitudes toward allergy, or access to AIT. Further research in other contexts would be valuable to

test the transferability of the patient profiles identified here. In summary, while significant advances have been made in treating allergic diseases, particularly with AIT, there remain substantial unmet needs throughout the patient journey. Many patients continue to struggle with inadequate symptom control, resulting in significant societal costs, including reduced productivity at work and school.³ The long-term success of AIT hinges on patient adherence, which is essential for achieving the desired outcomes. Addressing the barriers to adherence—through enhanced patient education, stronger physician support, shared decision-making, and more convenient treatment options—can maximize the potential of AIT in managing allergic diseases and improving patients' quality of life.

Funding source and its role

Stallergenes Greer (SG) funded this research. SG representatives participated in discussions on research hypotheses and survey design with the researchers. SG did not participate in the selection of participants or data collection. SG representatives were not involved in data analysis. SG representatives did participate to the review of the report and the decision to submit the article for publication but did not influence the selection of results to be presented.

Data availability

The data that support the findings of this study are available from the corresponding author, Julien Cottet, upon reasonable request.

Declaration of Generative AI and AI-assisted technologies in the writing process

Nothing to disclose.

Author contributions

1. Conceptualization & Methodology: [Julien COTTET, Cristiano CARUSO, Sarah COURT-DEVILLIERS, Léa AHMED, Oana TUCA RADU, Silvia SCURATI, Natalija NOVAK] – Conceived, designed, and developed the survey, including the formulation of the research question, survey protocol, data collection procedures, and data analysis strategies.

2. Data Collection: [Léa AHMED] – Conducted interviews and collected data from survey participants.

3. Data Analysis: [Julien COTTET, Cristiano CARUSO, Sarah COURT-DEVILLIERS, Léa AHMED, Ariana DELFINO SPIGA, Ludovica FABBRONI, Natalija NOVAK] – Analyzed the data and interpreted the results.

4. Writing - Original Draft: [Julien COTTET, Cristiano CARUSO, Sarah COURT-DEVILLIERS, Léa AHMED, Natalija NOVAK] – Prepared the first draft of the manuscript, including the introduction, methods, results, and discussion sections.

5. Writing - Review & Editing: [Julien COTTET, Cristiano CARUSO, Sarah COURT-DEVILLIERS, Léa AHMED, Ariana DELFINO SPIGA, Ludovica FABBRONI, Oana TUCA RADU, Silvia SCURATI, Natalija NOVAK] – Reviewed and revised the manuscript critically for important intellectual content.

Declaration of competing interest

1. ALK Abello, GlaxoSmithKline, Menarini, Sanofi, Stallergenes Greer.
2. Astrazeneca, GlaxoSmithKline, Stallergenes Greer and Sanofi Genzyme.
3. None.
4. AstraZeneca, Gilead, Roche, UCB, Stallergenes Greer, Sobi
5. None.
6. None.
7. Employee of Stallergenes Greer.
8. Employee of Stallergenes Greer.
9. Abbvie, Alk Abello, Almirall, Bencard Allergy Therapeutics, Blueprint, Biogen, Bristol-Myers Squibb, DocCheck, Eli Lilly, Galderma, HAL Allergie, Incyte, Leo Pharma, Janssen, Leti Pharma, Lofarma, Moonlake, Novartis, Phadia, Regeneron, Sanofi Genzyme, Stallergenes Greer, Streamed up, Thermo Fisher Scientific, UCB.

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