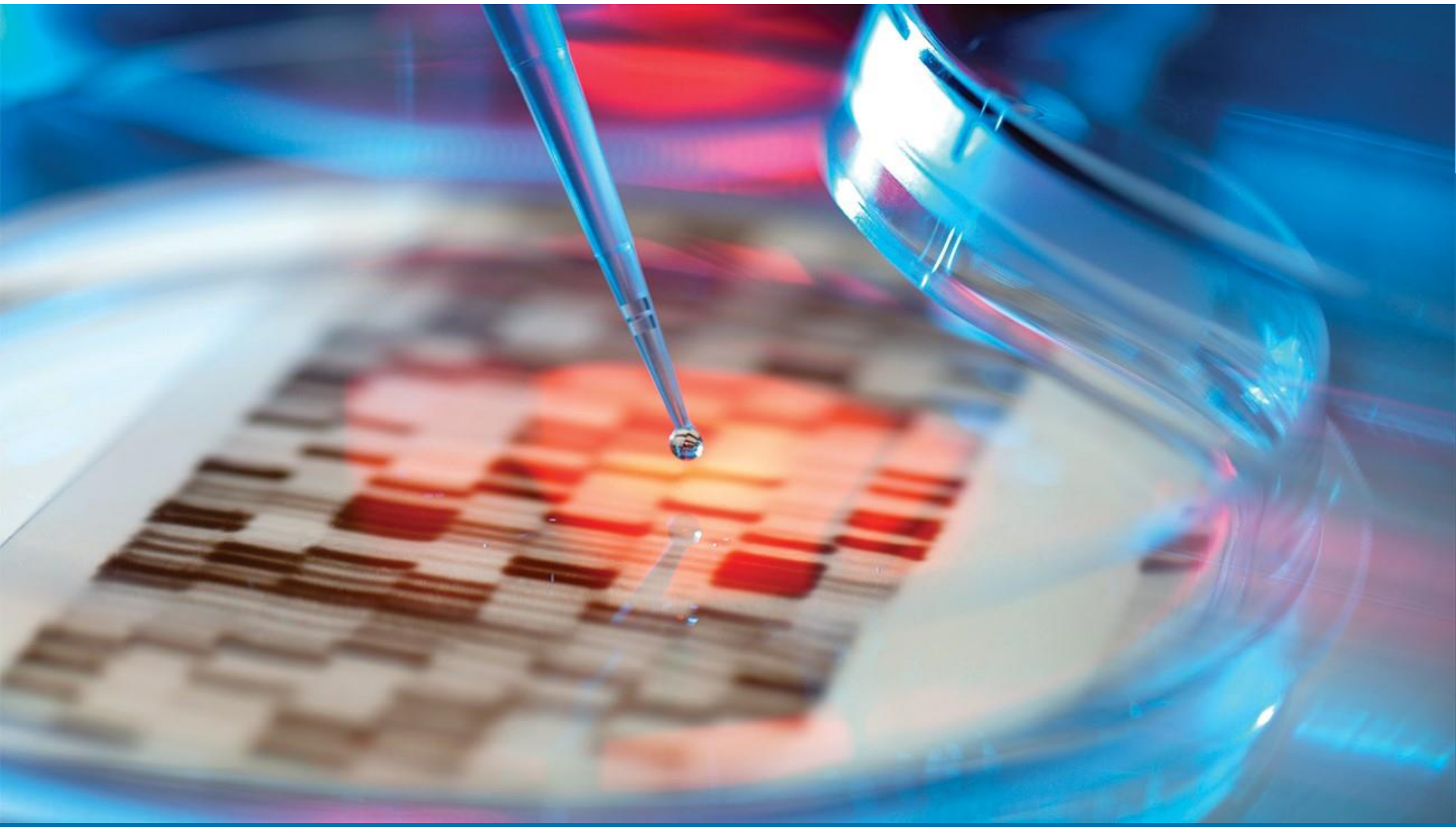

Policy action to improve the management of chronic rhinosinusitis with nasal polyps (CRSwNP) in Europe

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Funded by GSK

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Endorsers

The findings and recommendations in this report have been endorsed by the following organisations.

European Forum for Research and Education in Allergy and Airway Diseases (EUFOREA)

EUFOREA is an international non-profit organisation forming an alliance of all stakeholders from national and international organisations, institutions, and agencies with the common target to implement optimal patient care for allergies and airway diseases (asthma, chronic rhinosinusitis, rhinitis) and comorbidities.

Spanish Association for Patients with Nasal Polyps (AEPONA)

AEPONA is a non-profit association that was formed with the aims of offering support to people affected by nasal polyps and coexisting inflammatory diseases, raising awareness and giving visibility to the disease, and providing information to those affected by it.

Association Asthme & Allergies (French Asthma & Allergies Association)

The Asthma and Allergies Association is a French non-profit association whose main objectives are to inform and support patients with asthma or allergies, their parents and relatives as well as health care professionals. It promotes patient's education and supports patients in the French care system to allow them to benefit from the best possible care.

Respiriamo Insieme – APS

Respiriamo Insieme – APS is an Italian non-profit association dedicated to supporting patients – adult and paediatric – and caregivers impacted by respiratory diseases, to ensure the right course of treatment by reducing the burden of disease through support, advocacy, education, and research.

Additional collaborators

The authors would also like to thank the European Academy of Allergy & Clinical Immunology (EAACI) for their insights in developing the findings and recommendations in this report.

European Academy of Allergy & Clinical Immunology (EAACI)

The European Academy of Allergy and Clinical Immunology (EAACI) is the primary source of expertise in Europe for all aspects of allergy. EAACI is an association of clinicians, researchers and allied health professionals, dedicated to improving the health of people affected by allergic diseases with more than 18,430 members from 142 countries and over 54 National Allergy Societies.

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Foreword from BeyondTheNose

Chronic rhinosinusitis with nasal polyps (CRSwNP) is a debilitating long-term condition caused by ongoing inflammation in the nose and sinuses that can have an enormous impact on patients' physical and mental health, social life, fatigue and sleep. Despite this, there are significant shortcomings in awareness of the disease's impact, meaning that people with CRSwNP often feel unheard and overlooked. Patients may suffer for years without receiving a diagnosis and continue to experience challenges once receiving treatment, including a lack of multidisciplinary coordination or continuity in their care.

The BeyondTheNose initiative, organised and funded by GSK, is an alliance of ear, nose and throat (ENT) physicians; patient advocacy group representatives; and societies with the objective of improving CRSwNP care across Europe. We are working to develop practical solutions and tools to help ENTs and patients break through the barriers that must be urgently targeted in CRSwNP, and we challenge both ourselves and others to continue inspiring and innovating to improve the standard of care to benefit patients.

This report from Charles River Associates highlights the integral role that policymakers, working at different levels, can play in improving the care and management of CRSwNP. The report sets out the scale of challenges impacting patients today, and how policy change can drive the improvements that are urgently needed in the care of patients. These actions would deliver much-needed benefits for patients' quality of life, while increasing their participation and productivity in the labour market, and enabling more efficient healthcare resource utilisation.

There is a great opportunity to ease the substantial burden of this chronic inflammatory disease, by addressing the lack of policymaker recognition and broader disease awareness, accelerating the speed of diagnosis and referral, optimising and modernising care pathways, and promoting access to the treatments that best serve patients.

Together, we can start to take steps to improve care for all patients living with CRSwNP.

Executive summary

Chronic rhinosinusitis with nasal polyps (CRSwNP) is a chronic inflammatory disease that has a daily impact on around 8.9 million people in Europe,[1] yet the burden of the disease on patients is rarely recognised by policymakers. Growing evidence demonstrates the impact of the disease, including on patients' physical health, the subsequent effects on mental health and quality of life,[2] and the indirect impact on patient missed workdays and reduced productivity.[3] A new survey of 168 patients in Europe has added to this evidence by capturing the impact of the disease on patients' lives:[1]

- CRSwNP—which is also known as nasal polyp syndrome—has a large impact on the quality of life and physical health of patients. Overall 69% of patients reported a high impact on their life, such as on their sleep quality, overall physical health, and mental health.
- Patients can suffer negative financial consequences and reduced productivity due to the disease. Patients lose on average more than five weeks of work every year because of the condition, increasing to almost seven weeks for patients with severe disease. This is a major contributor to the significant indirect costs of the disease.
- Patients face an extensive and complicated treatment burden and often undergo multiple different types of treatment. In many cases, this reflects delayed and suboptimal management of the disease, leading to worsening of symptoms and increased healthcare costs.
- The disease places a significant burden on health systems, particularly for patients with disease recurrence or in instances of treatment failure. The chronic inflammatory nature of the disease can lead to high rates of revision surgery in which patients required further surgical intervention due to polyp regrowth and the return of symptoms.

Despite the widespread impact of the disease, there has been little research to understand the challenges experienced by patients navigating the healthcare system, the underlying barriers in the policy environment, or what policy actions could be taken to improve the care and management of the disease. The objective of this report, commissioned by the BeyondTheNose initiative organised and funded by GSK, is to assess the challenges affecting provision of care for those with CRSwNP and the role of the policy environment, and to develop recommendations for policy changes that could address the challenges in patient care and management.

Our findings are based on a four-step methodology: (1) the development of a research framework of policy areas impacting CRSwNP patients; (2) a literature review to populate this framework in five countries (Belgium, France, Germany, Italy, Spain); (3) an assessment of case studies from similar therapy areas to derive potential solutions; and (4) discussions of findings with a working group of patient and healthcare professional (HCP) experts.

Policy challenges impacting patients with CRSwNP

We find some shared challenges in the current experience and management of CRSwNP patients that are common across all five of the countries studied. A summary of these challenges is shown in Figure 1. This includes insufficient awareness and recognition of the disease and its burden; barriers to timely diagnosis and referral to specialists; lack of modernised approaches to care provision that are patient-centric and multidisciplinary and reflect the need for ongoing management; and variations in access to different therapies between and within European countries.

There are differences in the extent to which countries have sought to address the challenges in the policy environment. Key areas of difference include the extent of initiatives underway to raise public awareness of the disease (e.g. only Spain has a dedicated CRSwNP patient organisation, though this is a relatively new and news stronger support from the public and private sectors to carry out more initiatives to raise awareness of the disease), the development of disease registries (with only Germany and Italy having dedicated CRSwNP registries) and access to new treatments (particularly of concern in Spain, where biologics are reimbursed only after two endoscopic sinus surgeries).

Figure 1: Summary of policy challenges impacting patients with CRSwNP

Policy advocacy and recognition	A root cause of the multiple challenges impacting patients is the **lack of policymaker recognition of the disease** and the specific issues affecting people with CRSwNP: no evidence of policymaker action addressing these issues was identified in the countries assessed. There are also **challenges in evidence generation and disease registries**, and in the **level of public awareness**, although there are ongoing initiatives to address this.
Diagnosis and referral	Patients **wait over four years on average for an accurate diagnosis**, and a high number of people with CRSwNP are assumed to be undiagnosed. Many CRSwNP patients **face delayed referrals to specialists**, which in turn delays initiation of the treatment they need.
Approach to care provision	There is a **lack of modernised care pathways** to manage patients, such as **insufficient patient involvement in decision-making** despite the need for personalised approaches. There are also **shortcomings in multidisciplinary care** and a **lack of standardised follow-up**, suggesting low recognition of the chronic inflammatory nature of the disease.
Access to treatment	**Patient access to different therapies varies significantly**, both between and within European countries, and **patient perspectives are generally not considered in the value assessment** of new treatments. Patients may also not receive holistic ongoing management due to the **lack of incentives that exist in funding systems**.

Source: Charles River Associates (CRA) analysis; additional detail and sources in the full report

Policy recommendations to improve the diagnosis and management of CRSwNP

Given the different challenges that exist along the patient pathway, we considered the actions which policymakers could take to drive improvements in the care and management of CRSwNP, and whether there are best practices that could be shared. The feasibility of the identified solutions was tested through discussion with CRSwNP experts and using case studies from other inflammatory and respiratory diseases. These solutions are intended to be relevant to different stakeholders who shape the systems and frameworks impacting patients, including those in political positions (e.g. ministries of health, members of parliament), those within health systems (e.g. national and subnational payers, regional health system authorities), and those responsible for healthcare administration (e.g. hospital administrators).

The recommendations to policymakers are set out in Table 1. Firstly, regarding **policy advocacy and recognition**, the starting point for a more supportive policy environment is **greater recognition of CRSwNP as a disease by policymakers**. This is important as ultimately policymakers impact the prioritisation of a disease within the health system, and the funds allocated for timely diagnosis, patient care, and reimbursement of treatments. Solutions could involve **policymakers convening societies and patient advocacy groups** to discuss **the impact of including CRSwNP within national and regional respiratory disease plans**. Policymakers also could support and leverage initiatives (such as CRSwNP awareness days) that improve societal awareness of CRSwNP, and facilitate initiatives to address evidence gaps, such as disease registries.

The second group of recommendations sets out how **policymakers could address diagnostic and referral delays** by providing **support for primary care physician (PCP) training** and **enable**

improved referral by introducing relevant tools for HCPs (such as patient checklists and virtual consultations). Linked to this is a **need for policies that increase ear, nose and throat (ENT) physician capacity** so that patients can see a specialist sooner, though this needs to **be complementary to the availability of tools empowering patient self-management**.

The third group of recommendations is focused on how national and regional policymakers could work together to **ensure a modernised and personalised approach to care provision**. This could be achieved through **targeted care pathway redesign** to ensure that patients receive multidisciplinary and patient-centric care that reflects the need for ongoing management.

Finally, policymakers can **address rules that affect access to treatments across and within countries** and the use of sequential treatment protocols. By removing relevant barriers, policymakers could ensure that patients have **broad access to different treatment options**. A part of this, given the heterogeneity in how CRSwNP can be treated and the low recognition of the disease's impact on patients, it is important to ensure that **the patient perspective is incorporated into decisions** about access to new therapies.

We distinguish between foundational actions, to drive immediate improvements for patients or establish the prerequisites for longer-term improvements, and longer-term actions. These recommendations follow the sequence of the four areas of the patient journey framework used to structure the research (and therefore do not indicate a recommended order of prioritisation).

Table 1: Specific recommendations to policymakers

Area	Recommendation	Timing
Policy advocacy and recognition	National/regional health policymakers and parliamentarians should facilitate cross-stakeholder discussions (e.g. legislative groups and roundtables) on the barriers to care and potential solutions for chronic respiratory diseases, including CRSwNP.	**Foundational**
	Health system policymakers should leverage initiatives that already exist (e.g. Global CRSwNP Awareness Day) to educate the public on the importance of timely presentation to the health system.	
	National/regional policymakers should implement or update dedicated plans, with allocated funding, for respiratory diseases broadly, including for CRSwNP, to establish a comprehensive framework that would address challenges across the patient journey.	**Long-term**
	The EU should launch (and provide financial support for) a dedicated initiative to define a common protocol for national CRSwNP disease registries to support comparability and data pooling.	

Diagnosis and referral	National/regional policymakers should provide support for PCP training on early diagnosis of CRSwNP, including for development of diagnostic-related key performance indicators (KPIs) to track the impact on the diagnostic pathway, within the framework of a national/regional plan.	**Foundational**
	Health system policymakers should act to first identify and then implement tools (such as patient checklists, virtual consultations, and closer collaboration between physicians) that will accelerate referral times for uncontrolled patients.	
	National health system policymakers should monitor and evaluate ENT capacity and take targeted actions to increase specialist numbers in underserved areas.	**Long-term**
Approach to care provision	Health system policymakers should support timely implementation of treatment guidelines by using KPIs to monitor their uptake, including to assess long-term management, e.g. repeated surgeries, oral corticosteroid overuse.	**Foundational**
	EU funding should be allocated to support research and pilots on the optimum care pathway for CRSwNP.	
	Policymakers should support multistakeholder expert panels to advise on local care pathway redesign, to include the need for ongoing management, and support subsequent rollout of recommendations through available guidance documents and funding.	
	EU funding should be used to support ongoing research into evidence gaps needed for guidelines, e.g. long-term biologic use and patient selection.	**Long-term**
	As part of care pathway redesign, regional/local policymakers should investigate introducing type 2 respiratory outpatient clinics with designated funding for multidisciplinary teams, digital tools, and monitoring of patients.	
Access to treatment	Payers should enable broad access to different therapies by removing restrictions that are not evidence-based or which prevent patient/physician choice of options included in up-to-date guidelines.	**Foundational**
	Payers should be open to innovative agreements, including risk-sharing agreements, where there are financial and evidence uncertainties that risk blocking access to therapies for patients.	
	Payers and health authorities should provide opportunities to consult and/or grant voting rights to patient associations in decisions on access to new CRSwNP treatments.	**Long-term**
	Health systems should implement pilots for innovative funding approaches for chronic respiratory diseases that ensure multidisciplinary and holistic management.	

1. Introduction

1.1 Background

Chronic rhinosinusitis with nasal polyps (CRSwNP)—also known as nasal polyp syndrome—is a chronic inflammatory disease of the nasal and paranasal sinuses of the upper airways. It has persistent symptoms of nasal congestion, rhinorrhoea and loss of smell that have a significant impact on patients' quality of life and social function, particularly in young adults and middle-aged populations.[4] The disease is present in at least one percent to two percent of the European population,[5] meaning that around 8.9 million patients are living with the disease,[1] though its prevalence may be as high as four percent according to some studies.[6,7] As a chronic inflammatory disease, CRSwNP has a daily impact on patients with a range of debilitating symptoms and multiple negative effects.[1] The quality-of-life impairments are exacerbated for the up to two-thirds of patients with comorbidities, such as asthma, bronchiectasis and chronic obstructive pulmonary disease (COPD).[8]

In recent years there has been considerable advances in understanding of the disease and in developing new treatment options. The majority of patients with CRSwNP show a type 2 inflammatory signature (a specific immune response), and it is now understood that type 2 inflammation underlies the pathophysiology of multiple airway diseases, including CRSwNP, other types of rhinitis, asthma and COPD.[9] Advances in understanding the drivers of the chronic respiratory inflammation in CRSwNP have resulted in the development of novel therapies such as type 2 targeting biologics. These offer a new treatment for more severe patients who currently lack options for long-term management.[10] Because different inflammatory and respiratory diseases have many comorbidities in common, biologics are an important option for ensuring alleviation of both upper and lower airway diseases.[11]

While advances in understanding how to manage and treat the disease offer increasing opportunities to deliver modernised care to patients (for example by equipping patients to engage in the management of their disease and in treatment decisions), in practice patients still face many challenges. Despite the persistent symptoms and impacted quality of life, contributing to a substantial burden on patients and health systems, concerns remain about a general lack of awareness of the disease.[12] As this report will set out, there are multiple shortcomings in the experience of patients affecting the time to diagnosis and ongoing management of the disease. Insufficient integration and continuity of care across the patient journey often result in delays in diagnosis and referral, a lack of consistent and coordinated specialist care, and limited patient contributions to treatment decisions.[13]

Although the impact of CRSwNP on patients is substantial, there has been little research to understand the challenges patients face and the extent this is affected by the policy environment, or what policy actions could be taken to drive improvements in the care and management of the disease. The objective of this report, commissioned by the BeyondTheNose initiative organised and funded by GSK, is to assess the policy environment impacting patients with CRSwNP and develop policy recommendations that will address the challenges that exist, thereby improving patient care.

1.2 The opportunity to advance CRSwNP policy change

Until recently CRSwNP received little attention in the policy debate around respiratory disease, and there was little evidence regarding its burden or the policies to reduce this. However, this is changing.

Firstly, global, European, and national societies and patient organisations are increasingly undertaking initiatives to raise awareness of the disease and the need for improvements in its management. As an example, in 2022, the European Forum for Research and Education in Allergy and Airway Diseases (EUFOREA)—an international alliance of stakeholders driving optimal patient care for allergies and airway diseases—launched the first Global Chronic Rhinosinusitis with Nasal Polyps Awareness Day, to raise awareness of CRSwNP and its impact on quality of life among physicians and policymakers and support education of healthcare professionals (HCPs) and patients.[14] EUFOREA also launched a dedicated patient portal for chronic rhinosinusitis (CRS), providing information to patients on the disease and its symptoms, documents to support preparation for HCP visits, and material on diagnosis and treatment.[15] The European Academy of Allergy and Clinical Immunology (EAACI), which is an association of clinicians, researchers and allied HCPs dedicated to improving the health of people affected by allergic diseases, is working to improve knowledge and expertise about the disease and its management, such as through the development of clinical practice guidelines.[16] In 2025 the Global Allergy & Airways Patient Platform (GAAPP) surveyed more than 1,000 patients and caregivers worldwide about their experiences with CRSwNP.[17] This was used to inform a patient charter of what people affected by the disease want and should expect from their care. The charter set out six principles, including the right to a timely and accurate diagnosis, access to specialist care, and access to innovative therapies.

Secondly, the initiative BeyondTheNose has united an alliance of ENTs, patient advocacy groups (PAGs) and societies. Key aims of BeyondTheNose include strengthening the patient voice with respect to the disease's impact on quality of life, bridging knowledge gaps around chronic inflammation in CRSwNP, and educating and empowering patients to engage in treatment decisions. BeyondTheNose has defined a manifesto for change to address the key barriers in CRSwNP and is undertaking targeted initiatives to address these barriers (Box 1). For example, in 2025 the BeyondTheNose Inflammatory Mindset Working Group discussed and developed a patient management plan to help improve long-term disease management and patient experience for CRSwNP, which could help optimise patient–HCP education, improve patient health literacy and facilitate shared decision-making.[18]

Box 1: The BeyondTheNose Alliance

- BeyondTheNose is an alliance of ENTs, PAG representatives and societies driving a movement across Europe to improve CRSwNP care. It brings together clinicians from Belgium, France, Germany, Italy and Spain as well as representatives from European and national societies and PAGs.
- BeyondTheNose has defined a manifesto for change that identifies three key improvement areas to be urgently targeted to address the existing barriers in CRSwNP management:[13]
    - Increased HCP and societal awareness of CRSwNP, with recognition of the quality-of-life impact of both the disease and the treatment burden on patients.
    - Improved HCP understanding of the underlying inflammatory mechanisms of CRSwNP and recognition of the chronic and recurring impact on patients.
    - Modernised management, including educating and equipping patients to engage in treatment decisions, as well as establishing long-term treatment goals that address individual patient needs.

As part of this increased activity by patient and HCP stakeholders to drive improvements in the care and management of CRSwNP, there is growing recognition of the need for policy action to alleviate the burden of the disease on patients and health systems. In 2025 a new global position paper was published by three allergy and airway disease organisations which set out the case for the inclusion and prioritisation of CRSwNP in global health policies to improve disease management and outcomes for patients.[19] The BeyondTheNose Alliance has also identified policymaker communities as a key stakeholder for driving improvements, alongside patients, ENTs and other healthcare professionals.[20]

Despite the progress that has been made in terms of recognising the disease and the need for policy change to address the burden of CRSwNP, greater policymaker awareness and policy action is needed. This report seeks to identify specific actions that would improve the lives of those living with CRSwNP (or nasal polyp syndrome).

CRSwNP is one of two dominant subgroups of CRS, and accounts for 25-30% of patients.[21] The remainder of patients—those with CRS without nasal polyps (CRSsNP)—share some common symptoms with CRSwNP, however these are understood to be less severe. Although the focus of this report is on CRSwNP, there are some commonalities in the management and challenges for both subtypes, and so some of the conclusions and recommendations may be relevant to CRS generally.

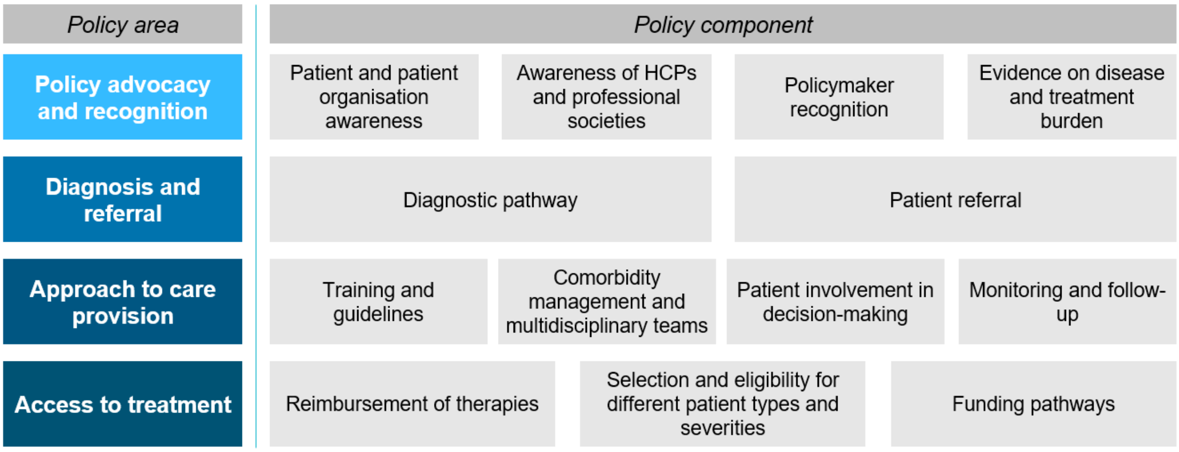
1.3 Methodology

To develop this report, we used a four-step approach:

1. Development of a research framework of the key policy areas impacting CRSwNP patients
2. Literature review to identify evidence to populate this framework for Belgium, France, Germany, Italy and Spain
3. Assessment of case studies of solutions from similar therapy areas
4. Discussion of findings in a series of meetings with a group of patient and HCP experts

Our first step was to define a research framework of key policy areas impacting patients with CRSwNP (Figure 2). The research framework was informed by a review of recent cross-country literature (e.g., studies or papers that discuss challenges relating to CRSwNP, mainly published since 2021) and by drawing on insights from BeyondTheNose.[4,12,13] Based on the identified challenges, we identified policy areas that could improve care and management. For each component we set out specific research questions to structure the analysis for each country.

Figure 2: Research framework of policy areas affecting patients with CRSwNP



Policy area	*Policy component*			
Policy advocacy and recognition	Patient and patient organisation awareness	Awareness of HCPs and professional societies	Policymaker recognition	Evidence on disease and treatment burden
Diagnosis and referral	Diagnostic pathway	Patient referral		
Approach to care provision	Training and guidelines	Comorbidity management and multidisciplinary teams	Patient involvement in decision-making	Monitoring and follow-up
Access to treatment	Reimbursement of therapies	Selection and eligibility for different patient types and severities	Funding pathways	

Our second step was to populate the research framework through a literature review of cross-country and country-based evidence pertaining to the identified research questions undertaken in January–March 2025. The geographic scope of the search was the five countries represented in the BeyondTheNose Alliance (Belgium, France, Germany, Italy, Spain). The literature review included both English and local language sources, spanning government publications, academic literature, online articles and grey literature, and professional and patient society resources. The academic literature included peer-reviewed articles available in academic and open-source databases (including PubMed, Springer and Google Scholar) published over the last 10 years. In total, the literature review included over 400 sources.

Our third step was to examine similar therapy areas, specifically inflammatory and respiratory diseases, that had faced similar challenges to those identified for CRSwNP; and understand the solutions adopted. Due to the common type 2 inflammation underlying multiple of these diseases, the learnings from these therapy areas are particularly important as in many instances CRSwNP patients may be comorbid with one or more of these other diseases. We reviewed local language literature for diseases such as asthma, COPD and atopic dermatitis, across the four areas of the research framework. We initially reviewed case studies from the five countries in scope and subsequently considered other European case studies if they had already been identified as a best practice.

Our fourth step was to discuss the findings with a group of patient and HCP experts (Table 2). Specifically, we convened an expert group drawn from the European BeyondTheNose Alliance. We used a series of one-to-one discussions and expert working group meetings to validate our approach, including on identification and definition of the research framework and questions; findings from the literature review, especially the evidence that exists on the challenges for CRSwNP patients; and potential solutions identified from similar therapy areas and their applicability to CRSwNP. Insights from the meetings are included in this report but are not attributed to individual participants.

Table 2: Members of the expert working group

Name	Affiliation
Xander Bertels	Head of Advocacy, EUFOREA
Ozlem Ceylan	Patient Organisations Committee Chair, EAACI
Adam Chaker	ENT Section Chair, EAACI; Centre for Allergy and Environment, Technical University of Munich, Germany
Peter Hellings	President, EUFOREA; Professor in Otorhinolaryngology at the Catholic University of Leuven, Belgium
Cristina Jacomelli	Foreign Relations Liaison, Respiriamo Insieme National Patients' Association, Italy
Vanessa Limonge	President, Spanish Association of Patients with Nasal Polyps (AEPONA)
Oliver Pfaar	Vice President Communications, EAACI; Section of Rhinology and Allergology at the University Hospital, Philipps-University Marburg, Marburg, Germany
Christine Rolland	Director, French Asthma & Allergies Association

1.4 Structure of the report

The remainder of this report is structured as follows:

- **Chapter 2** sets out the impact of CRSwNP on patients and health systems.
- **Chapter 3** summarises evidence on the policy challenges impacting patients with CRSwNP.
- **Chapter 4** sets out policy recommendations as to how the identified challenges can be addressed, building on case studies of successful initiatives in similar therapy areas.

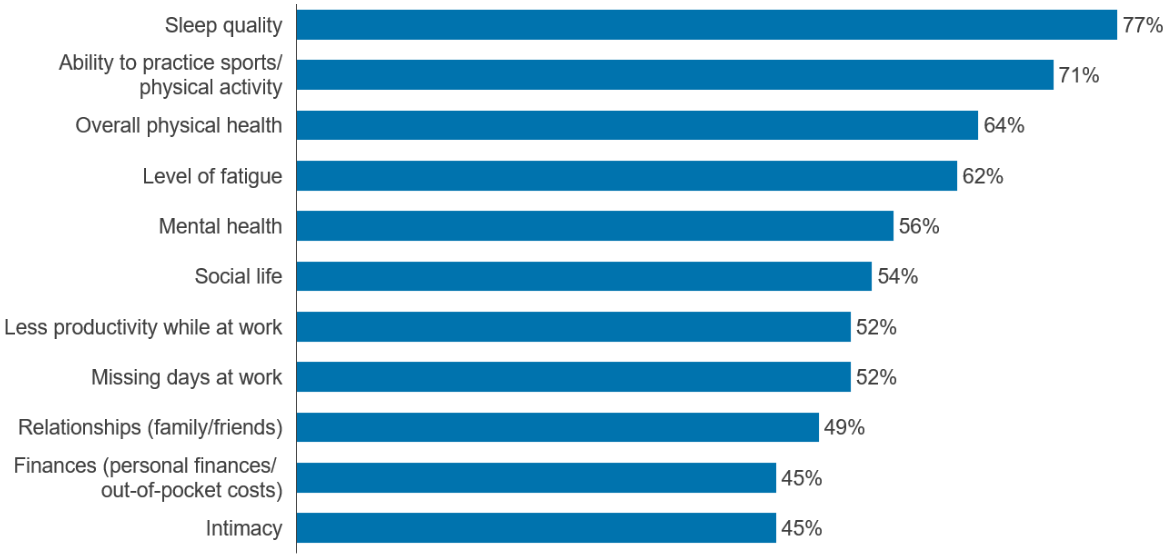
2. The impact of CRSwNP on patients and health systems

In this chapter, we review the evidence on the impact of CRSwNP on patients and health systems. There is a widespread misconception that CRSwNP is a minor and non-serious disease, often likened to the common cold with a minimal disease burden.[12] This chapter explores a growing body of evidence demonstrating the significant impact of CRSwNP (the challenges across the patient pathway are set out in the next chapter). In particular, it leverages a recent patient survey developed through the BeyondTheNose initiative by the Modernise Management Working Group; published in 2025, this survey of 168 patients in Europe aimed to capture the experience of care from diagnosis to follow-up while uncovering the impact of the disease on patients' lives.[1]

The experience of patients with CRSwNP

The most direct impact of CRSwNP is on patients' quality of life. Patients' lives are impacted across several areas, including sleep, physical health and mental health (Figure 3). Overall, 69% of patients experience a high impact in at least one of the areas investigated, with the most impacted areas being sleep, physical activity and health, fatigue, and mental health. Moreover, each patient reported on average a high impact in three different areas.[1] In addition to their physical health, patients' mental health is significantly impacted. This is consistent with a major French survey which found suicidal thoughts are twice as high among those affected by the disease as compared to those not affected.[22]

Figure 3: Share of patients affected to a high or some degree for each quality-of-life impact (n=168)

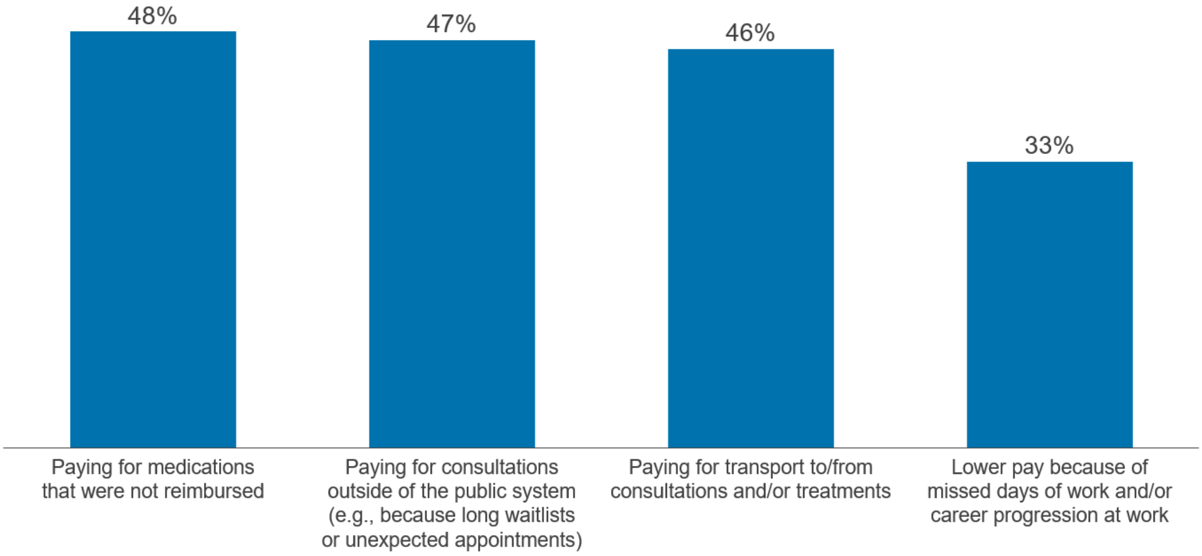


Source: Patient survey developed by the BeyondTheNose initiative (2025)

The disease burden of CRSwNP is exacerbated for up to two-thirds of patients who live with multiple comorbidities, including immunologic or inflammatory conditions such as allergic rhinitis and asthma.[8] For example, one study from Italy found that 41% of severe asthma patients have CRSwNP, which is associated with worse patient outcomes in terms of number of asthma exacerbations and dependence on oral corticosteroids (OCSs).[23] Patients with both asthma and CRSwNP present with more severe symptoms of one or both diseases, and comorbid CRSwNP patients have higher rates of recurrence and revision surgeries in which they require further surgical intervention due to polyp regrowth and the return of symptoms. These patients also have higher dependence on corticosteroids compared to patients who have asthma alone.[8]

CRSwNP patients also suffer from negative financial consequences, reduced productivity at work and work absenteeism, exacerbating the personal and broader socioeconomic impacts of the disease. The BeyondTheNose Quality of Care survey of 168 patients in Europe found that 83% of patients experienced a negative impact on personal finances, the causes of which are shown in Figure 4. Patients lost more than five weeks (27 days) of work every year because of the condition, increasing to almost seven working weeks (34 days) for patients with severe disease.[1] While evidence on the indirect costs of CRSwNP remains relatively limited, these new patient-reported findings are in line with a previous study which found that productivity losses during work and missing workdays contributed to a substantial indirect economic burden on society.[24]

Figure 4: Causes of negative financial impacts of the disease, share of patients (n=168)



Source: Patient survey developed by the BeyondTheNose initiative (2025)

Treatment burden

Patients with CRSwNP face an extensive and complicated treatment burden. This is because they undergo multiple different treatment types, ranging from low-complexity over-the-counter treatments to prescription or more intensive treatments.[1] For many patients, intranasal corticosteroids and short courses of OCSs are an effective treatment option. However, OCSs do not provide an option for ongoing management of the disease as there are significant systemic side effects observed with repeated courses, such as osteoporosis, diabetes, hypertension, anxiety, and insomnia, and therefore leading to higher healthcare resource utilisation to manage these complications.[25] Some real-world studies have suggested that corticosteroids do not provide ongoing improvements in symptoms for many patients, while biologic treatments have demonstrated durable improvements in symptoms and clinical outcomes for some patients.[26] However, patients are often forced to undergo multiple cycles of OCSs before receiving a biologic, irrespective of the systemic side effects: according to the Quality of Care survey (n=168), 65% of patients reported undergoing two to three cycles of OCS treatment in the previous year, and 22% four or more cycles.[1]

Another contributor to the treatment burden is the need for repeated surgeries, as the inflammatory and chronic nature of the disease cannot be controlled by surgery alone.[27] One study from Belgium found that 79% of patients were subject to disease recurrence and 37% to revision surgery over a 12-year period.[28] In France, around 11,000 patients with CRSwNP undergo surgery each year, with 13% requiring surgical revision within seven years.[29] Other studies have pointed to revision surgery rates of 20% within a five-year period, but may be as high as 50% on endoscopic examination.[11] Repeated surgeries often result in higher risk of complications, diminishing success rates, and permanent scarring, exacerbating the impact of the disease on patients' health and quality of life.[27]

The complexity of treatment regimens can contribute to suboptimal adherence. An average of 51% of patients do not adhere fully across treatment types, which is driven by treatment complexity, system design issues (e.g. challenges with booking appointments) and a decline in motivation.[1] Globally, adherence to intranasal corticosteroids has been estimated to be as low as 10%–20%,[30] while a recent Spanish study found that 43% of patients obtained from the pharmacy less than 50% of their prescribed vials of intranasal corticosteroids.[31] Treatments requiring ongoing use due to the chronic nature of the condition can also affect patients' emotional health, by serving as a repeated reminder of their disease: a recent survey of over 1,500 patients with CRSwNP and / or asthma found that 44% find it difficult to manage their disease, and 42% felt that their treatment contributed to a repeating reminder of their chronic condition, suggesting that access to biologics administered with less frequency may alleviate some of their burden.[32] For asthma patients the frequency of biologic therapy administration contributes to lack of persistence (i.e., treatment gaps between doses and low rates of refills), which is associated with increased rates of asthma exacerbations and OCS use.[33] Limitations in patient education can contribute to suboptimal adherence, as patients who understand the purpose and expected benefits of treatment are more likely to adhere to therapy.

Impact on health systems

The burden of the disease and treatments on patients also impacts health systems. Examples of significant costs to health systems include the cost of repeated surgeries and those related to the side effects of taking OCSs.[34] A study of Dutch CRSwNP patients found average direct medical costs annually of €1,501 per patient,[3] while a study on the disease burden in England found that surgical management of CRSwNP constitutes a significant direct financial burden on the healthcare system (£260 million).[35] A major challenge for health systems is managing the high disease recurrence, including the cost of repeated surgeries. The scale of these costs has been demonstrated in a real-world data study from Italy, which found that the highest costs were related to surgery: patients with one surgery were associated with healthcare costs of €4,167, however this increased to €7,010 for patients with disease recurrence (on average, 2.17 surgeries).[36]

Key takeaways: The impact of CRSwNP on patients and health systems

- The **most direct impact** on patients **of disease symptoms is on their quality of life.** Overall 69% of patients report a high impact on at least one area, such as sleep quality, overall physical health and mental health.
- Patients suffer **negative financial consequences and reduced productivity,** losing nearly seven weeks of work each year in cases of severe disease. This is a major contributor to the **significant indirect costs** of the disease.
- Patients **face an extensive and complicated treatment burden,** undergoing multiple different types of treatment. This often includes multiple surgeries, and repeated courses of OCSs despite the high side-effect burden. This can contribute to **suboptimal treatment adherence** and therefore worse health outcomes for patients.
- The disease has a **significant burden on health systems**, particularly for patients with disease recurrence or in instances of post-treatment failure, e.g. there are high rates of revision surgery and systemic side effects from OCS overuse.

3. Policy challenges impacting patients with CRSwNP

In this chapter we draw on our assessment in Belgium, France, Germany, Italy and Spain (where we have populated the framework set out in Figure 2) to identify the key challenges affecting patients with CRSwNP. There are some shared challenges across these countries in the current experience and management of CRSwNP patients (Figure 5), which the remainder of this chapter explains.

Figure 5: Summary of cross-country challenges

1 Policy advocacy and recognition	2 Diagnosis and referral	3 Approach to care provision	4 Access to treatment
• Lack of policymaker recognition • Gaps in evidence generation and disease registries • Low public awareness	• Misdiagnosis and diagnostic delays • Delays in referral to specialists	• Guidelines may not include recent treatments or long-term management • Lack of modernised care pathways (e.g. patient involvement, multidisciplinary care, standardised follow-up)	• Restricted access to medicines • Lack of incentives in funding systems for holistic patient management

Source: Charles River Associates (CRA) analysis

There are however differences in the experience of patients between countries (Table 3), and there is evidence that some countries have started to address these or initiated a plan.

Table 3: Summary of challenges by country

Challenge	Belgium	France	Germany	Italy	Spain
Lack of policymaker recognition	🔺	🔺	🔺	🔺	🔺
Gaps in evidence generation, registries	🔺	🔺	⚠	⚠	⚠
Low public awareness	🔺	🔺	🔺	🔺	⚠
Misdiagnosis and diagnostic delays	🔺	🔺	🔺	🔺	🔺
Delays in referral to specialists	🔺	🔺	🔺	🔺	🔺
Limitations in available guidelines	🔺	🔺	🔺	⚠	⚠
Lack of modernised care pathways	🔺	🔺	🔺	🔺	🔺
Restricted access to medicines	🔺	⚠	✓	⚠	🔺
Lack of incentives in funding systems	🔺	🔺	🔺	⚠	⚠

🔺 = Challenge identified ⚠ = Partially addressed or initiatives significantly underway ✓ = No challenge

Source: CRA analysis

3.1 Policy advocacy and recognition

Lack of policymaker recognition

To date CRSwNP has received relatively little attention in policy considerations around respiratory diseases. Across the five countries assessed, we identified minimal policymaker actions aimed at addressing issues associated with CRSwNP or examples of recognition of CRSwNP within wider debates or legislative discussions. The exceptions to this were in Italy, where a new policy paper on patient management in type 2 inflammation resulted in an event in the Italian Senate of the Republic,[37] and a parliamentary question in France in 2021, submitted to the minister of solidarity and health on the diagnosis of anosmia.[38] According to the expert working group, this lack of policymaker recognition of the burden of the disease for patients and healthcare systems is a key root cause of the policy challenges impacting patients.

Lack of policymaker recognition of CRSwNP is exacerbated by low policy prioritisation of chronic respiratory diseases (CRDs) broadly (in terms of CRD plans, for example), and the narrow focus of respiratory disease policies where these do exist. Of the five countries assessed, there has been more progress towards respiratory health prioritisation in Spain, Italy and France, either through coalitions of societies and patient organisations pushing for respiratory health prioritisation or recognition by policymakers in national policies (e.g. chronic disease and prevention plans). However, these initiatives generally focus on asthma and COPD and particularly neglect upper airway diseases. For example, in Spain, although several regions (e.g. Andalusia, Navarre) have plans for CRDs, these are limited to a subset of diseases such as asthma and COPD.[39,40]

Gaps in evidence generation and disease registries

Another indicator of prioritisation is whether efforts have been made to gather evidence on the impact of the disease, which could be used to encourage greater awareness and recognition of CRSwNP. There has been some progress towards cross-country evidence generation, such as the EUFOREA registry on the real-world effectiveness of biologics for CRSwNP.[41] The Chronic Rhinosinusitis Outcome Registry (CHRINOSOR) is an initiative bringing together ten tertiary referral centres across Europe to collect real-world data from CRS patients.[42] Recent publications from CHRINOSR have helped generate evidence on the real-world effectiveness of biologic treatment and characterising patients based on markers of type 2 inflammation.

However, at the national level the maturity of evidence generation and disease registries is highly heterogeneous, falling broadly into three groups (Table 4). This lack of national registries for consolidating data on patients that could be used to understand the disease and use of treatments is a shortcoming which can exacerbate the low recognition of the disease’s impact. At the same time, there are multiple national and international registries for other diseases, in particular severe asthma, which can provide valuable real-world data for comorbid CRSwNP patients, due to the common underlying type 2 inflammation. There are also some new initiatives at the national level to improve data collection for CRSwNP, such as the Spanish ENT society’s POLIdata initiative focusing on generating evidence from the use of surgery and biologics for CRSwNP management.[43]

Table 4: National disease registries for CRSwNP

Category	Country examples
Dedicated CRSwNP registry	**Germany:** German National CRS Registry (GenreCRS) is a national registry established in 2025 for patients with CRS, though it has not yet published data.[44] **Italy:** RINET, the Italian Registry for Severe Uncontrolled Chronic Rhinosinusitis, has been developed to collect real-life data and support the development of diagnostics and therapeutic approaches.[45] The first centres joined in 2021, however there have not yet been specific publications based on RINET data.
CRSwNP publications based on other disease registries	**Belgium:** The Belgian Severe Asthma Registry is a national database on adult severe asthma patients, which can be leveraged for CRSwNP data collection (e.g. a study on the response to biologics in severe asthma with CRSwNP).[46] **Spain:** The Spanish Society of Allergology and Clinical Immunology (SEAIC) implemented the Alergodata Registry to collect data on the use of biologics for allergic diseases, including nasal polyps.[47] Additionally, the POLIdata initiative on CRSwNP management is underway.
No relevant CRSwNP registry	**France:** No existing registry; however, the BIOPOSE study on biologics in severe CRSwNP is planned to extend into a permanent national registry.[48]

Low public awareness of the disease

Public awareness of a disease can also contribute to recognition of the disease burden and focus in terms of advancing policy action. However, there appears to be a significant issue with recognition of the impact and burden of CRSwNP. People with CRSwNP report that because their condition may be mistaken for other diseases with similar symptoms (the common cold, flu or headache), the severity of the disease is often misunderstood. In a series of interviews conducted by EUFOREA, CRSwNP patients indicated the need for greater societal awareness of the disease burden and understanding of the impact on social function and well-being that they suffer as a result of the disease.[12] Evidence from a survey in France found that 78% of French people do not know what CRSwNP is (a further 15% say they know about it without having any precise idea).[22] Although similar data is not available for other countries, the working group experts reported that the issue spans countries, and addressing low public awareness has been identified as a priority by organisations such as EUFOREA.[12]

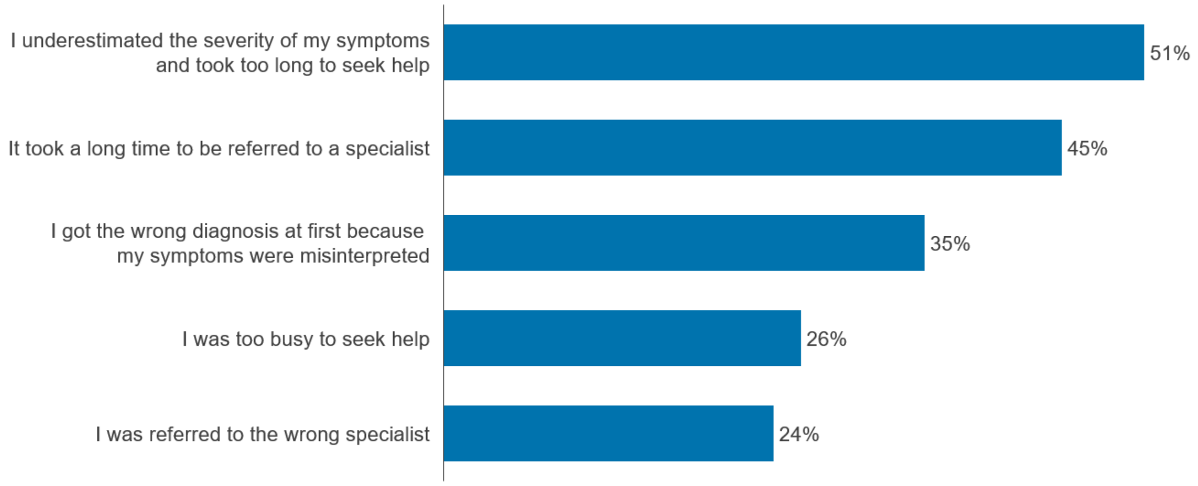
3.2 Diagnosis and referral

Misdiagnosis and diagnostic delays

Despite the importance of timely diagnosis in enabling patients to access specialist care and treatment, people with CRSwNP are forced to wait on average 4.2 years for an accurate diagnosis, with 97% of patients reporting that their diagnosis was delayed, according to the Quality of Care survey (n=168).[1] A large number of patients are believe to be undiagnosed, which is one of the reasons for the discrepancies between estimated and diagnosed prevalence. This is most thoroughly evidenced in Spain: the diagnosed prevalence there is between 0.5 percent and 0.8 percent, significantly below an estimated prevalence in the general population of four to five percent.[49,50,51] Diagnostic challenges also include underdiagnosis of CRSwNP in patients with other chronic respiratory diseases: one study found that 23% of COPD patients had CRS, and 82% of these were undiagnosed and subsequently untreated.[52] In the 2025 GAAPP survey of 1,000 patients and caregivers, 82% of respondents reported that timely and accurate diagnosis is a top CRSwNP patient right priority, making it the “patient right” that mattered to the most respondents.[17]

Diagnostic delays have numerous causes, several of which were captured in the Quality of Care survey (Figure 6).[1] The commonality of the symptoms of CRSwNP (e.g. runny nose, headaches) makes it difficult for HCPs, especially primary care physicians (PCPs) with less expertise in day-to-day management of CRSwNP, to accurately diagnose the disease. Difficulties in diagnosis for those patients are exacerbated by a lack of guidelines or trainings targeted directly at PCPs, meaning PCPs may be slow to recognise the disease. Even in countries where there has been progress in developing consensus documents and guidelines on the diagnostic pathway, such as Italy, these are targeted at specialist healthcare professionals (e.g. ENTs and pulmonologists) rather than PCPs.[53]

Figure 6: Identified causes of delayed diagnosis (n=168)



Source: Patient survey developed by the BeyondTheNose initiative (2025)

Delays in referral to specialists

The patient journey for many people with CRSwNP involves referral from a PCP to a specialist with expertise in managing CRSwNP. These specialists are primarily ENTs, though pneumologists, allergologists and immunologists can all play a role based on the specific patient symptoms and healthcare system. Although referral to a specialist may be needed when first-line therapy is insufficient to achieve control of the disease, in practice many CRSwNP patients face delayed referral.[12] In the Quality of Care survey (n=168), 45% of patients reported waiting for what they consider to be a long time to be referred to a specialist.[1]

According to the expert working group, this delay in referral from primary to secondary care can at least be partially attributed to the lack of sufficient training and materials directed at PCPs. Additionally, insufficient contact and collaboration between primary care and specialist physicians increases the number of patient visits necessary before referral.[54]

Due to the commonality of comorbidities for CRSwNP patients, an important aspect of managing the disease is collaboration between specialists for different diseases (e.g. COPD, asthma), such as through multidisciplinary teams (MDTs), as there may be both a specialist in CRSwNP and a specialist in a comorbid disease involved with managing the patient. Therefore, referrals between specialists are as important as referrals from primary to specialist care, and it is important for specialists managing common CRSwNP comorbidities to be aware of sinonasal symptoms. In particular, upper and lower airways are often managed separately despite the shared pathophysiology, meaning that it is important for specialists of other airway diseases (e.g., pulmonologists managing asthma) to be aware of potential comorbid CRSwNP. For the most part, interdisciplinary referral pathways are not well described in existing guidelines, meaning that patients feel that a lack of attention is given to comorbid conditions, and this is the case in most of the five countries examined in this report.[17] One notable exception is the Italian guidelines on the management of patients with severe asthma and CRSwNP, which offer a best practice for other specialists and countries across Europe by outlining the preferred patient journey and multidisciplinary approach depending on the difference profiles of patients.[55]

3.3 Approach to care provision

Limitations in available guidelines

At the European-level, professional societies have published several timely updates to treatment guidelines for CRSwNP. For example, in 2023 an updated version of the European Position paper on Rhinosinusitis and Nasal Polyps, EPOS, was published by the European Rhinologic Society in collaboration with EUFOREA, to provide practical guidelines for patients on biologic treatment, including criteria for selection, monitoring of treatment effects, and decisions on continuation, switching, or discontinuation.[56] Some progress has been made in guiding evidence-based decisions for patients who may benefit most from biologic treatment initiation, including evidence of type 2 inflammation, significant loss of smell, and a diagnosis of comorbid asthma.[11] However, current guidelines are not comprehensive in guiding decisions on patient selection for biologic treatment, driven by the need for further understanding of clinically relevant biomarkers to select responders to current available biologics.[56]

At the country-level, many European countries do not have national guidelines for CRSwNP that adequately set out diagnosis, care and treatment recommendations which can aid HCPs in their decision-making. This can include a failure to recognise recent therapeutic advances, such as the use of biologics. Of the countries assessed, the greatest challenge is in Belgium, where no specific guidelines on CRSwNP have been published since 2007, although it is likely that the EUFOREA guidelines are used in place of a national guideline. In Germany, although specific guidance on the use of biologics to treat CRSwNP was published in 2023,[57] the official S2K guidelines on rhinosinusitis more broadly (including CRSwNP) are considered out of date, with their last update in 2017.[58] Other countries have shown progress: Italy has multiple recent guidelines and consensus documents on the diagnosis and treatment of, multidisciplinary care for, and use of biologics in CRSwNP,[34] and in Spain the POLINA 2.0 guidelines are an up-to-date, country-specific consensus on the management of CRSwNP that is patient-centric and multidisciplinary.[59]

Nonetheless, even where scientific societies have published updated guidelines more recently, they have some limitations. Although the 2023 Spanish POLINA 2.0 guidelines expand on the EPOS2020 guidelines within their specific national context, many gaps remain related to defining ‘disease control’ and optimal monitoring of patients during and after treatment. There may also be inconsistencies between the guidelines and actual criteria for reimbursement and clinical decision making at the local level. Furthermore, both the Italian and Spanish guidelines focus largely on advice for specialists, which does not address the lack of awareness and expertise among PCPs. Finally, many guidelines lack a clear consensus on the optimum treatment course for comorbid patients, creating difficulties in multidisciplinary management where different specialists may favour different treatment options.

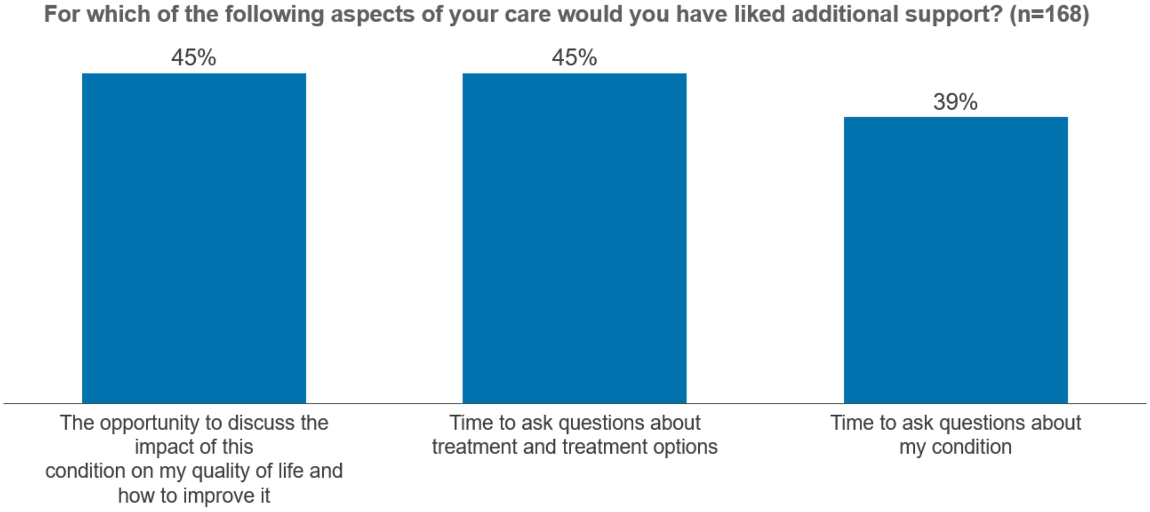
Lack of modernised care pathways

Although there is a consensus among experts that modernised care pathways (which we refer to as the process of physician and patient decision-making and organisation of care processes, from the onset of patients' symptoms through to their long-term management)[60] are necessary for successful management of CRSwNP patients, current evidence suggests such pathways are not commonly in place in Europe. Through the BeyondTheNose initiative, a new patient management plan has been developed, which aims to help improve long-term disease management and patient experience by setting out clear activities to perform for agreeing treatment goals, managing comorbidities, and ongoing follow-up and monitoring.[18] Furthermore, EUFOREA has developed a CRS pocket guide with a new treatment algorithm aiming to expedite access to diagnosis and treatment, simplify clinical care pathways, and facilitate coordinated care.[61] However, at present there is still a significant challenge in terms of modernised management in clinical practice. Three challenges are particularly important given the nature of CRSwNP: care pathways do not adequately consider the patient perspective, facilitate multidisciplinary care, nor sufficiently consider the chronic aspect of the disease and the need for long-term management.

Firstly, patient perspective on treatment choice is particularly important for CRSwNP due to the range of different treatments and the variable impact they can have depending on the patients' symptoms and comorbidities.[62] Dialogue between patients and HCPs, on topics such as alternative treatment options and possible side effects, is vital to personalise treatment and improve patient outcomes,[13] and studies have shown that patients whose preferences are reflected in decision-making derive the most clinical benefit.[62] While recognition of the importance of patient involvement in decision-making has grown, it remains highly variable. The Quality of Care survey found that that 96% of patients felt under-supported in their patient journey, specifically highlighting insufficient time and opportunities to discuss their disease and treatment options as a key area for improvement (Figure 7).[1]

Secondly, analysis of the patient experience suggests that current care is fragmented and uncoordinated. There is a broad consensus on the importance of multidisciplinary care and an integrated care pathway for their treatment due to the significant rate of comorbidities.[13] However, a survey of 255 Italian specialists, including ENTs, pneumologists and immunoallergologists, found that only a limited number of centres (45%) had established a multidisciplinary team to treat patients with CRSwNP, although a greater number of respondents did have experience referring patients between specialities.[63] Alongside reducing the quality of care that patients are likely to receive, a lack of coordination between specialists can lengthen the patient journey, with 79% of patients reporting having to repeatedly state their symptoms and patient history every time they have an appointment with a new specialist.[1]

Figure 7: Patient-reported experiences of involvement in decision-making



Source: Patient survey developed by the BeyondTheNose initiative (2025)

Finally, the nature of CRSwNP as a chronic disease necessitates a care pathway which is standardised and takes a long-term perspective on patient treatment, including on how best to monitor treatment. A 2024 study of 111 allergists and 83 ENT specialists in Northern Italy found significant differences in how patients with CRSwNP were treated based on specialty, with these differences especially striking in terms of differences in the timing and management of biologic therapy, suggesting variability in how patients are managed in the long term.[64]

3.4 Access to treatment

Restricted access to medicines

There are a range of approaches to treating CRSwNP, including systemic corticosteroids, endoscopic sinus surgery and targeted biologic therapies.[25] Biologics are a more recent treatment option which could benefit uncontrolled patients; however, many cannot access them.[19] In some countries, reimbursement of biologics is restricted to patients after multiple previous treatment failures. For example, in France reimbursement of biologics is limited to patients whose disease is insufficiently controlled by both corticosteroids and a specific type of functional endoscopic sinus surgery, and in Belgium patients must have been treated with intranasal corticosteroids and endoscopic sinus surgery and meet at least three additional criteria (e.g., comorbid asthma and OCS use).[65,66] Among the countries assessed for this report, there is a particular challenge in Spain, as novel biologics for CRSwNP are reimbursed only for patients who have had two endoscopic sinus surgeries. Although not reviewed as part of this report, working group experts reported that in other countries (such as the UK and Sweden) there is no access to biologics for CRSwNP, leading to inappropriate medical therapy for severe cases in these countries.[20] As such, despite the importance of a personalised and modernised approach to treatment, patient access to different therapies varies significantly between and within European countries.[19] Overcoming restricted access to innovative therapies was one of the six principles set out in the GAAPP patient charter, with 47% of respondents considering it a top CRSwNP patient right priority.[17]

As part of the working group discussions, experts reported that a common concern across different countries is that the perspective of patients is not considered in the assessment of new treatments. Only in France have patient organisations been systematically involved in the health technology assessment (HTA) process for novel CRSwNP therapies.[65] Although this is not specific to CRSwNP but rather applies broadly to the system for assessing new treatments, it is likely to be a particular challenge in this disease area due to the low understanding of the disease or recognition of the burden on patients.

Lack of incentives in funding systems affecting treatment choice

Some experts and patient groups are concerned that systemic barriers contribute to a lack of financial incentives for holistic ongoing management of CRSwNP, and precluding incentives for the use of treatment options that might be more effective as complementary or alternative approaches to surgery.[20] Part of the reason for this could be funding systems, specifically, fee-for-service remuneration based on the number of procedures conducted. Although there is no direct evidence of the impact of funding systems on physician treatment decisions, one indicator is the high number of patients receiving multiple surgeries (the Quality of Care survey found that 19% of patients had already had three or more surgeries).[1] It is therefore possible that the funding system contributes to a prevalence of surgery over alternative treatment approaches that patients might prefer.

Key takeaways: Policy challenges impacting patients with CRSwNP

- A **root cause of the multiple challenges** impacting CRSwNP patients is the **lack of policymaker recognition of the disease** in all countries. The maturity of **evidence generation and disease registries** and the **level of public awareness is a concern**, although initiatives are ongoing to address these.
- Patients wait **over four years on average for an accurate diagnosis**, and a large proportion of people with CRSwNP are believed to be undiagnosed. Many patients face **delayed referrals to specialists**, which in turn delays initiation of the treatment they need.
- There is a **lack of modernised care pathways** to manage patients once diagnosed, with specific challenges being **insufficient patient involvement in decision-making, shortcomings in multidisciplinary care** and **lack of standardised follow-up**.
- **Patient access to different therapies varies significantly**, both between and within European countries, and patients are generally **not considered in the value assessment of new treatments**. Patients may also not receive **holistic ongoing management** due to the lack of incentives in funding systems.

4. Policy recommendations to improve the management of CRSwNP

The focus of this report is on the role of policymakers in driving system improvements across the patient pathway. In this chapter, we set out policy actions—including at the European Union (EU), national and subnational levels—that could address the challenges identified in Chapter 3. We draw on case studies from other inflammatory and respiratory diseases to identify potential solutions that could also apply to CRSwNP and discussions with the expert group. We have split the recommendations into two categories:

- **Foundational actions:** Shorter-term actions to drive immediate improvements for patients or which are prerequisites for longer-term systemic improvements in the policy environment.
- **Long-term actions:** These actions may not address the more immediate needs for patients but will affect patients over time, often requiring foundational actions to maximise their impact.

4.1 Policy advocacy and recognition

Lack of policymaker recognition

The first potential action to improve the policy environment is addressing the lack of policymaker recognition. This requires greater understanding of the perspectives of different stakeholders on the challenges for CRSwNP and CRDs broadly. In other CRDs, policymakers have supported discussions by convening multistakeholder forums that capture a range of perspectives on policy needs. CRD legislative groups (e.g. the European Parliament Interest Group on Allergy and Asthma) could be leveraged or established to share expertise and align on priorities. These forums can also be used to convene cross-stakeholder discussions. There is evidence that this approach has been successful in other therapy areas: in Spain, the Ministry of Health and parliamentarians attended discussions on a proposal for a Strategy on Respiratory Diseases, supporting policymaker recognition of CRDs.[67]

Recommendation 1: National/regional health policymakers and parliamentarians should facilitate cross-stakeholder discussions (e.g. legislative groups and roundtables) on the barriers to care and potential solutions for chronic respiratory diseases, including CRSwNP.	**Foundational**

There is a need for a comprehensive approach addressing the different policy challenges that exist across the patient pathway. Evidence from Finland shows that broader policy frameworks can be used to systematically set out the changes that are needed (Box 2). Due to the common pathophysiology of different respiratory diseases (particularly those with type 2 inflammation), it is increasingly important to have an integrated policy framework.

Box 2: Finland national plans for respiratory diseases

- Since the 1990s the Finnish government has launched multiple highly impactful funded plans for respiratory diseases. The first of these was the Asthma Programme (1994-2004), the success of which served as a model for programmes for COPD and allergies.
- The Asthma Programme was a comprehensive approach to address multiple challenges; its specific goals included early diagnosis and anti-inflammatory treatment, self-management, and improved knowledge around the disease. It resulted in a 70% decrease in hospitalisation, a 50% reduction in costs per patient, and the absolute number of individuals with disability pensions caused by asthma decreased by 76%.[68]

Recommendation 2: National/regional policymakers should implement or update dedicated plans, with allocated funding, for respiratory diseases broadly, including for CRSwNP, to establish a comprehensive framework that can address challenges across the patient journey.	**Long-term**

Gaps in evidence generation and disease registries

As set out in the previous chapter, there has been notable progress in evidence generation and disease registries, including the development of national registries and a EUFOREA registry on the real-world efficacy of biologics. As CRSwNP registries continue to develop, the standardisation and comparability of different registries will become important to consider, so that registry data can be pooled across countries and a network of registries can be built. This would allow a larger dataset to be analysed across countries and provide greater evidence on the disease and its impact. Considering that this needs to take place above the country level, the European Commission could play a role in supporting standardisation. Evidence for this approach can be found in the International TREatment of ATopic Eczema (TREAT) Registry Taskforce (see Box 3). This example demonstrates the potential value of an initiative with dedicated funding and a specific platform that would define a common protocol for national CRSwNP disease registries to support comparability and data pooling.

Box 3: International TREatment of ATopic Eczema (TREAT) Registry Taskforce

- Through the PARENT Joint Action cross-border Patient Registries Initiative (2012–14), the international TREatment of ATopic eczema (TREAT) Registry Taskforce was established.
- As part of the program, a Delphi panel was conducted to reach international consensus on a core set of domains for what to measure in patient registries.
- Based on this, national research registries collaborate to collect the same data, using the predefined core dataset, allowing direct comparability of individual country data and facilitating potential data pooling between countries. This has led to several studies.[69]

Recommendation 3: The EU should launch (and provide financial support for) a dedicated initiative to define a common protocol for national CRSwNP disease registries to support comparability and data pooling.	**Long-term**

Low public awareness of the disease

Patient organisations are increasingly active in undertaking initiatives to raise awareness and promote education, such as the launch of an annual Global CRSwNP Awareness Day in 2022. This increases understanding of CRSwNP as a chronic disease that has a substantial quality-of-life impact. These initiatives are both an opportunity to raise policymaker awareness of the disease and a mechanism which policymakers can leverage to play a complementary role to societies and patient organisations in raising public awareness. Raising public awareness is closely tied to the importance of supporting education of patients, which is needed for empowering their participation in treatment decision-making and self-management. Policymakers have played a role in increasing disease awareness across other therapy areas; for example, in Spain regional health authorities such as Castilla y Leon have used World COPD Day to raise awareness at the regional level and launch a programme for improving patient self-care.[70]

Recommendation 4: Health system policymakers should leverage initiatives that already exist (e.g. Global CRSwNP Awareness Day) to educate the public on the importance of timely presentation to the health system. **Foundational**

4.2 Diagnosis and referral

Misdiagnosis and diagnostic delays

Considering the vital role of PCPs in diagnosing CRSwNP and the challenges with timely diagnosis, policymakers can support policies that enhance PCP education to improve timely disease recognition. Where there are initiatives or plans to address CRSwNP or respiratory diseases broadly, these could include provisions for PCP training on diagnosis and initial patient management. This has been successful in other therapy areas. For example, in Spain the Andalusia Ministry of Health Plan for Care of people with chronic respiratory diseases included objectives supporting early diagnosis in primary care, such as trainings to increase the use of spirometers by PCPs.[39] The plan was developed through collaboration of a multidisciplinary group of stakeholders and under the supervision of a regional panel of policymakers. Other therapy areas have also demonstrated the importance of developing policies on diagnosis in conjunction with specific key performance indicators (KPIs), such as on the quality of care and diagnostic journey (e.g., time to diagnosis), or on the supporting processes and structures (e.g., number of PCPs trained). These KPIs should be monitored to track progress on optimisation of the patient care pathway (Box 4).

Box 4: An audit of COPD care by PCPs in Franconia, Germany

- To determine the success of a disease management program for COPD in primary care in Germany, a cross-sectional study was conducted in collaboration with a primary care network.
- The existing COPD guidelines were analysed to develop key quality indicators by which the quality of care provided for patients could be measured and analysed.
- The audit allowed for an assessment of COPD care by PCPs, identifying areas for improvement through future policies. It also pointed to the need for improved KPIs for quality assessment, as this was challenging with available health records data due to non-standardised and insufficient documentation.[71]

Recommendation 1: National/regional policymakers should provide support for PCP training on early diagnosis of CRSwNP, including for development of diagnostic-related KPIs to track the impact on the diagnostic pathway, within the framework of a national/regional plan. **Foundational**

Delays in referral to specialists

Policymakers can take various actions to address delays in referral. Part of the solution may involve supporting educational initiatives that are needed to avoid delays for uncontrolled patients to see a specialist.[72] However, a range of other tools have already been considered and developed by societies and patient organisations to address this challenge. This could include the development of a patient checklist, for example, building on the work conducted by EUFOREA, where global key opinion leaders developed a pocket guide for CRS which aims to address delays in the patient pathway through expediting access to diagnosis and treatment, and simplifying clinical care pathways.[61] Increase collaboration between different HCPs, both between PCPs and specialists and between different specialists, could be effective in reducing the barriers to referral and the number of hospital visits a patient would require. One approach to achieve this closer collaboration could be to follow the Pneumocafé Project proposal for COPD in Italy (Box 5).

Box 5: The Pneumocafé Project for COPD, Italy

- The Pneumocafé Project was introduced across regions of Italy as a pilot project to improve diagnosis and care provision for patients with COPD by PCPs. The project had specific goals to increase early diagnosis, correct care provision and referral to specialists.
- This was facilitated through informal regional gatherings between PCPs and respiratory specialists where groups could discuss current practices, analyse the problems in diagnosis and managing patients, and sharing the possible solution at the community level.[73]
- The project has been shown to improve PCP education and facilitate better referral between PCPs and specialists by providing a more integrated care pathway.

Recommendation 2: Health system policymakers should act to first identify and then implement tools (such as patient checklists, virtual consultations, and closer collaboration between physicians) that will accelerate referral times for uncontrolled patients. **Foundational**

Even after referral to the relevant specialist, 77% of patients in the Quality of Care Survey (n=168) reported waiting for a significant period of time to have their consultation with a specialist.[1] Another area for policymaker action could therefore be to address insufficient ENT specialist capacity. The issue of lack of access to specialists is more pressing in rural areas, since many ENT specialists are based at larger, urban hospitals.[20] Therefore, health systems could take steps to enable patients to have equitable and sufficient access to ENT specialists by initially determining the level of ENT coverage in different regions, assessing whether the demands of the patient population are adequately met, and using this to inform measures to address any discrepancies in the number of ENT specialists—for example, by providing targeted education on CRSwNP to non-specialist ENTs.

Recommendation 3: National health system policymakers should monitor and evaluate ENT capacity and take targeted actions to increase specialist numbers in underserved areas. **Long-term**

4.3 Approach to care provision

Limitations in available guidelines

There was consensus in the expert working group, across physicians and patient representatives, that having up-to-date treatment guidelines is an important contributor to the quality of patient care, by offering a clear pathway for disease management and setting out the standard of care. Guidelines are particularly important for chronic diseases and diseases which require multidisciplinary care, such as CRSwNP, as patients are often treated across multiple specialties and healthcare settings. To support timely and equitable uptake of guidelines across regions, policymakers could ensure they are frequently updated—which is especially relevant to CRSwNP due to the ongoing development of different treatment options—and that HCPs are equipped with the tools to best treat their patients. Updates could therefore be coupled with trainings to improve implementation and KPIs to monitor uptake and indicate where additional resources may be required to support guideline implementation. Support for the use of KPIs to address limitations in guidelines comes from examples from other therapy areas, such as COPD (Box 6).

Box 6: Assessment of guideline adherence for COPD management, Puglia, Italy

- The Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines for treating COPD have been demonstrated to improve patient outcomes and reduce healthcare costs. However, a lack of adherence to these guidelines in Italy was resulting in poorer economic efficiency for the treatment of COPD.
- Regional policymakers collaborated with pulmonology centres to develop an IT platform where pulmonologists could fill in a number of indicators which offered insight as to how they treated patients with COPD and the extent to which this adhered to the GOLD guidelines.
- The findings from the assessment provided an overview of COPD management in Puglia, and therefore a resource to improve appropriateness and reduce the waste of health resources.[74]

Recommendation 1: Health system policymakers should support timely implementation of treatment guidelines by using KPIs to monitor their uptake, including to assess long-term management, e.g. repeated surgeries, OCS overuse.

Foundational

Specific solutions are also required to address the gaps in guidelines on key treatment decisions, such as long-term biologic use, biologic differentiation and patient selection. This requires research identifying clinically relevant biomarkers to select respondents to biologics and the evaluation of the required duration of treatment and discontinuation criteria.[11] Funding could be made available at the EU level to support research that addresses these gaps and supports the best outcomes for patients.

Recommendation 2: EU funding should be used to support ongoing research into evidence gaps needed for guidelines, e.g. long-term biologic use and patient selection.

Long-term

Lack of modernised care pathways

To improve the quality of life of patients and the efficiency of healthcare systems, there needs to be an improved approach to care provision by ensuring that treatment practices reflect the most recent understanding of the disease. Policymakers could support improved care pathways that deliver multidisciplinary, patient-centric, long-term treatment by outlining the ideal care pathway. This could be used as starting point for care pathway redesign that allows for differences in health systems between and within countries. The five-year EU Horizon–funded project, EU-PAL COPD, provides a case study for how this could be achieved, by investigating the optimum care pathway for patients with COPD. The project aimed to improve patient health and reduce costs through designing a care pathway which emphasised patient-centric shared decision-making, multidisciplinary team care, and continuity of care between hospital and community settings, which could be tailored to individual healthcare settings through collaboration of local stakeholders.[75]

Recommendation 3: EU funding should be allocated to support research and pilots on the optimum care pathway for CRSwNP. **Foundational**

Tailoring of treatment plans within specific care settings (aligned to the specific patient population and health system infrastructure) is a vital aspect of local pathway redesign. Specific local care pathway redesign could involve the establishment of a national referral and MDT pathway that is supported by a corresponding national tariff system. Additionally, the identification of KPIs for the healthcare pathway can facilitate continued refinement of key policymaker recommendations. A successful model for policymakers looking to achieve local care pathway redesign, which includes MDT pathways and the development of KPIs, can be taken from Spain and the CARABELA initiatives for two other type 2 respiratory diseases: COPD and asthma (Box 7).

Box 7: The CARABELA initiatives for COPD and asthma, Spain

- The CARABELA initiatives employs a methodology to redesign and optimise the care pathway and improve patient outcomes for patients with COPD and asthma.
- The initiatives emphasise multidisciplinary collaboration and individualised patient treatment, using a four-part methodology to optimise the treatment pathway. In Phase 1, a multistakeholder panel of experts analyse the current care pathways and identify any unmet needs. In Phase 2, key healthcare quality indicators are identified which can be used to understand any progress in addressing care pathway barriers. Phase 3 involves establishment of regional solutions and recommendations, while Phase 4 involves the ongoing local rollout of the results of the CARABELA initiatives. [76]
- Specifically for the management of severe asthma, the initiative identified 87 improvement areas and co-created 112 solutions and healthcare quality indicators which, as of March 2025, had resulted in tailored care pathway improvement plans in 36 hospitals.[77]

Recommendation 4: Policymakers should support multistakeholder expert panels to advise on local care pathway redesign, to include the need for ongoing management, and support subsequent rollout of recommendations through available guidance documents and funding. **Foundational**

Finally, when looking to modernise care pathways, policymakers should consider the most recent research on CRSwNP, which has emphasised the role of type 2 inflammation in determining a patient's symptoms and what their optimum choice of therapy will be. This is especially relevant with the introduction of biologics as a treatment option and considering the level of comorbidity of CRSwNP with other type 2 inflammatory diseases such as severe asthma and COPD. Future care provision for CRSwNP could consider the possible role of type 2 inflammatory outpatient clinics in optimising treatment of patients with CRSwNP who require a biologic (Box 8). This would ensure multidisciplinary and coordinated care for patients while facilitating long-term management with continuous specialist monitoring of patient responses and subsequent personalisation of treatment. Outpatient clinics aiming to improve the care pathway for patients with severe asthma already exist in Spain and Italy and provide a potential opportunity for improving CRSwNP patient care. Spain has been a global leader in introducing Specialised Asthma Units (SAUs), and patients treated at one of the 100 accredited SAUs in 2025 are more likely to have their symptoms well controlled, experience fewer exacerbations and reduce costs for the healthcare system.[78]

Box 8: Outpatient clinic for the care of severe asthma patients, Veneto, Italy

- In 2017, the Veneto region of Italy established the multistakeholder Regional Technical Commission to generate recommendations on improving severe asthma care pathways.
- The outcome was an outpatient clinic with a structured, integrated, multidisciplinary, patient-centred care structure. The clinic treated 146 patients in 2018 and ensured greater patient personalisation of treatment, a more long-term perspective on care and improved treatment compliance. As a result, the initiative was shown to have the potential for stricter control of asthma and optimisation of therapies.[79]

Recommendation 5: As part of care pathway redesign, regional/local policymakers should investigate introducing type 2 respiratory outpatient clinics with designated funding for MDTs, digital tools and monitoring of patients. **Long-term**

4.4 Access to treatment

Restricted access to medicines

Ensuring appropriate access to medicines is central to supporting a shared decision-making approach for CRSwNP, since patients need to have access to a range of different therapeutic options. This will become increasingly important as new options, each with different profiles and dosing schedules, become available. For example, access to biologics administered with less frequency may in the future help alleviate some of the treatment burden on patients,[32] as well as optimising persistence and improving clinical outcomes for patients.[33] Payers could ensure that patients benefit from long-term, ongoing management through a shared decision-making approach with their physician by removing restrictions which are not evidence-based or in line with the options set out in clinical guidelines. This removal of restrictions on access to treatment can be seen in Spain: although biologics for CRSwNP are still restricted to patients who have had two surgeries, in 2023 the Ministry of Health removed a restriction on access to triple therapy for COPD that required prior authorisation. This change was supported by medical societies and patient organisations, including the Spanish Society of Pneumology and Thoracic Surgery (SEPAR).[80]

Recommendation 1: Payers should enable broad access to different therapies by removing restrictions that are not evidence-based or which prevent patient/physician choice of options included in up-to-date guidelines. **Foundational**

Where there is a risk of patients being denied access to a treatment due to payer budget impact concerns over the number of patients eligible for a treatment if it had broad access, payers could be open to more flexible and innovative approaches to mitigate financial and evidence uncertainties. For example, to address concerns over the cost-effectiveness of a biologic for severe asthma, the Dutch advisory body to the Ministry of Health recommended a pay-for-performance agreement to prevent blocking of access for patients by removing the treatment from the basic healthcare package.[81]

Recommendation 2: Payers should be open to innovative agreements, including risk-sharing agreements, where there are financial and evidence uncertainties that risk blocking access to therapies for patients. **Foundational**

The low recognition of the patient burden or unmet need for new treatments for CRSwNP is a barrier preventing patient access to innovative therapies. Engaging with patients during the HTA process is an important mechanism for payers to understand the experience of the disease and how a new treatment might impact patient quality of life. Patient input into HTA requires a well-informed and educated patient community who are able to articulate treatment gaps, outcomes that matter to them, the burden of the disease, and the changes that are needed to improve care and management. The degree of patient involvement varies widely between countries. In France, for example, the Haute Autorité de Santé provides patients with opportunities to contribute to the assessment of new medicines through questionnaires. This was done by the Asthma and Allergies Association and Association of Severe Asthmatics submissions to the Transparency Committee appraisal of a recent biologic for CRSwNP, and was used to explain the limitations of existing therapies and convey patient testimonials on the disease burden.[65]

Recommendation 3: Payers and health authorities should provide opportunities to consult and/or grant voting rights to patient associations in decisions on access to new CRSwNP treatments. **Long-term**

Lack of incentives in funding systems affecting treatment choice

Although the structure of funding flows is generally determined at the system level rather than for individual diseases, the experience of other therapy areas demonstrates how policymakers could take action to incentivise more holistic and long-term management of patients. For example, in COPD, countries such as Hungary and the Netherlands have piloted or implemented a system of bundled payments which incentivise HCPs to keep patients healthier over the long term (Box 9). In France, the national health insurance organisation introduced dedicated funding to improve adherence to asthma treatments and ongoing management of the disease; specifically, a national amendment to the law on the pharmacist and health insurance agreement provided dedicated funding for a series of interviews to address the high rates of improper inhaler use.[82] A similar mechanism for pharmacist support exists in Belgium for diseases including asthma and COPD.[83] This approach could be impactful in CRSwNP considering the increased recognition of the need for long-term management. CRSwNP would be a good candidate for piloting alternative funding approaches such as outcomes-based or bundled payments which align incentives with long-term outcomes, and could therefore help reduce the practice of repeated surgeries and ongoing OCS use.

Box 9: Hungary bundled payment methods for COPD

- The government launched a pilot of bundled payment methods for COPD, consolidating payments for both hospital and ambulatory care into a single, comprehensive fee that spans the entirety of a patient’s care journey.
- Supported by the European Commission’s Directorate General for Structural Reform Support and the World Health Organisation’s technical assistance, the government tested this method through an operational study in 2021-23 involving 2,000 COPD patients.[84]
- This pilot resulted in reduced hospitalisation rates, improved patient communication tools and strengthened focus on patient adherence to treatment plans.

Recommendation 4: Health systems should implement pilots for innovative funding approaches for chronic respiratory diseases that ensure multidisciplinary and holistic management. **Long-term**

4.5 Summary of recommendations

Key takeaways: Policy recommendations to improve the management of CRSwNP

- Policymakers should build on the wider momentum of awareness raising to **recognise the impact of CRSwNP** within national and regional plans, playing their part to **improve societal awareness** of CRSwNP and facilitating funding to help address gaps in evidence generation, such as disease registries.
- To **address diagnostic and referral delays**, policymakers should provide **support for PCP training** and enable improved referral by introducing relevant tools for HCPs.
- National and regional policymakers should work together to ensure a **modernised and personalised approach to care provision**, achieved through targeted **care pathway redesign** in tandem with up-to-date guidelines.
- Policymakers should enable patients to **receive broad access to different treatment options**, by removing barriers to both reimbursement and healthcare funding. As part of this, there should also be **consideration of the patient perspective** on decisions on access to new therapies.
- A **summary of the specific actions recommended to policymakers**, following their testing with CRSwNP experts and using case studies from other inflammatory and respiratory diseases, is set out in Table 5.

Table 5: Policy recommendations

Area	Recommendation	Timing
Policy advocacy and recognition	National/regional health policymakers and parliamentarians should facilitate cross-stakeholder discussions (e.g. legislative groups and roundtables) on the barriers to care and potential solutions for chronic respiratory diseases, including CRSwNP.	**Foundational**
	National/regional policymakers should implement or update dedicated plans, with allocated funding, for respiratory diseases broadly, including for CRSwNP, to establish a comprehensive framework that can address challenges across the patient journey.	**Long-term**
	The EU should launch (and provide financial support for) a dedicated initiative to define a common protocol for national CRSwNP disease registries to support comparability and data pooling.	**Long-term**
	Health system policymakers should leverage initiatives that already exist (e.g. Global CRSwNP Awareness Day) to educate the public on the importance of timely presentation to the health system.	**Foundational**

Diagnosis and referral	National/regional policymakers should provide support for PCP training on early diagnosis of CRSwNP, including for development of diagnostic-related KPIs to track the impact on the diagnostic pathway, within the framework of a national/regional plan.	**Foundational**
	Health system policymakers should act to first identify and then implement tools (such as patient checklists, virtual consultations, and closer collaboration between physicians) that will accelerate referral times for uncontrolled patients.	**Foundational**
	National health system policymakers should monitor and evaluate ENT capacity and take targeted actions to increase specialist numbers in underserved areas.	**Long-term**
Approach to care provision	Health system policymakers should support timely implementation of treatment guidelines by using KPIs to monitor their uptake, including to assess long-term management, e.g. repeated surgeries, OCS overuse.	**Foundational**
	EU funding should be used to support ongoing research into evidence gaps needed for guidelines, e.g. long-term biologic use and patient selection.	**Long-term**
	EU funding should be allocated to support research and pilots on the optimum care pathway for CRSwNP.	**Foundational**
	Policymakers should support multistakeholder expert panels to advise on local care pathway redesign, to include the need for ongoing management, and support subsequent rollout of recommendations through available guidance documents and funding.	**Foundational**
	As part of care pathway redesign, regional/local policymakers should investigate introducing type 2 respiratory outpatient clinics with designated funding for MDTs, digital tools and monitoring of patients.	**Long-term**
Access to treatment	Payers should enable broad access to different therapies by removing restrictions that are not evidence-based or which prevent patient/physician choice of options included in up-to-date guidelines.	**Foundational**
	Payers should be open to innovative agreements, including risk-sharing agreements, where there are financial and evidence uncertainties that risk blocking access to therapies for patients.	**Foundational**
	Payers and health authorities should provide opportunities to consult and/or grant voting rights to patient associations in decisions on access to new CRSwNP treatments.	**Long-term**
	Health systems should implement pilots for innovative funding approaches for chronic respiratory diseases that ensure multidisciplinary and holistic management.	**Long-term**

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