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Living with Moderate-to-Severe Persistent Asthma

Perspectives from Patients and Caregivers

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LIVING WITH MODERATE-TO-SEVERE PERSISTENT ASTHMA:

PERSPECTIVES FROM PATIENTS AND CAREGIVERS

An informational report provided by Genentech, South San Francisco, CA

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INTRODUCTION

THE 2017 GENENTECH RESPIRATORY TREND REPORT

The mission of *The 2017 Genentech Respiratory Trend Report: Perspectives from Payers, Specialty Pharmacies, Practicing Physicians, and Provider Administrators* (The 2017 RTR) was to provide timely and useful information on the latest respiratory care trends and developments, serving as a unique resource for those seeking an understanding of the issues surrounding respiratory management and practice. The report addressed respiratory conditions with high aggregate costs to the healthcare system – including highly prevalent diseases such as asthma and chronic obstructive pulmonary disease, and less common diseases such as cystic fibrosis and interstitial lung diseases (ILDs). Payer, provider, and specialty pharmacy trends with respect to these respiratory conditions were researched and reported in detail.

FOCUS OF THIS REPORT

This supplemental report, *Living with Moderate-to-Severe Persistent Asthma: Perspectives from Patients and Caregivers*, captures patient perspectives on one of the sentinel conditions discussed in The 2017 RTR. It seeks to identify aspects of the asthma patient's experience that could be better and facilitate conversation about opportunities to improve patient care. The content of this report was prepared by Navigant at Genentech's request, and is based on primary research with patients, as well as review of published sources. Statements and opinions contained in the report do not necessarily reflect those of Genentech.

To obtain the patient input required for this report, qualitative and quantitative research was conducted with patients with moderate-to-severe asthma and their caregivers. These first-hand patient experiences were then reviewed side-by-side with the payer, provider and specialty pharmacy viewpoints summarized in The 2017 RTR. Key topics addressed include:

- **Burden of Disease:** What aspects of the burden are most impactful to patients and caregivers? What are patients struggling with most in managing moderate-to-severe asthma?
- **Diagnosis:** In what care settings are patients being diagnosed with moderate-to-severe asthma? What challenges do they face in obtaining their diagnosis?
- **Treatment:** What barriers do patients face in accessing treatment? What challenges do they face in fulfilling specialty asthma medications? How do patients wish to be engaged in their care decisions?
- **Patient Education and Self-Management:** Where are patients going for information about their condition? What self-management strategies and tools are they using? What payer, specialty pharmacy, and manufacturer programs are they taking advantage of, and how helpful do they find them?

Patient perspectives on other conditions in scope of The 2017 RTR may be similarly captured in future supplemental pieces.

MODERATE-TO-SEVERE ASTHMA

Asthma is a chronic obstructive lung disease characterized by inflammation and narrowing of the airways, causing recurring episodes of wheezing, chest tightness, shortness of breath, and cough.[1] Medical therapies for asthma include inhaled therapies, oral medications, and injectables.

In this report, we use the term "moderate-to-severe asthma" to include patients who experience daily asthmatic symptoms, wake up at least once a week due to symptoms, require rescue medication daily or multiple times a day, and have some or extreme limitations when participating in normal activity. Patients may currently be experiencing these symptoms, or they may have gained better control since initiating their current therapy regimen.

METHODOLOGY

QUALITATIVE PATIENT RESEARCH

Double-blinded qualitative interviews were conducted with moderate-severe asthma patients and caregivers to learn first-hand about their experiences living with and obtaining appropriate care and treatment for their condition.

Potential participants were informed of the research study via e-mail. These individuals were assured that their names would be held in strict confidence, and that the final report would reflect aggregated responses. Those who qualified for the study and agreed to the research terms participated in a 60-minute interview conducted by telephone.

Research participants were required to meet specific prequalifying criteria to ensure the integrity of their responses: patient or caregiver of a child with asthma; managed by a specialist (allergist or pulmonologist); self-identifying as having moderate-to-severe persistent asthma symptoms; and currently or recently having been treated with therapies commonly used in the management of moderate-to-severe asthma.

QUANTITATIVE PATIENT RESEARCH

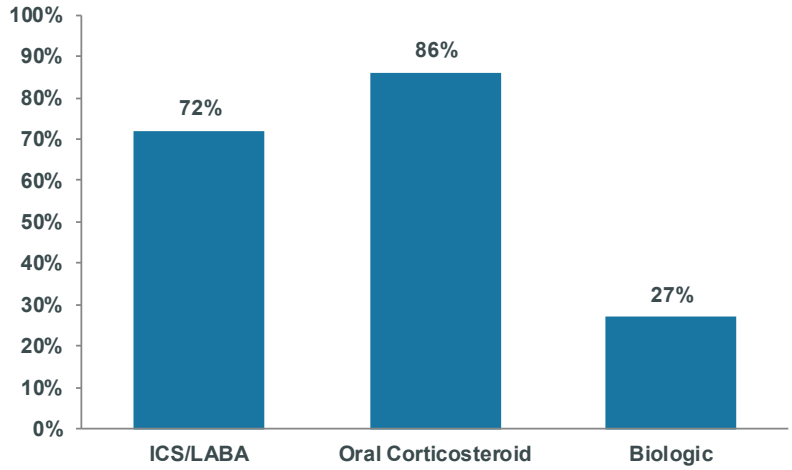
A quantitative research survey was developed and deployed to 93 patients meeting the same prequalification criteria as for the qualitative research. The survey investigated patient and caregiver experiences living with and managing moderate-to-severe asthma. No specific pharmaceutical products were asked about in the course of the research.

Like the qualitative research, potential survey participants received information about the research opportunity via e-mail. These individuals were assured that their names and individual responses would be held in strict confidence, and that the final report would reflect aggregated responses. Those who agreed to participate were directed to an online survey link. Survey programming logic directed participants to relevant and appropriate questions based on their individual characteristics.

RESPONDENT DEMOGRAPHIC INFORMATION

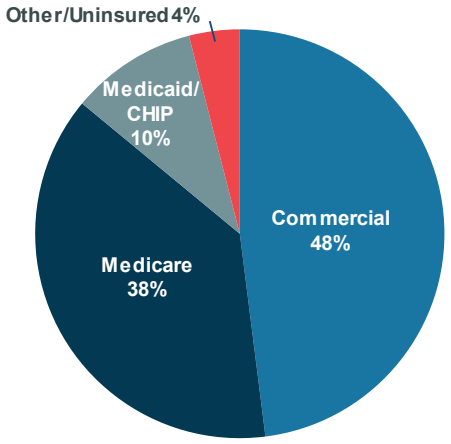
This section summarizes pertinent demographic data describing the aggregate sample of respondents who qualified for participation in the quantitative patient research. The sample included 84 patients (30% male, 70% female; average age 54), and 9 caregivers of children (22% male, 78% female; average age 14). As a result of respondent selection criteria, many respondents (72%) were treated with an ICS/LABA, and most (86%) had current or prior exposure to a course of oral corticosteroids; 25 patients (27%) had current or prior exposure to biologic therapy. Respondents had a variety of different types of insurance coverage, depicted in Figure 2.

Figure 1: Patient Reported Usage of Medications (N=93)



Nearly all patients were on or had been on an inhaled corticosteroid/LABA combination or an oral corticosteroid. About a quarter of survey respondents were on or had been on a biologic therapy

Figure 2: Patient Sample by Insurance Coverage Type (N=93)



Half of respondents reported being covered by private insurance, and half by some form of government insurance

SECONDARY RESEARCH

In addition to primary research, a literature review was conducted to supplement the research topics explored within this report. Detailed references are included at the end of the piece.

BURDEN OF DISEASE

PATIENT VIGNETTES

Patients with moderate-to-severe asthma were interviewed to gain first-hand insights into their experiences. Three of their "vignettes" are introduced below; names have been changed to maintain anonymity.

Sarah is the caregiver of a 9-year-old-daughter

Sarah speaks about the severe hardship on both her daughter and their family due to asthma

James is a retired truck driver

Since developing moderate-to-severe asthma, James needs to take frequent breaks while gardening, walking his dogs, and playing with his grandkids

Anthony is an IT executive

Receiving a diagnosis of allergic asthma in his teens caused worry over being able to keep up with his peers. He likes to stay well-informed about new treatment options

35% of respondents
agreed that the social stigma of asthma affects their confidence and how they feel in public

LIVING WITH ASTHMA

Over the past few decades, both asthma prevalence and incidence have been increasing worldwide. This increase can be attributed to some degree to genetic causes, but primarily to the effect of many environmental and lifestyle risk factors.[2] Approximately 25 million patients suffer from asthma in the U.S. (2015).[3] Prevalence figures of severe asthma are lacking. Longstanding estimates vary between 5% and 10% of all asthmatic patients, although a recent study of Dutch patients indicated that 3.6% of asthmatic adults qualified for a diagnosis of severe refractory asthma.[4]

Moderate-to-severe asthma is a significant burden to patients

Moderate-to-severe asthma can substantially limit physical, social, and professional or student aspects of life, especially when uncontrolled. Asthma flare-ups often necessitate the use of emergency care and even hospital admission, leading to missed days of school and work. In the extreme, asthma can cause permanent disability and even death.[2] In The 2017 RTR, payers and physicians suggested that the patient as well as the economic burden of asthma increases with severity. Another study estimated that 50% of all annual healthcare costs related to asthma come from the most severe asthma population, constituting only about 20% of patients with asthma.[2] Qualitative interviews conducted with patients and caregivers underscore the profound burden and impact of moderate-to-severe asthma on those it affects.

Patients with moderate-to-severe asthma reported that asthma limited their ability to do what they enjoy: **45% of survey respondents agreed that asthma episodes and exacerbations have substantially impacted their daily lives.** Physical activity is a common trigger for many patients, and limitations on physical activity were qualitatively noted to be particularly burdensome.[5] Children may be unable to play with their peers, young adults who enjoy sports may see their performance reduced, and older adults may have difficulty with everyday tasks. Parents or other caregivers of children with moderate-to-severe asthma also see their daily lives affected. Many must take time off from work to care for their children, and qualitatively emphasized the emotional burden of seeing a sick child struggle with their condition.[2] Furthermore, **35% of respondents agreed that the social stigma of asthma affects their confidence and how they feel in public,** adding an additional emotional aspect to the burden and perhaps precluding optimal disease management outside of the home.

As with many chronic conditions, out-of-pocket costs may also contribute to the patient and caregiver burden of asthma, especially for patients with moderate-to-severe disease. Among surveyed patients not on injectable biologic therapy (n=68), half (49%) considered out-of-pocket costs to be a burden. More than half (56%) of surveyed patients on injectable biologic therapy (n=25) considered out-of-pocket costs to be a burden. Moreover, **patients on biologic therapy spent twice as much on office visits including medical benefit cost-sharing for physician-administered therapies.** This sentiment was echoed by surveyed asthma specialists in The 2017 RTR, where out-of-pocket costs were reported as the top challenge that patients with severe asthma face in managing their condition.

> ***"Playing around she will run, then be upset because she can't breathe, and she will still try to push herself and get a burning in her chest. That is really hard."***
>
> ***– Sarah, Mother***

> ***"For a time, my asthma was so bad I was really hesitant about going out in public."***
>
> ***– James, Truck driver***

Table 1: Self-reported monthly out-of-pocket costs*

Category	Patients not on Biologic Therapy (n=68)	Patients on Biologic Therapy (n=25)
Retail Medications	$75	$40
Office Visits	$30	$60

Comorbidities confound challenges associated with management of moderate-to-severe asthma

The majority (89%) of survey respondents indicated that they are managing a comorbid condition. It has also been reported in the literature that asthma patients experience a greater burden of comorbidities than similar patients not suffering from asthma.[6] The most commonly reported comorbidities were allergies, arthritis, and hypertension; with over a third of respondents experiencing at least one of these. Only 11% of patients did not indicate experiencing a common comorbid condition**.

The majority (89%)
of survey respondents indicated that they are managing a comorbid condition

In The 2017 RTR, patient education about comorbid conditions impacting asthma control was cited by specialists as one of the key concerns for patients with severe asthma, as comorbidities are increasingly recognized as being associated with inadequate disease control, higher health care use, and reduced quality of life.[7] Comorbidities can impact a patient's asthma severity in multiple ways: they may be responsible for progression towards a different asthma phenotype, they may directly worsen symptoms by acting on the same physiological processes, or they may act as confounding factors in the diagnosis and management of asthma symptoms.[8] All of these effects further confound challenges associated with management of an already complex condition. In one study of asthma patients aged 40-75 years, it was reported that having one comorbid condition doubles a patient's odds of scoring poorly on a general health-related quality of life test; and having two or more comorbid conditions increases those odds to nearly seven times that of asthma patients without comorbidities.[9]

* Median monthly spend is representative of respondents covered under commercial insurance. Patients on government insurance have more complicated coverage, though generally they reported similar average OOP.

** Common comorbidities listed for selection in the survey: Food allergies, allergies (no food), arthritis, hypertension, chronic bronchitis, diabetes, chronic sinusitis, emphysema, atopic dermatitis/eczema, obesity, none of the above

The substantial patient and caregiver burden of moderate-to-severe asthma underscores the importance of optimizing disease management approaches, and continuing the dialogue about remaining needs and opportunities for improvement. It is with this context that the rest of this report discusses patient experiences and challenges, obstacles to use of best practices and solutions that alleviate the asthma burden, and opportunities to improve management of moderate-to-severe asthma.

FALSE SENSE OF ASTHMA CONTROL

Many patients consider their asthma controlled despite ongoing symptoms and attacks

Analysis of the survey data indicated that some asthma patients may under-estimate the severity of their condition, or have a false sense of asthma control. The majority (71%) of patients indicated that their moderate-to-severe asthma symptoms are currently controlled. However, many reported a need for occasional escalation of therapy and frequent attacks. Among patients who considered their symptoms currently controlled (n=66), one-third (33%) agreed that asthma substantially impacts their daily lives. Furthermore, these patients reported up to 20 flare-ups per year (average of 2.9). For comparison, 74% of patients who considered their asthma currently uncontrolled (n=27) agreed that asthma substantially impacts their daily lives; and these patients reported up to 25 flare-ups per year (average of 7.4).

74% of patients

who considered their asthma currently uncontrolled agreed that asthma substantially impacts their daily lives

these patients reported up to

25 flare-ups per year

(average of 7.4)

CHALLENGES AND PATIENT PERSPECTIVES

Living with and achieving optimal control of moderate-to-severe asthma is often an arduous journey for the patient. While the condition and patient experience is heterogeneous, this research suggests several common themes and challenges in navigating the system. In this section, patient experiences and pain points related to diagnosis, treatment, education, and self-management are explored.

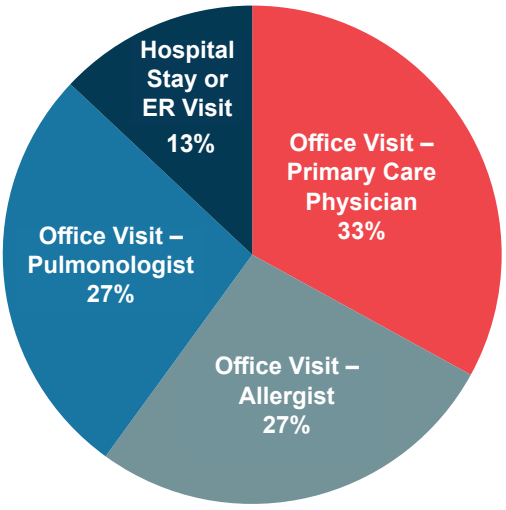
DIAGNOSIS

There can be delays in diagnosis and referral, and some patients are still diagnosed in the hospital

Many patients with moderate-to-severe asthma are first diagnosed with asthma as a child; though adult onset may occur as well.[10] Severe asthma may develop over time, or shortly after onset of the disease. Questions persist regarding the natural history for development of severe asthma; and it is not certain whether any patient with asthma is at risk for development of severe asthma, or only a poorly defined subset.[11] As a consequence, many patients suffer with inadequate or ineffective asthma treatment for some time, often months or years, before a correct diagnosis of moderate-to-severe asthma is made. This can be a frustrating experience for patients. Among surveyed patients, **35% agreed that it took too much time and effort to reach their current asthma diagnosis.**

In The 2017 RTR, about 45% of payers and physicians indicated that a patient's ability to obtain an appointment with the appropriate specialist hinders optimal outcomes. Interestingly, only a quarter (26%) of surveyed patients agreed that scheduling an appointment with a specialist was a challenge. However, it is notable that just half of patients received their diagnosis of moderate-to-severe asthma during a planned specialist office visit (27% allergist, 27% pulmonologist). One-third of respondents were diagnosed by a primary care provider, and 13% learned of the severity of their condition

Figure 3: Setting in which Patients Received Diagnosis of Moderate-to-Severe Asthma (N=93)



Half of patients were diagnosed with moderate-to-severe asthma by a specialist, 13% during an episode requiring hospitalization

during an episode requiring hospitalization. These data may raise questions about referral practices. Specialist referrals have a substantial impact on disease prognosis and the patient's health status, but recommendations for referrals established in consensus guidelines may not be optimally followed in practice.[12] This issue is discussed further later as it relates to the role of the specialist in introducing and evaluating eligibility for add-on specialist therapies (see *Treatment*).

TREATMENT

Treatment Classes & Shared Decision-Making

Medical therapies for asthma include inhaled therapies, oral medications, and injectables

Based on severity, asthma may be managed with a variety of medications, with inhaled corticosteroid (ICS) and long-acting beta^2-agonist (LABA) medications being a common mainstay of therapy in moderate and severe asthma.[13] Among surveyed patients with moderate-to-severe asthma, 90% reported using an inhaled therapy.

> ***"Getting on the right medication was a trial and error process."***
>
> ***– Anthony, IT Executive***

Some patients with asthma may be managed with oral pharmacotherapies. Half (48%) of surveyed patients reported taking an oral medication other than oral corticosteroid (current or prior use or consideration of oral corticosteroids was a condition for participation, for patients not on or previously on an injectable biologic therapy).

88% of surveyed patients agreed that it is important that they play a role in decisions about their treatment.

Some patients with moderate-to-severe asthma may be candidates for injectable biologic therapy. The survey informing the perspectives in this report included n=25 patients on or previously on injectable biologic therapy.

It can take months or years to find the right medication regimen to optimize asthma control

Often moderate-to-severe asthma patients must cycle through different drugs before finding the right medication regimen to manage their condition. In fact, **59% of patients agreed that it took too much time and effort to identify the right medication(s) to control their moderate-to-severe asthma after diagnosis**. Qualitatively, interviewed patients emphasized the frustration of frequent follow-up visits with different providers, insurance hurdles and unpredictable out-of-pocket costs, and the disappointment of treatment failure, as they find the right medication.

Patients desire to participate in decisions about their treatment

The majority (88%) of surveyed patients agreed that it is important that they play a role in decisions about their treatment. Shared decision-making describes the participation of individuals in decisions about their care.[14] Asthma guidelines increasingly recognize the role of "the patient and healthcare provider partnership" for a shared-care approach, and some studies support the benefits of shared decision-making in asthma, including potential for improved patient quality of life and asthma control, reduced healthcare visits, improved inhaler compliance, greater patient satisfaction and empowerment.[14,15]

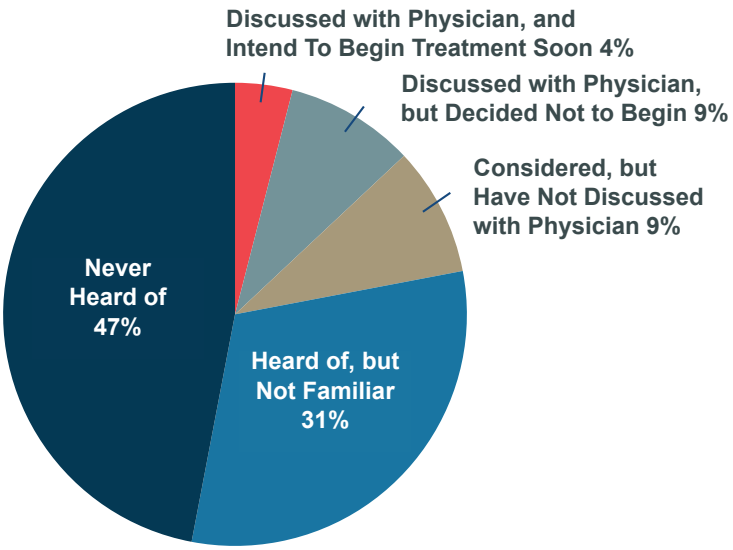
Overall, most surveyed patients (76%) generally agreed that their opinions and preferences are adequately considered by their physician. Yet, this data may be at odds with the frustration that patients also reported regarding their asthma journey. Interventions to encourage patient-centered care across a range of conditions generally place the responsibility on the provider, but some are aimed at providing a pathway for patients or caregivers to better engage in their asthma care. Interventions aimed at changing health provider behavior might include more open communication, identifying and addressing patient and caregiver concerns, discussing treatment preferences and barriers to implementation, shared development of treatment goals, and encouraging active self-assessment and self-management.[15]

Therapy escalation for moderate-to-severe asthma patients often requires referral to a specialist

To help attain the best possible clinical outcomes in patients with asthma, several guidelines provide recommendations for patients who will require a referral to a specialist. Such referrals can help in clearing the uncertainty from the initial diagnosis, provide tailored treatment options to patients with persistent symptoms, and offer the patients access to health care providers with expertise in the management of asthma. Referring a patient to a specialist may allow them access to additional health care resources and add-on therapies which may not be available in the primary care setting, including biologics which may require a broader diagnostic setup.[12]

The important role of the asthma specialist in introducing and evaluating patient eligibility for injectable biologic therapy was apparent from the patient survey data: over two-thirds of surveyed patients who had considered a biologic therapy (n=39) rated their specialist as highly influential on their decision to start or not to start biologic therapy (Allergist 73%; Pulmonologist 70%). Still, however, patient awareness of biologic options for moderate-to-severe asthma remains low: **more than three-quarters (78%) of surveyed patients not previously exposed to biologic therapies (n=68) indicated that they had never heard of biologic treatment options, or didn't know anything about them**. It is possible that under-referral may contribute to low patient awareness of biologic therapy options. A recent Italian and German study highlighted that 12% of patients who were being treated by PCPs and office-based respiratory consultants were eligible for a specific biologic, but were not receiving this therapy.[12]

Figure 4: Familiarity with Biologic Among Those Not Treated with Injectibles (n=68)



Three-quarters (78%) of respondents not currently or previously on biologic had no familiarity with this class of treatment option

Access to Therapy

Many patients encounter barriers to accessing asthma medicines

> ***"I am considering starting [biologic]. It is really expensive. I spoke to my pulmonologist about it and he is jumping through some hoops right now to see if I might be able to get insurance approval for it."***
>
> ***– James, Truck driver***

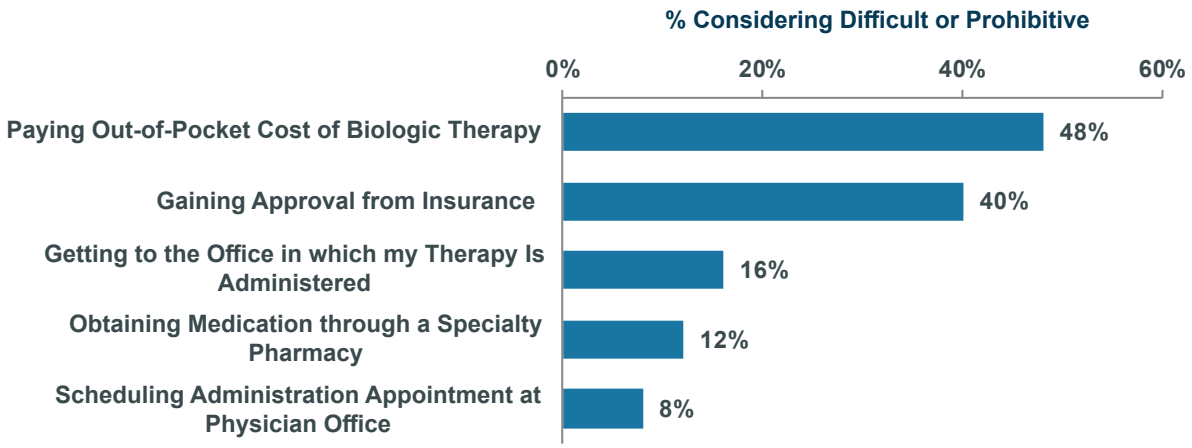
In The 2017 RTR, 73% of surveyed payers reported that management of drug-related costs was an important priority for their organization, specifically as it relates to asthma. Surveyed payers indicated that inhaled medications account for the largest portion (45%) of current drug expenditures for common respiratory conditions including asthma; with oral medications accounting for 32% and injectable medications for 23%. Furthermore, surveyed payers reported a high willingness to manage use of these products: 60% were "very or extremely" willing to manage the inhaled medications; 63% the orals; and 59% the injectables.

Surveyed payers reported that their organizations have adopted a wide range of approaches to manage the retail medications for asthma (inhalers and oral tablets), with member copays and formulary tiering most commonly reported. Utilization management of the asthma injectables was also assessed; surveyed payers likewise reported a wide variety of utilization management approaches, including use of coverage policies and prior authorization (across both pharmacy and medical benefits).

Another 2015 study assessed coverage of innovator asthma medicines by plans in the health insurance exchanges (silver plans) and employer plans. Innovator asthma medicines were found to be listed on both exchange and employer plan formularies about 86% of the time. However, patients often take more than one asthma medicine and may have difficulty accessing all of the medicines prescribed to manage their condition. Furthermore, the research concluded that patients with asthma in exchange plans face higher use of utilization management and cost sharing.[16]

The patient survey informing the content of this report included questions about access to injectable therapy. Among patients who had used or considered injectable therapy, 35% considered their insurer to have played an important role in their decisions. Reimbursement-associated barriers also emerged when patients were asked about specific challenges in accessing injectable therapy: **40% of patients on or previously on a biologic therapy indicated that obtaining insurance approval was either difficult or prohibitive**. Nearly half (48%) of patients indicated that their out-of-pocket costs associated with biologic therapy were difficult to afford.

Figure 5: Patient Challenges to Accessing Biologic Therapy (n=25)



Reimbursement-related issues are the most frequently reported access barriers faced by patients, with 40% having struggled with insurance approval and 48% with out-of-pocket costs

Patient experiences with prescription fulfillment and treatment can be positive with proper support

Retail prescriptions including inhalers and oral tablets are readily fulfilled via retail or mail-order pharmacy. Fulfillment of add-on specialty medicines including the injectable biologic therapies, however, may entail more complex logistics. Prescribers of injectable biologic therapy may face additional administrative barriers to obtain authorization to begin treatment and coordinate prescription dispensing with both the insurer and dispensing pharmacy, and arrange for drug administration and billing. Patients must similarly navigate the administrative and practical complexities associated with use of specialty medications.

The patient research conducted to inform this report suggested that, despite added complexities of specialty drug fulfillment, asthma patients on injectable biologic therapy are satisfied with the support they receive and are able to obtain biologic therapy with relative ease. More than nine in ten patients (92%) on biologic therapies considered it "easy" to obtain their appointment for provider administration of their injectable. Eight in ten (84%) considered it "easy" to get to the office in which their injectable is administered. About two-thirds of patients on biologic therapy reported working with a specialty pharmacy to obtain access to their injectable therapy, and the majority (82%) of these patients considered the process "easy." This corroborates the physician viewpoint articulated in The 2017 RTR that specialty pharmacies have a positive impact on outcomes in severe asthma.

Care Coordination and Continuity

One-quarter (26%) of patients reported poor coordination between their providers, and patients spoke of difficulty staying ahead of their asthma through geographic moves or other life changes. Suboptimal care coordination and continuity may confound other challenges in asthma management, including adherence and compliance.

26% of patients
reported poor coordination between their providers

"I see three doctors: a family doctor, an allergist, and a pulmonologist. They are all supposed to communicate with each other since they are in the same network, but things seem to get lost and I get asked the same questions over and over."
– James, Truck driver

PATIENT EDUCATION AND SELF-MANAGEMENT

As a chronic condition that is often substantially related to environmental factors, patient self-management outside of healthcare settings is important for optimal outcomes.[17] The importance of providing information, skills and tools for asthma self-management was underscored by both payers and physicians in The 2017 RTR, and is well documented in consensus guidelines.

Asthma Self-Management Education

Teach and Reinforce:

- Self-monitoring to assess level of asthma control and signs of worsening asthma (e.g., peak flow monitoring and assessing symptom frequency)
- Using a written asthma action plan
- Taking medication correctly (inhaler technique and use of devices)
- Avoid environmental factors that worsen asthma
- Agree on treatment goals and address concerns
- Encourage education at all points of care: clinics, emergency departments, hospitals, pharmacies, school and childcare centers, other community settings, and patients' homes
- Provide instructions for daily management (long-term control medication), environment control measures, and managing worsening asthma (how to adjust medication; know when to seek medical care)
- Involve all members of the health care team in providing/reinforcing education, including physicians, nurses, pharmacists, respiratory therapists, and asthma educators

Trigger Reduction Components:

- Determine exposures, history of symptoms in presence of exposures, and sensitivities
- Advise patients on ways to reduce exposure to those allergens and pollutants. Multifaceted approaches are beneficial; single steps alone are generally ineffective. Avoid exposure to tobacco smoke
- Consider allergen immunotherapy; consider treatment of co-morbidities that may worsen asthma (e.g., gastroesophageal reflux, obesity, obstructive sleep apnea, rhinitis and sinusitis, and stress or depression)
- Consider inactivated influenza vaccine for all patients over 6 months of age

NAEPP Guidelines (full report 2007)[18]

Patient Education

Many patients look to nurses, physician assistants, and online resources to learn more

Asthma education is an integral part of effective asthma management. Surveyed patients indicated that they look to a variety of sources to learn more about managing their symptoms including their physician (85%), online resources (41%) and ancillary providers such as nurses or physician assistants (40%). While most patients rely on their doctor to learn about their condition, many (78% of patients engaging them) also find nurses and physician assistants to be especially helpful.

> ***"After having suffered from this for decades, I am a pretty informed person. Also, with the ubiquity of information available on the internet, I can come into discussions with my doctor somewhat informed."***
>
> ***– Anthony, IT Executive***

Table 2: Where patients go to learn more about managing moderate-to-severe asthma

Information Source	% of Respondents Consulting (N=93)	% Users Considering "Very or Extremely Helpful"
Physician	85%	71%
Website or Other Online Resource	41%	45%
Nurse, Physician Assistant, Other Healthcare Personnel	40%	78%
Family, Friends, or Others Knowledgeable about Asthma	30%	57%
Asthma and Allergy Foundation	29%	48%
Pharmacist or Pharmacy Resource	28%	46%
Insurance Provider Resources	19%	44%
Patient Organization or Advocacy Group	5%	40%
	FEWER	MORE

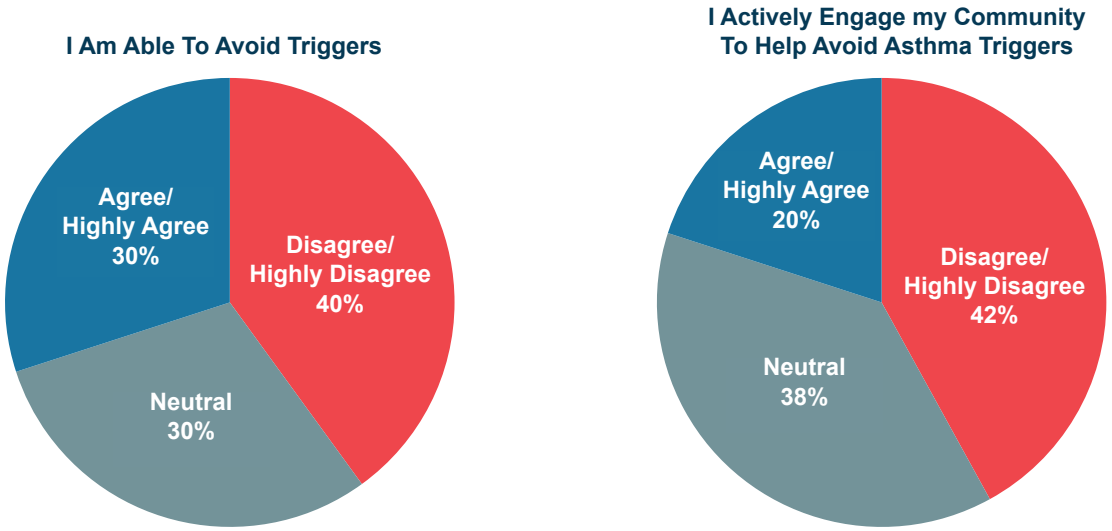
Trigger Avoidance

Many patients struggle with trigger avoidance

Asthma triggers vary by patient, and learning to avoid specific triggers can help minimize asthma attacks.[19] Among surveyed patients, the majority (65%) were aware of their asthma triggers, more than one-third (35%) were not (or don't have any asthma triggers) – a potential area for improvement. Surveyed patients who have identified their triggers (n=60) indicated improved quality of life (68%) and fewer flare-ups (63%) since identifying their triggers.

Even when asthma triggers were known by patients, many reported challenges in avoiding triggers. **Four in ten patients (40%) that were aware of their triggers reported that they were unable to avoid them**. A confounding factor may be unwillingness or inability to engage their community (e.g., schools, day care and workplace). Just one in five (20%) patients reported actively engaging their community to help avoid asthma triggers and achieve asthma control. In The 2017 RTR, payers and physicians also reported that challenges related to trigger identification and avoidance are a top driver of suboptimal outcomes in asthma.

Figure 6: Attitudes about Asthma Triggers (n=60)



Among those who have identified their specific triggers, 40% of patients reported that they were unable to avoid their asthma triggers. Only 20% reported engaging their community in avoiding triggers

Asthma Action Plans

Very few patients have a written asthma action plan

An asthma action plan is developed between the patient or caregiver and their physician, and includes information on how to recognize and respond to worsening asthma symptoms. According to the Asthma and Allergy Foundation, everyone with asthma should have an asthma action plan in writing.[20] The Joint Commission's Children's Asthma Care (CAC) measure set also includes a core measure stipulating that a complete asthma action plan or Home Management Plan of Care (HMPC) be given to the caregiver of eligible patients (hospitalized children with a primary discharge diagnosis of asthma). This has been shown to be a difficult asthma core measure with which to comply, requiring five subcomponents:

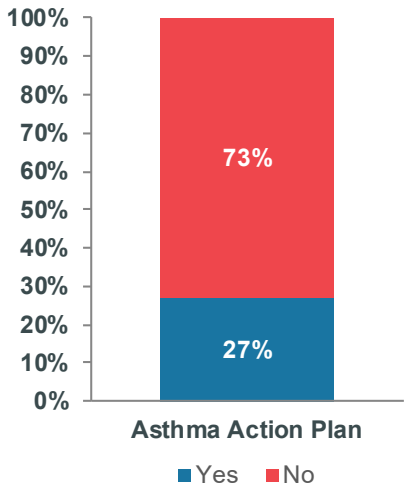
- Arrangements for an appointment for follow-up care (HMPC-1);
- Environmental control and control of other triggers (HMPC-2);
- The method and timing of rescue actions (HMPC-3);
- Name and instructions for prescribed controller medications (HMPC-4); and,
- Name and instructions including stepwise method of adjusting any prescribed reliever medications based on severity of symptoms (HMCP-5).[21]

Only 27% of patients
surveyed in this research reported having a written asthma action plan

Studies have shown that patients with a written asthma action plan have substantially fewer acute asthma events, fewer hospitalizations, and overall better quality of life.[17] However, only one-quarter (27%) of patients surveyed in this research reported having a written asthma action plan. This may represent another opportunity for improvement of asthma management. The majority (68%) of patients with a written action plan agreed that this tool improved their confidence about what to do in case of an emergency, and a similar proportion (60%) indicated that they rely on the action plan when their symptoms escalate.

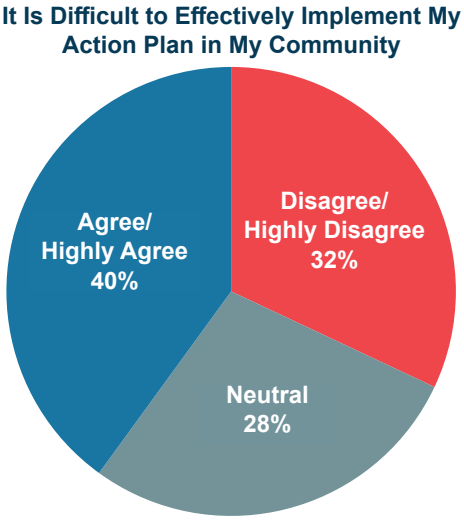
Qualitatively, patients without written asthma plans reported feeling that they "didn't need one" because they had developed a high degree of familiarity with their condition over many years. This attitude neglects that individuals may forget what to do, that treatment plans may change, and that others may benefit from clear, written instructions in case of an asthma-related emergency. In addition, an interviewed caregiver suggested that a written asthma action plan is a useful discussion aid and leave-behind for community stakeholders involved in a child's asthma care.

Figure 7: Percentage of Patients with a Written Asthma Action Plan (N=93)



Only a quarter of all respondents have a written asthma action plan

Figure 8: Percentage of Patients who Agree/Disagree with the Statement (n=25)



40% of patients with an action plan agree that it is difficult to implement in their community

"I have an asthma action plan for my daughter, and she understands it very well. It tells her what levels are and when she needs to get help, when she needs to use her rescue inhaler, or when she or her siblings need to contact a doctor."

– Sarah, Mother

"I don't have a written asthma plan, but informally, I know what to do. I talked about this with the case manager from my insurance company."

– James, Truck driver

Insurer, Specialty Pharmacy & Other Resources

In The 2017 RTR, representatives of payer, specialty pharmacy, and provider organizations reported offering a wide range of resources to patients with asthma, including programs which aim to:

- Improve medication access
- Improve medication adherence
- Provide continuous access to care
- Ensure asthma best practices
- Introduce new technologies

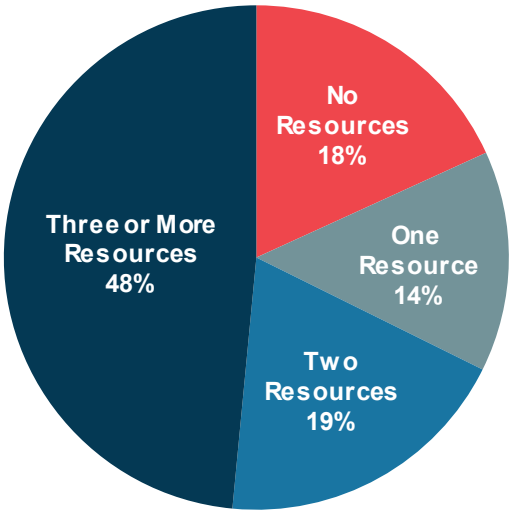
Specific programs and resources, along with the extent to which survey respondents are using them and find them helpful, are reported in Table 3.

Some of the most helpful programs and resources available to patients are under-utilized

Surveyed patients indicated that they are taking advantage of the resources that payers, specialty pharmacies, manufacturers and health systems are making available to them, with **four in five (82%) using at least one and nearly half (48%) using three or more**. The most widely used resources were training on proper inhaler technique (42% of patients using), internet-based communication with their healthcare team (41%) and reminders to get vaccinated (34%). These resources were also widely considered helpful by patients using them.

Some resources used by relatively few patients were considered particularly helpful. These included copay assistance/coupons (25% of patients using), smoking cessation programs (10%), and new technologies (fewer than 20%).

Figure 9: Percentage of Patients Using Insurer, SP & Other Resources (N=93)



Nearly half of all respondents indicated using 3 or more of the patient programs and resources listed. 18% indicated using none

Table 3: Where patients go to learn more about managing moderate-to-severe asthma

Information Source		% of Respondents Consulting (N=93)	% Users Considering "Very or Extremely Helpful"
Medication Access	Verification of insurance coverage	28%	46%
	Copay assistance/coupons	25%	61%
	Manufacturer programs to help you access medications	17%	44%
Medication Adherence	Training on proper inhaler technique	42%	51%
	Reminders to take or fill your medication	30%	57%
	Kits/materials provided along with your medication	13%	42%
Continuous Access to Care	Internet based communication with your care team	41%	32%
	Access to a nursing hotline	20%	32%
	Access to a case manager	14%	8%
Asthma Best Practices	Reminders to get vaccinated	34%	53%
	Programs to help with smoking cessation	10%	56%
New Technologies	Digital inhaler	18%	47%
	Mobile apps to help with asthma management	6%	50%
	Telehealth consultation	6%	50%
		FEWER	MORE

KEY TAKEAWAYS

In The 2017 RTR, stakeholders described a range of challenges related to the management of respiratory conditions. This supplemental report introduced critical patient experiences and perspectives on moderate-to-severe asthma. The data point to several key insights:

- Patients experience serious physical, educational and professional, financial and psychosocial impacts
- Some patients have a false sense of asthma control or reduced expectations for quality of life
- The journey to diagnosis may be long and arduous, and some patients still learn of their asthma severity during an unplanned hospitalization
- Many patients wish to be involved in their treatment decision-making
- Patients may face barriers to accessing therapy
- Despite added complexities of specialty drug fulfillment, patients on injectable biologic therapy are satisfied with the support they receive and obtain therapy with relative ease
- There is still work to be done as it relates to asthma education and self-management, particularly in the areas of trigger avoidance and written asthma action plans
- Many patients take advantage of resources available to them, but some of the most helpful programs and innovations may be under-utilized

It is hoped that this informational resource will advance the dialogue surrounding management of moderate-to-severe asthma, identifying opportunities for improvement of patient care.

REFERENCES

The 2017 Genentech Respiratory Trend Report: Perspectives from Payers, Specialty Pharmacies, Practicing Physicians, and Provider Administrators. 1st ed. South San Francisco, CA: Genentech; 2017.

1. What is Asthma? *National Heart, Lung, and Blood Institute*. August 2014. https://www.nhlbi.nih.gov/health/health-topics/topics/asthma Access Jan 17, 2018.
2. Asthma Costs and Social Impact. *Asthma Research and Practice*. 2017.
3. Most Recent Asthma Data – National Prevalence. *CDC*. June 2017. https://www.cdc.gov/asthma/most_recent_data.htm Access Jan 17, 2018.
4. The Prevalence of Severe Refractory Asthma. *American Academy of Allergy, Asthma & Immunology*. October 2014.
5. Asthma Triggers and Management. *American Academy of Allergy Asthma and Immunology*. https://www.aaaai.org/conditions-and-treatments/library/asthma-library/asthma-triggers-and-management Access Jan 17, 2018.
6. Prevalence of Comorbidities in Asthma and Nonasthma Patients. *Medicine*. June 2016.
7. Describing and Quantifying Asthma Comorbidty: A Population Study. *Public Library of Science*. May 2012.
8. Influence of Comorbid Conditions on Asthma. *European Respiratory Journal*. 2009.
9. The influence of co-morbidity on health-related quality of life in asthma and COPD patients. *Respiratory Medicine*. 2003.
10. Asthma Incidence among Children and Adults: Findings from Behavioral Risk Factor Surveillance System Asthma Call-back Survey. *Journal of Asthma*. January 2012.
11. Severe Asthma in Adults. *American Journal of Respiratory and Critical Care Medicine*. April 2005.
12. Asthma referrals: a key component of asthma management that needs to be addressed. Journal of Asthma and Allergy. July 2017.
13. National Heart, Lung, and Blood Institute. *National Asthma Education and Prevention Program*. https://www.nhlbi.nih.gov/health-pro/guidelines/current/asthma-guidelines. Accessed July 2017.
14. Can shared decision-making between the patient and the healthcare professional help people with asthma? *Cochrane Airways Group*. October 2017
15. Shared decision-making for people with asthma. *Cochrane Airways Group*. August 2016
16. Access to asthma medicines in exchange plans. *Avalere Health*. 2015
17. Supported self-management for asthma. *Breathe*. June 2015.
18. Approaches to Enhancing Reimbursement. *CDC*. 2013.
19. Common Asthma Triggers. *CDC*. August 2012. https://www.cdc.gov/asthma/triggers.html Access Jan 17, 2018.
20. Asthma Action Plan. *Asthma and Allergy Foundation of America*. September 2015. http://www.aafa.org/page/asthma-treatment-action-plan.aspx Access Jan 17, 2018.
21. The Joint Commission's Asthma Care Measure Set: How Does It Measure Up? *U.S. Department of Health and Human Services*. April 2013.

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