ASTHMA SOCIETY OF IRELAND

TOWARDS OPTIMAL SEVERE ASTHMA CARE

RESEARCH REPORT ON THE CHALLENGES EXPERIENCED BY PATIENTS AND STAKEHOLDERS' RECOMMENDATIONS ON IMPROVING SEVERE ASTHMA SERVICES

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EXECUTIVE SUMMARY

An estimated 450,000 people in Ireland currently have asthma[1], with approximately 900,000 people expected to develop the disease during their lifetime. An estimated 3-10% of the asthma population will develop severe asthma[2]. As one of Ireland's most common chronic diseases, asthma puts a significant economic burden on patients, their families, wider society, the health system, and the Exchequer. Due to the additional healthcare needs of severe asthma patients, and the challenges they face in their day-to-day lives, severe asthma can represent an even more profound burden.

The Asthma Society of Ireland's vision is an Ireland where everyone with asthma can live a full and symptom-free life. In pursuit of this vision, the Asthma Society advocates on behalf of people with asthma and delivers supports and services to patients and their families.

By conducting this research, the Asthma Society aims to highlight the particular experiences and needs of people with *severe* asthma, a small subset of those we represent, who can face disproportionate challenges in navigating the Irish health system and, indeed, their daily lives.

It has been directly informed and shaped by insights gathered from those using and delivering Ireland's severe asthma healthcare services, making it the first report of its kind in Ireland. It examines the standard of severe asthma care in Ireland and the challenges faced by patients and their healthcare professionals in optimising that care. Furthermore, it identifies measures to address these challenges through concrete and immediate recommendations to policymakers.

As a matter of urgency, experts underlined the need for Statutory funding to support the establishment and maintenance of a severe asthma registry in Ireland, as a means of enhancing healthcare and health outcomes, and serving as a vital foundation for enhanced research. If done correctly, a registry can provide accurate, valid, reliable and timely information about the severe asthma patient population and about the disease. This, in turn, enables accurate reporting for health service planning and management, and monitoring and improvement of treatment and care of affected individuals[3].

A registry could deliver the evidence base required to underpin the implementation of the recommendations identified in this report, outlined below.

RESEARCH RECOMMENDATIONS

1. **Allocate multiannual funding for the establishment and maintenance of a Severe Asthma Registry**

The Asthma Society calls on Government to provide ringfenced and multiannual funding to support the establishment and maintenance of a Severe Asthma Registry. The annual cost of this measure is estimated at €400,000 - €500,000, which would include costs for 2-3 dedicated staff.

This registry would provide evidence into the prevalence of the disease, the effectiveness of care and treatments, and patient outcomes. This would in turn support a more efficient allocation of healthcare resources, facilitate research and support clinical trials for new treatments, helping to standardise care and tailor strategies to individual patient needs.

Importantly, the registry should be interoperable with the planned introduction of digital health records and, potentially, integrated with the International Severe Asthma Registry (ISAR) to ensure Ireland can exchange learning and best practices through international collaboration.

Critically, a severe asthma registry will provide new evidence which will guide the way for a more data-led and patient-centred approach to severe asthma care. Moreover, it will support the accelerated delivery of further measures, including those recommended below.

2. **Continue to increase the allocated funding for biologic treatments**

Government should increase the funding provided for biologic treatments so that every patient who would benefit from them has access to these life-transforming treatments.

While the high cost of biologics is acknowledged, their effectiveness in improving health outcomes and patient's quality of life is universally recognised by patients and healthcare professionals alike. Increasing the number of patients on biologics could also help reduce healthcare utilisation, such as emergency departments, unscheduled GP visits and hospital admissions, thereby reducing the long-term burden on the healthcare system.

3. **For the HSE to progress the implementation of standardised care protocols**

The Asthma Society calls for a more standardised approach to severe asthma care across each service level of our health system to ensure consistent and effective treatment for all severe asthma patients, regardless of their location or healthcare provider. By establishing and implementing uniform guidelines for referral, treatment, and follow-up care, in primary and emergency services in particular, the HSE can reduce regional disparities and improve health outcomes for patients. A severe asthma registry would greatly inform and enhance this change in approach.

4. **Fund dedicated self-management education and supports for severe asthma patients**

The Asthma Society calls for increased funding to expand its supports for severe asthma patients through the establishment of a dedicated multidisciplinary team to design and deliver dedicated self-management and peer-support programmes. To combat both the personal and financial costs of severe asthma, international guidelines recommend self-management programmes as the norm to help those with chronic disease. Asthma self-management programmes typically include education on the disease, asthma triggers, medications and medication use, inhaler technique, personalised asthma action plans, responding to an asthma attack, and preparing for medical appointments. Across Europe, these programmes have been found to actively empower patients, improve health outcomes, and reduce asthma-related deaths and healthcare utilisation. During the patient focus group conducted to inform this report, participants highlighted the importance of speaking to and learning from fellow severe asthma patients, many commenting that they have never had the opportunity to do so.

5. **Initiate a benefit-cost analysis of full subsidisation of asthma medication, in particular combination inhalers**

The Asthma Society calls on the new government to initiate a benefit-cost analysis to examine the value of full subsidisation of asthma medications, and in particular combination inhalers that contain anti-inflammatory medicine, beyond the scope of a health technology assessment. The HSE estimates that approximately half of all asthma patients do not take their medication as prescribed. Patients routinely report to the Asthma Society that medication cost (€100+ per month) is a preclusive factor in their adherence to treatments. Respiratory experts, working at the coalface of asthma patient care, also highlight medication costs as a decisive factor in patients' ability to manage their disease. A benefit-cost analysis which applies a health economics lens should seek to establish the direct and

indirect costs to the State of reducing asthma medication costs, and in particular combination inhalers, the potential of such a measure to impact adherence rates among the almost half a million people with asthma in Ireland, and explore the efficacy of including asthma in any future subsidisation programmes in light of the HSE review of the Long-Term Illness Scheme.

METHODOLOGY

In a first step, the current status of severe asthma services in Ireland and internationally is set out within a literature review. Moreover, diagnostic pathways, treatment options and, crucially, the individual, societal, and financial impacts of severe asthma are highlighted.

A survey of 273 people with severe asthma and their carers was then conducted, which revealed personal insights into the gaps in the Irish healthcare system, which were then explored in more detail during a focus group of 14 people with severe asthma and their carers. The survey and focus group findings exposed inconsistencies in care standards, diagnostic hurdles, significant financial strain on patients and a lack of understanding of severe asthma in some healthcare settings and workplaces and among the general public.

These findings were in turn presented at a roundtable of clinical experts, made up of specialist respiratory consultant physicians, specialist nurses, and a pharmacist, and while there was broad agreement on the challenges and potential solutions highlighted through the patient engagement, the overwhelming need for a standardised method of collecting and collating patient data on severe asthma, and sufficient resourcing of specialist clinics to manage a registry, emerged as critical measures in healthcare optimisation.

Recommendations arising from the data generated through these methods focus on the systematic collection of data to inform health care planning and delivery, leveraging digital applications and self-management programmes to optimise health outcomes, promoting an awareness of severe asthma as a distinct and debilitating disease, and protecting people with severe asthma from associated social and economic hardships.

The findings and recommendations of these initiatives are brought together in this report with key recommendations, set out above, to be included within the next Programme for Government.

INTRODUCTION

In 2022, 87 people died from asthma in Ireland.[4] Often underestimated and misunderstood as a disease, asthma can not only be gravely disruptive, challenging and at times, frightening for those who have it, but if left uncontrolled and untreated, can be fatal. Tragically, it is estimated that about 90% of all asthma deaths are preventable through appropriate management and care. For people with severe asthma, timely diagnosis and access to specialist care, appropriate treatment, and sustained education to support disease management can have transformative results on their health outcomes and quality of life.

The implementation of Sláintecare, despite not being implemented quickly enough, offers opportunities for enhanced asthma diagnosis and care in the community for many severe asthma patients through the roll-out of the Chronic Disease Management Programme in primary care and multidisciplinary respiratory care hubs across the country. Increased investment over recent years into high-tech biologic therapies for severe asthma, by both the pharmaceutical industry and the Irish State, has offered a growing number of treatment options and enhanced access to these life-transforming drugs, giving hope to patients and their healthcare professionals. Currently available biologic medicines for asthma in Ireland include anti-IgE (omalizumab/"Xolair"), anti-IL5 (mepolizumab/"Nucala"; reslizumab/"Cinqaero"), IL-5 receptor alpha (benralizumab/"Fasenra") and anti-IL-4/IL-13 (dupilumab/"Dupixent") therapies. These are funded either through existing hospital budgets or the High Tech Drug scheme including the Managed Access Protocol. However, access to timely and accurate data and timely and optimal care remains restricted due, in part, to limited funding for these medicines and gaps in the healthcare system. So, before high technology therapies are even considered, patients must first face the challenges of navigating a healthcare system that is not fully fit for their purpose.

This report contains new research into those challenges, and the barriers, delays and misconceptions faced by people with severe asthma in Ireland. Despite the profound and debilitating effects of the disease, patients report that access to treatment and medical support remains inconsistent across health services, highlighting a critical need for improvement. The research acts to counteract the dearth of national data on the disease and the patient population and provide insights and evidence to support policy making and service planning, and to furnish patients - and their healthcare professionals – with a solid foundation from which to advocate for optimised care.

The report contains the perspectives of severe asthma patients and healthcare professionals on existing barriers to optimal severe asthma care and it makes recommendations to government and policymakers on how severe asthma services in Ireland can be optimised.

The Asthma Society of Ireland would like to sincerely thank everyone who shaped, oversaw and participated in this research project for their contributions, insights and time, in particular the patients and healthcare professionals who gave generously of their time.

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LITERATURE REVIEW

An introduction to severe asthma

Definition

Asthma is a complex and variable disease typically involving chronic inflammation of the airways, which may limit expiratory airflow. Symptoms usually include wheeze, shortness of breath, chest tightness, and cough that vary over time and in intensity.[5] In most cases, asthma cannot be cured or prevented, so treatment focuses on controlling it in order to enhance patients' quality of life.[6]

Difficult-to-treat asthma describes asthma that "is not controlled despite high or medium doses of inhaled steroids or in which high doses of treatment are required to maintain an adequate control of the symptoms and to reduce the risk of exacerbations".[7]

The Global Initiative for Asthma defines **severe asthma** as asthma "that is uncontrolled despite adherence with optimised high dose ICS-LABA therapy and treatment of contributory factors, or that worsens when high dose treatment is decreased."[8, 9, 10] However, there is currently no reliable single "standard" diagnostic test.[11] The opinion-leading American Thoracic Society and the European Society have a joint guideline for severe asthma describing it as "asthma which requires treatment with high dose inhaled corticosteroids (ICS) plus a second controller (and/or systemic corticosteroids) to prevent it from becoming 'uncontrolled,' or which remains 'uncontrolled' despite this therapy."[12]

Prevalence in Ireland and internationally

Ireland has one of the highest rates of asthma worldwide. Approximately **450,000 or 8% of the population currently has asthma**, making it the most common chronic respiratory disease in Ireland.[13, 14, 15] Moreover, an estimated 890,000 people in Ireland experience asthma at some stage in their life.[16]

In 2019, the reported asthma prevalence stood at 5.06% across Europe and at 11.25% in the United States, the highest prevalence globally. Asia and Africa had the lowest reported prevalence of asthma at 3.44% and 3.67%, respectively. An examination by Rabe *et al.* in 2023 pointed to the level of Healthcare, Access and Quality (HAQ) as a possible explanation for the geographic distribution in asthma prevalence. HAQ describes the "level of quality and access within the healthcare system"[17] and is particularly important in diagnostic procedures. HAQ is often lower in low- and medium-income countries. However, the authors also point out that "[even] in countries with a higher HAQ, clinicians may struggle to

diagnose asthma and provide care" and that severe asthma, in particular, is frequently misdiagnosed.[18]

Ireland, unlike many European countries, does not have a severe asthma registry. It is estimated that between **3% and 10% of asthma patients worldwide suffer from severe asthma**.[19] The severe asthma population in Ireland could, on that basis, be conservatively estimated at least to be 13,500.

The UK Severe Asthma Registry has been collecting standardised data on patients in England, Scotland, and Northern Ireland who were referred to specialist asthma services since 2015. The availability of a registry means that it is possible to categorise the patient population, standardise high-quality care, and facilitate research into the assessment and clinical management of the disease.[20] Other countries with a severe asthma registry in Europe include Spain, Italy, Norway, Germany, and Poland.[21]

The lack of quality data here in Ireland represents a significant challenge to optimising care. A severe asthma registry could provide accurate, reliable and more up-to-date information about the treated and not-yet-treated patient population, and the disease. Data like this would significantly enhance research, health service planning and management and, crucially, treatment and care for people with different forms of severe asthma. The International Severe Asthma Registry (ISAR) offers a potential solution to Ireland's registry requirements. It is a global collaborative initiative to gather anonymous, longitudinal, data for patients with severe asthma.[22] Irish integration with ISAR could provide a reputable and relatively low-cost, efficient and effective solution.

<u>Demographic information on affected populations</u>

Asthma tends to be more prevalent among children than the wider population. 1 in 5 children in Ireland experience asthma at some stage in their life[23], making it the most common chronic disease in children.[24]

Risk factors for developing asthma include maternal smoking (in utero), parental smoking (post-natal), occupational exposure to pollutants, a family history of asthma, pre-term birth, low birth weight, exposure to infections early in life and adverse environmental conditions. Asthma can be triggered by various factors, including cigarette smoke, viral respiratory infections, exercise, exposure to allergens, drugs, foods, medical conditions or exposure to irritants.[25]

For patients with uncontrolled or poorly managed asthma, non-adherence to inhaled therapies or poor inhaler technique often play a role. Other factors include insufficient education on their disease/medications/triggers, limited access to medical experts, low

health literacy, age and socio-economic status. Equally, of course, physiological factors may also play a critical role. Gosai *et al* note that there is a need for an objective monitoring in asthma and the treatment strategies need to be modified accordingly[26].

Asthma control and the success of asthma treatments can also be influenced by numerous comorbidities. Some of the most significant comorbidities include allergic rhinitis, chronic rhinosinusitis, gastro-oesophageal reflux disease (GORD), obesity, chronic pulmonary obstructive disorder (COPD), allergic bronchopulmonary aspergillosis, bronchiectasis, obstructive sleep apnoea syndrome, type 2 diabetes mellitus, inducible laryngeal obstruction, dysfunctional breathing, and anxiety and depression. Symptoms typical of these conditions often overlap with one another and their frequent coexistence create diagnostic challenges. Where comorbidities can be remedied, asthma control, exacerbation frequency, lung function and quality of life often improve.[27]

Pathways towards a severe asthma diagnosis

Diagnosing severe asthma

The respiratory community is yet to come to a consensus on how to diagnose asthma.[28] In the national End-To-End Model of Care for Asthma in Adults, the HSE also notes that no gold-standard diagnostic test exists for either severe or difficult-to-control asthma. This is due to severe asthma resembling a syndrome rather than a single disease entity.[29]

The International European Respiratory Society / American Thoracic Society guidelines on severe asthma recommend a three-stage diagnostic process. In the first instance, the patient's asthma diagnosis will need to be confirmed and managed by an asthma specialist for more than three months in order to minimise the impact of comorbidities, eliminate any non-adherence and, in turn, confirm whether a case involves difficult-to-treat asthma.

Once a case of difficult-to-treat-asthma is identified, the patient's response to a high dose inhaled corticosteroids plus a second controller is examined. This step aims to identify severe asthma: such patients will either depend on therapy of this type to prevent their condition from becoming uncontrolled or their asthma will remain uncontrolled despite this therapy.

In a third step, tests are undertaken to examine whether the severe asthma is controlled or uncontrolled. A patient's severe asthma is uncontrolled if one of the following criteria is fulfilled:

1) poor symptom control, i.e. Asthma Control Questionnaire (ACQ) consistently 1.5 or Asthma Control Test (ACT), 20 (or ''not well controlled'' by National Asthma

Education and Prevention Program or Global Initiative for Asthma guidelines over the 3 months of evaluation[30, 31]).

2) frequent severe exacerbations, defined as two or more bursts/courses of systemic corticosteroids (each course at least 3 days long) in the previous year;
3) serious exacerbations, defined as at least one hospitalisation, intensive care unit stay or mechanical ventilation in the previous year;
4) airflow limitation, i.e. forced expiratory volume in 1 s (FEV1) of 80% predicted (in the presence of reduced FEV1/forced vital capacity (FVC) ratio defined as less than the lower limit of normal) following a withhold of both short- and long-acting bronchodilators.[32]

Diagnostic challenges

Diagnostic challenges continue to persist in Ireland and misdiagnosis of asthma occurs frequently.[33] This is due to a number of factors, including the overlap in symptoms between asthma and other conditions, as previously referenced and suboptimal implementation of pulmonary function testing for confirmation of the diagnosis.

As the most common chronic respiratory condition in Ireland, patients with suspected asthma generally present first in a primary care setting. Kavanagh *et al*. note that in these scenarios medical professionals may fail to correctly recognise asthma symptoms, leading to both under- and overdiagnosis of asthma. According to the Global Initiative for Asthma, of the 12–50% of people assumed to have severe asthma, asthma is not found to be the correct diagnosis.[34]

A patient-reported study in Denmark and Sweden found long paths towards a diagnosis to be common, with some patients reporting a delay of over 10 years. Both patients and physicians experienced difficulty in relating reported symptoms to asthma and, on average, study participants were aged 23 years when receiving an asthma diagnosis and 33 years when receiving a severe asthma diagnosis.[35]

Healthcare professionals depend on the accuracy of patients reporting symptoms. The Irish College of General Practitioners cautions that many patients under-report their asthma symptoms, which impacts the accuracy of diagnostic assessments and can lead to asthma cases going undiagnosed.[36] Insufficient access to diagnostic tools in primary care can contribute further to misdiagnosis[37] and missed diagnoses.

Once referrals to specialists are made, they can involve lengthy waiting periods where the patient remains under the care of their GP. As such, education is essential for healthcare professionals, especially in primary and emergency care.

Access to specialist care

Monthly waiting list data collected by Irish hospitals shows that significant numbers of patients are required to wait for prolonged periods to access specialist respiratory care. These figures have steadily increased in recent years and, as of May 2024, over 11,000 patients had been waiting 6 months or longer to be seen by a respiratory specialist.[38]

A 2023 study of these figures found that asthma control accounted for approximately 1 in 10 of referral indications. Researchers concluded that large numbers of patients referred to general respiratory clinics had not undergone any initial diagnostic tests and that better community access to diagnostic tools could alleviate pressure on the waiting list and reserve specialist care for complex cases.[39]

Research conducted by the Irish Lung Health Alliance in 2022 highlighted the issue of under-resourcing in respiratory services, which conduct pulmonary function tests (PFT), an important diagnostic tool for asthma and severe asthma. The survey which examined resourcing levels in 19 of the 33 pulmonary function laboratories in Ireland, found that two-thirds had vacancies for respiratory physiologists, with most of them having multiple vacancies.[40]

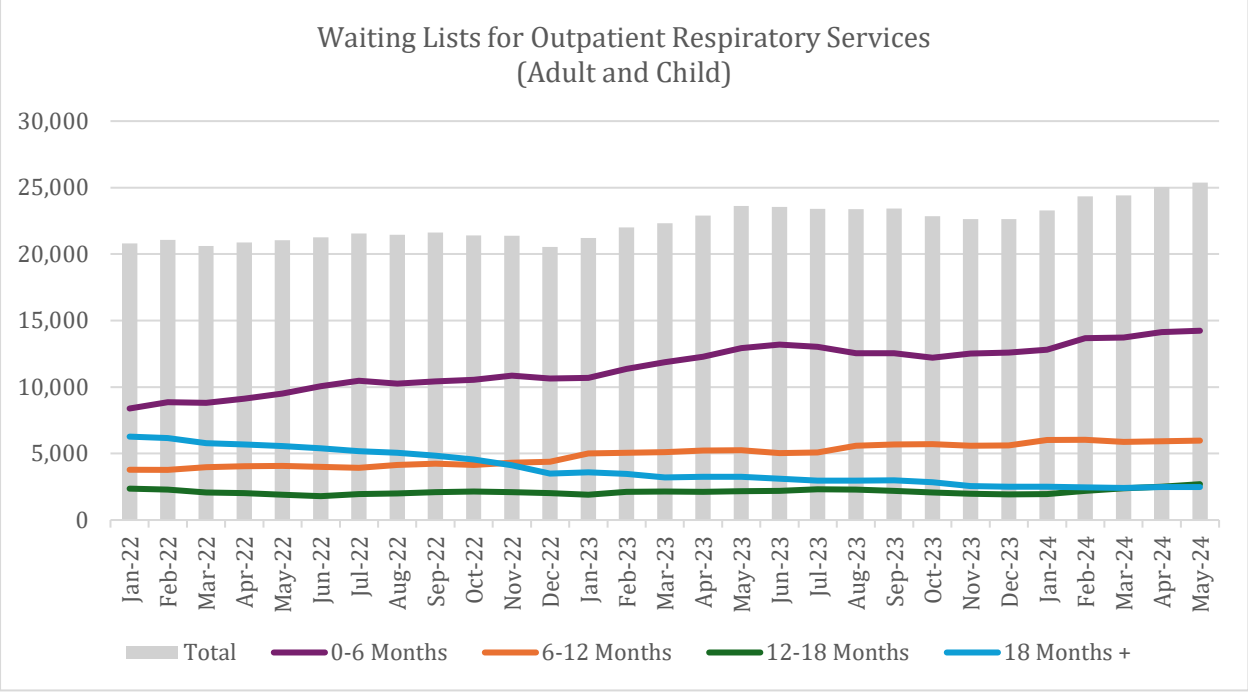
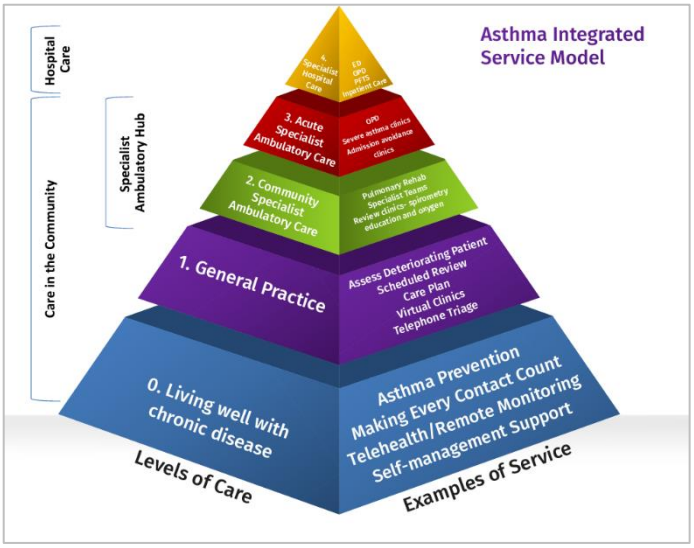


Figure 1: Waiting lists for outpatient respiratory services (Data from the National Treatment Purchase Fund 2024)[41]

In response to these challenges, the HSE is rolling out the Enhanced Community Care Programme (ECCP) which, in line with Sláintecare priorities, has seen the establishment of integrated care hubs across the country. These new ambulatory care hub pathways include community-based respiratory specialist teams who provide asthma management services in an enhanced primary care setting. The hubs also offer specialist multi-disciplinary care for patients with severe and complex asthma.[42] GPs can refer their patients directly to the hub, thereby avoiding hospital waiting lists.[43] The roll-out of the ECCP has already begun to yield positive results. The Galway City Integrated Care Hub, for example, has achieved positive results, cutting waiting times for respiratory conditions to a mean of 6 weeks.[44]



Once an adult patient has received a formal severe asthma diagnosis, care is provided through a severe asthma centre, such as the severe asthma clinics in Cork University Hospital, Galway University Hospitals, University Hospital Limerick, Letterkenny University Hospital, St. Vincent's University Hospital, Beaumont Hospital, Tallaght University Hospital, Mater Misericordiae University Hospital, and St. James's Hospital, Dublin among others. Severe asthma clinics must fulfil these criteria[45]:

- A stand-alone clinic with at least one Consultant Respiratory Physician with an interest in severe asthma.
- Capacity to review patients in a day unit or similar to provide expert care.
- Facilities to provide patients with high-cost novel biological therapies that are currently in clinical trials.

Medications and Treatments

Asthma medication

Asthma can be managed through a combination of treatments, and frequently this includes different types of asthma inhalers.

Controller inhalers (or preventer inhalers), on the other hand, are often prescribed for use once or twice a day and work by reducing inflammation of the airways gradually. They

contain a very small amount of steroids, which treat inflammation and have minimal side effects such as voice weakness and oral thrush compared to swallowing oral steroid pills.

The newly developed **combination inhalers** combine different forms of medication with inhaled steroid, specifically for patients whose asthma is not controlled. Certain types of combination inhalers, when used as part of an asthma treatment plan are called maintenance and reliever therapy or **MART**.

Reliever or rescue inhalers help to relieve symptoms during an asthma attack by relaxing and widening the airways. They are also called 'blue inhalers' and should not be used more than twice per week. The Asthma Society of Ireland and the Global Initiative for Asthma (GINA) have warned of the risk of overreliance on traditional reliever/rescue inhalers as they do not treat the underlying inflammation of the lungs and can increase the risk of an asthma exacerbation or even asthma death if overused.[46, 47] A preferred approach in GINA guidelines, and in UK guidance from BTS/SIGN/NICE for initial reliever choice is to use an anti-inflammatory reliever or AIR, a type of combination inhaler. This reliever type combines quick-acting airway widening medication with very small amounts of steroid, to be used within a range of daily doses that are guided by a written asthma action plan. Compared to traditional "blue inhaler" relievers, they dramatically lower the rate of asthma exacerbations and hospitalisations, and improve patient adherence to correct asthma medication. Furthermore, they are more cost-effective compared to alternatives.

A "spacer" device can be used with a metered dose inhaler to improve medication delivery to the lungs.[48]

Other types of asthma medication include **leukotriene receptor antagonists** (LTRAs) that are taken daily, and typically in tablet form. LTRAs help reduce inflammation of the airways. They have rare neuropsychiatric side effects. Where symptoms remain uncontrolled, patients may be prescribed **steroid tablets**. Steroid pills (also known as oral corticosteroids) are an anti-inflammatory medicine prescribed for a wide range of conditions, including asthma and COPD. They are mainly used to reduce inflammation and suppress the immune system. They are an effective and inexpensive treatment for asthma and short courses are commonly used to treat asthma flares. However, due to associated side effects, it is advised that they are prescribed at the lowest effective dose for the shortest possible time. Steroid tablets have been sometimes prescribed as part of daily maintenance therapy for patients with severe asthma. Potential side-effects of frequent or prolonged use of the treatment include cataracts, glaucoma, hypertension, Diabetes, depression, adrenal suppression and osteoporosis.

Severe asthma medication

Typically, severe asthma patients continue to experience severe and/or inadequately controlled symptoms despite adherence to many of the above treatments. Wenzel *et al.* note that based on clinical characteristics, severe asthma can be categorised into two inflammatory reactions, Type 2 high expression and type 2 low expression, with high and low eosinophils, respectively.[49] The 'type-2' or 'T2' immune pathway is recognised as the dominant inflammatory pathway underpinning severe asthma and in recent years, several **targeted biologic therapies** have been developed which reduce airway inflammation associated with the T2-high endotype without the side effects caused by steroid tablets. According to Hearn *et al.*, "these therapies have transformed the lives of many people with severe asthma and have significantly reduced their steroid burden."[50]

In Ireland, biologic medicines for asthma have been available for two decades. The first of these to have been available, Omalizumab (Xolair®) is funded from within the prescribing hospital's own medicines budget. The biological therapies Benralizumab (Fasenra®), Mepolizumab (Nucala®) and Reslizumab (Cinqaero®) are approved for reimbursement and can be accessed only through a Managed Access Protocol (MAPs), overseen by the Acute Hospital Drug Management Programme. Dupilumab (Dupixent®) is reimbursed on the High-Tech Arrangement since November 2023 and also involves MAP for the treatment of severe asthma. In all cases, patients must meet a set of eligibility criteria, based on a specialist assessment, and applications can only be submitted by a Consultation Respiratory physician within a recognised asthma centre that specialises in severe asthma.[51, 52] The treatment is administered as an injection in a healthcare setting. While these biologic treatments can decrease the need for hospitalisation and doctor visits by up to 50% (by even more in real-world studies), they are costly. The Asthma Society of Ireland has been calling for continued expansion of State investment to ensure that every patient who would benefit from biologics can access them in a timely manner.[53]

Medication adherence and Self-Management

Only 50% of the overall asthma population is reported to adhere to their treatment. Contributing factors can be poor inhaler technique, the cost of inhalers, insufficient education on the various inhalers, a perception that treatment is not needed and confusion about the correct dose. This challenge drives the number of uncontrolled asthma cases and increases hospitalisation rates.[54] The patient plays an important role in diagnosis, which relies, in many respects, on their ability to self-advocate and report symptoms, which in turn informs treatment. Where optimal treatment is not achieved, disease management is inevitably compromised. For some severe asthma patients, there can be an assumption at

primary care level that their worsening symptoms and diminishing health is a result of poor adherence. Standardised protocols for severe asthma in the primary care setting, including signs and indicators of severe asthma, would support earlier detection and referral. The Irish College of General Practitioners has produced a guide for asthma in 2020 that includes aspects of severe asthma care. Ongoing Self-Management education for people with asthma, such as that delivered by expert nurses on the Asthma Society's free Adviceline and WhatsApp messaging service, significantly enhances health literacy and self-advocacy.

The impact of severe asthma

Severe asthma not only represents a challenge for the health system and for patient's health but can also cause significant financial constraints and limit personal, social, family and work life.

The economic cost burden

In 2017, the total cost of asthma in Ireland was estimated to stand at €472 million, which translates to €1,242 per person. A quarter of this cost (€116 million) arose from treating asthma in hospitals, including specialist/consultant care, emergency department and hospital stays. There were 133,000 asthma related visits to the emergency department and close to 8,000 asthma-related hospitalisations. Primary care services for asthma patients cost the Irish State approximately €108 million in 2017. Medication accounted for ca. €45 million in spending with 44% of these costs attributed to preventer treatments.

While the health economics literature frequently focuses on asthma, little research currently exists on the costs of severe asthma in Ireland. Severe asthma patients interact more frequently with the healthcare system and biologic therapies comes at a substantially higher cost than other asthma medications. Severe asthma patients treated with maintenance steroid tablets are at increased risk of developing additional comorbidities that require supplementary healthcare. As a result, severe asthma patients account for a disproportionally high share of the economic burden of asthma on the State. According to one study on severe asthma in South Korea, despite only one in ten asthma patients suffering from severe asthma, it is estimated that they account for more than half of all costs of asthma treatment.[55] Improving access to combination inhalers would drive down costs and off-set the cost of subsidising these effective medications in severe and difficult-to-treat asthma.

Societal costs

The impact of severe asthma goes beyond the economic burden. People with severe asthma are at greater risk of experiencing asthma flares, sometimes limiting day-to-day activities.[56]

Severe asthma symptoms, the risk of exacerbations and regular hospitalisation can restrict patients in their ability to participate in employment, family life, social activities, sports or travelling. The social life of severe asthma patients was especially limited throughout the Covid-19 pandemic when patients were asked to 'cocoon' for prolong periods to avoid infection.[57] Cold or hot ambient air temperatures, spikes in poor air quality and high pollen levels can all act as triggers and restrict patients' ability to be outdoors.

The physical and mental health burden

In their exploration of severe asthma patients perspectives of living with severe asthma in Denmark and Sweden, Papapostlou *et al*. highlight that a "[a] common goal for patients and health care is that patients get empowered to live a life free of disease symptoms, and to reduce the number of hospital and emergency care visits, the loss of school and workdays, and the constraints placed on the patients' daily lives"[58]. The paper notes the long wait times for severe asthma specialist appointments, which negatively impact patients' physical and mental wellbeing. The authors also highlight that all patients interviewed in their research reported restrictions on their daily life, including on travel, social life, household chores and having to plan around their condition to prevent any further deterioration. Most notably, respondents reported "feelings of fear, frustration, hopelessness and anxiety"[59]. Additionally, 23 of the 33 interviewed patients reported that they experienced panic if they did not have access to their short-acting bronchodilator (rescue inhaler).[60]

Patients also shared that they did not expect their symptoms to improve, and that the effect their treatment had on their symptoms was minimal. Patients reported feelings of frustration, anxiety, and in isolated cases suicidal thoughts. Respondents would have "appreciated access to professional psychology support"[61], with only one respondent being offered this service. The paper alluded to the vast number of respondents that reported fears of dying, anxiety, social isolation, and depression, pointing to "undiagnosed conditions secondary to severe asthma burden on psychological well-being"[62]. The paper concludes that its findings identify the need for a varied plan which covers a structured patient education, raised awareness of the disease as well as access to other healthcare professionals who have a deep understanding of the disease.[63] In the focus groups session conducted as part of this research, many of these perspectives were echoed.

Remedial measures identified through the Literature Review

Public awareness and education

Urrutia and Resler found that individuals experiencing severe asthma tend to underestimate the disease and once diagnosed 20% of patients underestimate their asthma severity, resulting in disease denial and passivity. Similarly, physicians may also find it challenging to

correctly categorise a patient's symptoms and make a correct diagnosis, pointing to a need for further awareness among medical staff. Several authors also stressed the importance of increasing the general public's awareness of severe asthma as a severe chronic disease.[64] Pinnock *et al*. point out that approaches which "explicitly address patient education, professional training and organisational commitment are associated with improvement in process measures, markers of asthma control and reduced use of unscheduled healthcare.[65]

Severe asthma registry

Unlike many other countries, Ireland currently does not have a severe asthma registry, which means stakeholders rely on estimates and indicative data in external jurisdictions. The dearth of reliable and up-to-date Irish data has inevitably hampered the researcher in completing the literature review and has substantial implications outside this context. Introducing a registry of persons diagnosed with severe asthma would allow for better tracking of the incidence, prevalence and clinical features of severe asthma in the Irish population. This could help inform decision-making of stakeholders in the health service and in government. It could also provide academia with more reliable data for the purpose of accelerating research into severe asthma in Ireland.

Leveraging digital applications

A recent study, co-developed by Royal College of Surgeons Ireland and Trinity College Dublin, tested the use of digital technology to provide an objective assessment of how patients use their inhalers by measuring acoustic or sound-wave signals from the inhaler. Data collected by the so-called "INCA" device is sent to the patient's healthcare provider through a digital clinical decision platform which advises the best treatment. By monitoring and improving medication adherence, the Inhaler Adherence in Severe Unstable Asthma (INCA-SUn) study has shown promising results in helping to distinguish between patient participants with severe asthma and difficult-to-treat asthma.[66] The study has also unearthed previously largely unexplored factors in poor adherence, such as neurodiversity. The study, published in *The Lancet Respiratory Medicine*, shows the potential new technologies hold for asthma care in Ireland.

Self-management programmes

To combat both the personal and financial costs of severe asthma, international guidelines recommend self-management programmes as the norm to help those suffering from asthma. Self-management programmes typically include education on asthma triggers, medications and medication use, inhaler technique, action plans, how to respond in an asthma attack and preparing for medical appointments. It is noted that across Europe these programmes have actively reduced asthma related deaths; and are designed to reduce the cost and

remove pressure from primary and secondary healthcare, whilst actively empowering the patient and reducing the patients' overhead costs too. This also frees up capacity in the healthcare system for more severe cases.

Financial supports for severe asthma patients

The cost of asthma medication is preclusive to a significant number of patients, leading to an unmet need in the Irish patient population. Subsidisation of asthma medications could improve equitable access to treatment. One way to do so would be the inclusion of asthma on the list of conditions applicable to the long-term illness scheme, or future iterations of the programme.[67]

SURVEY ON THE EXPERIENCES OF PATIENTS

Overview and methodology

Building on the findings of the literature review, a survey was conducted to gather up-to-date quantitative and qualitative insights from adult patients and carers of children with severe asthma in Ireland. The purpose of this survey was to collect data in Ireland on the key challenges facing those with severe asthma and the solutions which should be addressed at the policy and clinical level. The findings of this survey subsequently informed a patient focus group and a roundtable of healthcare professionals and experts.

The survey was targeted at adult patients and parents/carers of children with severe asthma in Ireland. Patients included those with a formal diagnosis (i.e., diagnosed by a GP, specialist, or specialist nurse with severe asthma) and those that fulfil a certain set of criteria but have not been formally diagnosed at this stage. These criteria were set by the Asthma Society's Medical Advisory Group and contacts were sourced via the Asthma Society. Typeform was used to conduct the survey.

A total of 273 responses were collected between 22 and 30 August 2024, of which 248 were qualified responses. Of those qualified responses:

- 81% were from participants answering for themselves, and 19% from participants answering on behalf of someone else.
- 91% had a formal diagnosis, and 9% did not but fulfil one of the following criteria:
    - To keep my / their asthma controlled, I / they need treatment with high dose inhaled steroids, plus a second controller inhaler and / or steroid tablets.
    - My / their asthma is still not controlled with high dose inhaled steroids, plus a second controller inhaler and / or steroid tablets.

Findings

The impact of severe asthma on patients' well-being and quality of life

Severe asthma is a life-threatening condition that has a downstream impact on the patient's overall well-being and quality of life.

- Co-morbidity is common amongst severe asthma patients, with nearly four in five (78%) saying they have been diagnosed with another condition or multiple other conditions. The most common ones are allergic rhinitis (hay fever – 48%), gastro-oesophageal reflux disease / gastric reflux (31%), and anxiety (22%). This means poor

or lack of support for severe asthma can have a ripple effect on the other conditions the patients are experiencing.

- Moreover, severe asthma can potentially limit a patient's ability to manage their other physical and mental health conditions. Nearly seven in ten (69%) respondents report that severe asthma is affecting their ability to physically exercise[1] which is important for the management of noncommunicable diseases and a person's physical and mental well-being[68]. One in three (36%) say that their social life is being impacted by their severe asthma, which can further complicate the management of mental health conditions such as anxiety and depression, as social support is a key factor in the coping and improvement of mental health issues[69].
- Additionally, severe asthma affects not just the patient's health but their overall quality of life. Patients have expressed asthma affecting their ability to undertake daily tasks including household chores (40%) and holding down full-time employment (19%), suggesting these patients need additional support to improve their lifestyle quality.
- Amongst those who remember how many times over the last 12 months they have visited a GP or other healthcare specialist due severe asthma, the average number is 7 times.
    - 12% of them have visited a GP or other healthcare specialist 12 times or more – i.e. more than once a month.
    - *Please note that one person answered 70 times which may or may not be an exaggeration. If this answer is excluded, then the average is 6.*
- Amongst those who remember how many times over the last 12 months they have had to attend an emergency department due severe asthma, the average number is once.
    - 44% of them have not had to visit the emergency department over the last 12 months.
    - 56% have had to visit the emergency department at least once.
    - *Please note that one person answered 18 times which may or may not be an exaggeration. If this response is included, then the average number of times is 2.*

[1] See appendix for a more detailed breakdown of how severe asthma affects a patient's life.

Diagnosis and access to treatment

Getting a diagnosis of severe asthma can be a pain point for patients as patients don't feel that GPs take the conditions seriously or have the knowledge to make an early diagnosis. And getting referred to a specialist can be a lengthy wait.

- Patients have a mixed experience of receiving their diagnosis. For those with positive stories, the process is typically very smooth, with referrals being made to specialists in a timely manner. Negative experiences tend to revolve around low awareness of the GPs about the condition, leading to slow diagnoses or sometimes misdiagnoses. Some patients had to change doctors in order to get the right opinion and treatment needed.
- Amongst patients who received their diagnosis later than when their symptoms first appeared, the average delay is 6 years.
- Patients have shared their experiences of their diagnosis journey:

  "Confusion, mixed opinions, differing diagnoses leading to uncertainty and frustration."

  "Difficult, took 10 years to be given correct medication, and later when asthma worsened it took another 2 changes of doctors before I was sent to a specialist."

  "Slow, reluctant."

Despite the impact severe asthma can have on a person's health and quality of life, access to treatment and medical support is inconsistent, leading to an overwhelming agreement that improvement is needed.

- More than four in five (86%) say that improvements are needed in relation to patients accessing severe asthma treatment in Ireland.
- Responses are largely mixed in terms of the level of knowledge healthcare professionals have regarding severe asthma, with 40% saying it's good / excellent, 48% saying the level of understanding and awareness is OK, and 28% saying it's poor / terrible.
- Long waiting time is the most common issue, and this can happen at every stage of the patient journey. Those who have waited a long time to see a GP about their condition might then have to wait even longer to get referred to a specialist. Access to certain tests, such as lung function test and X-rays, and approval for treatments,

such as biologics, can also take time. Patients have shared their experiences of their treatment journey:

"[I was] waiting in the hospital for 6 hours."

"I was back and forth with a nurse every couple of months and about 1 year till I started seeing a consultant."

"The journey of waiting for [a biologic] was long and hard."

- As a result of the variations in HCP knowledge and the long waiting time in general, respondents expressed mixed levels of confidence in the Irish healthcare system's ability to provide adequate care for severe asthma patients. Nealy half (48%) say they are not confident, 23% say they are neither confident nor unconfident, and only 29% say they are confident.

For a substantial portion of the patients, financing their own medications can be challenging, which further worsens the inequality of access.

- Whilst a significant portion (57%) of respondents reported having never experienced financial difficulties with their asthma medications, a substantial minority (42%) have faced challenges in paying for their treatment.
- Notably, one in five individuals has struggled to afford their medications more than three times (included in the 42%).

Education on severe asthma

Education regarding severe asthma is crucial for patients, HCPs, and the general public. This will ensure that patients are aware of treatment and supports available, that HCPs and society at large take the condition seriously and know what to do in critical situations, and that social stigma is tackled. Efforts put into education can then have a ripple effect – for example, when healthcare professionals are better educated on severe asthma, they can then provide patients with more information on how to manage their condition and the available treatments.

- Educate patients on symptoms and available treatment or support.
    - Two in five (45%) say they do not currently have or use an Asthma Action Plan. This is particularly concerning given that nearly two in three patients surveyed could be at risk of an asthma exacerbation – 63% say they have used

3 or more canisters of reliever inhalers over the last 12 months, a known risk factor for asthma death.

- Access to information is unequal as 39% say it is difficult to find reliable information on severe asthma, whilst 36% say it is easy to find reliable information.
- Patients have shared experiences and suggestions regarding the need for better education:

  "GPs need to be better trained in providing their patients with more information about the condition and possible treatments especially when initially diagnosed."

  "More time should be spent explaining to parents and patients… on how to use inhalers and the symptoms to look out for when to bring a person to hospital."

  "I had mild symptoms for 12 years and never knew it."

- Educate HCPs so that they take the condition seriously, and can offer the help patients need, especially in life-threatening situations:
  - Patients have shared experiences and suggestions regarding the need for better education:

    "I've been told several times by medical professionals "to just breathe" when I'm having an attack which is very unhelpful and causes anxiety as it feels like they think I'm faking."

    "I think that if [an asthma patient] feels an attack coming on, either the GP or pharmacist should be more attuned."

    "GPs [should have] more knowledge on the types of inhalers available."

- Educate the general public so that they can help a patient in need. This can also potentially help with the social stigma associated with the condition.
  - Patients have shared experiences and suggestions regarding the need for better education:

    "Education for schools / work for how to help if someone is on asthma flare / attack."

    "Asthma needs to be taken more seriously within our schools and sports clubs."

"I know years ago I was at an event again organised by the Asthma Society who went through the inhalers, their purpose and proper use, but again the HSE or government never educates the public on this. More awareness is required and highlighted."

- Two in five (44%) say there is a social stigma associated with severe asthma.

<u>The need for more attention from the government</u>

Perceived to be at the root of the unequal access to treatment and support and the lack of education is a lack of appreciation for the seriousness of the disease within government and in the healthcare system.

- The overwhelming majority (86%) agree that severe asthma is not receiving enough attention from politicians and the Department of Health and is not recognised as a priority by them.
- To show that severe asthma is taken seriously by the government and the healthcare system, respondents made the following suggestions based on the open-ended responses:
  - Medical cards should be made available to all severe asthma patients.
  - Availability of specific medications or treatments, in particular biologics, needs to be improved, such as through optimising the eligibility criteria.
  - Cost of medicine should be covered by the government as it's a chronic condition and can be financially draining for the patients.
  - Specialists should be made more available, such as through opening more asthma clinics.
  - Access to lung function tests needs to be optimised.

Conclusion

Severe asthma is a life-threatening condition that significantly impacts patients' overall well-being and quality of life, with a high prevalence of co-morbidity among sufferers. Despite its profound effects, access to treatment and medical support remains inconsistent, highlighting a critical need for improvement.

Diagnosis of severe asthma presents a considerable challenge, as GPs have often been reported by respondents to lack the necessary knowledge to make early diagnoses or may not take the condition seriously, and referrals to specialists can involve lengthy waiting

periods. As such, education is essential for healthcare professionals (HCPs), especially for primary care.

Additionally, respondents see value in educational programmes to ensure that patients are informed about available treatments and support, and that society recognises the severity of the condition and knows how to respond in critical situations, and that social stigma is addressed.

Respondents have provided suggestions to tackle unequal access to treatment and support, as well as the lack of education, such as making medical cards available to all severe asthma patients, and improving the availability of specific medications or treatments, in particular biologics by reforming eligibility criteria.

FOCUS GROUP OF SEVERE ASTHMA PATIENTS

Overview and methodology

On September 5th, 2024, the Asthma Society of Ireland conducted an online focus group which convened adults living with severe asthma and carers of children living with severe asthma in Ireland. Approximately 14 female participants of various ages joined the session, which was moderated by Eilís Ní Chaithnía, CEO of the Asthma Society of Ireland. The participants consented to the recording of the conversation and were informed that all contributions would be anonymised.

The aim of this discussion was to better understand the key challenges facing those with severe asthma and gather their recommendations on how issues can be addressed at the policy and clinical level. The participants shared their personal experiences and details of their medical history, including their journeys towards diagnosis, optimal treatments, their interactions with the healthcare system and the impact of the condition on their daily lives.

Challenges faced by patients

The focus group discussion revealed several key challenges that patients and their carers face while dealing with this chronic condition.

Diagnosis and treatment

A majority of participants reported ***difficulties in obtaining a timely and accurate diagnosis***. Many participants shared experiences of delays, with some waiting several years before being accurately diagnosed with asthma. One participant recalled that they were:

"told it was all in [their] head and that [they were] just stressed. It took a long time before anyone took [their] symptoms seriously."

This delay often resulted in prolonged suffering and inadequate treatment, as patients were misdiagnosed, or their symptoms were attributed to other causes such as anxiety or incorrect inhaler use. Delayed diagnosis not only exacerbates the condition but also leads to frustration and a sense of helplessness among patients.

Participants shared ***distressing experiences of visiting emergency departments***, where they faced long waits, inconsistent treatment, and sometimes a lack of understanding from medical staff about the severity of their asthma. One participant recalled their experience:

“I had terrible experiences in the emergency department. They don't seem to understand how serious my asthma is”

Highlighting how co-morbidities impact severe asthma care, another added: *"I've been screamed at by a doctor in relation to chronic pain that it was all in my head when it wasn't."*

The lack of standardised care protocols in emergency departments means that patients may not receive the prompt and appropriate treatment they need during an asthma attack. These negative experiences in emergency departments add to the overall stress and anxiety experienced by patients.

The ***inconsistency in asthma care across different healthcare settings*** poses another significant challenge. Participants expressed that the quality of care varied significantly depending on the healthcare provider or location.

"The care I received varied so much depending on which doctor I saw. There needs to be a uniform approach to asthma care."

This lack of standardised care means that some patients receive optimal treatment while others do not, leading to disparities in health outcomes. The need for a uniform approach to asthma care was a recurring theme in the discussion, with participants advocating for consistent treatment protocols and access to specialist care.

Participants expressed concerns about ***inconsistent practices in follow-up care*** after the initial diagnosis and treatment. In the experience of patients, asthma is often managed on a crisis basis rather than through regular monitoring and management.

"After my diagnosis, there was no follow-up. I was left to manage my asthma on my own."

This approach leaves patients to manage their condition on their own, without the necessary support and guidance from healthcare providers. The absence of regular follow-up care can lead to poorly controlled asthma and an increased risk of severe asthma attacks.

The ***high cost of medication*** was a significant concern to participants. Many patients struggle to afford their medication, impacting their ability to manage their asthma effectively with a patient noting that:

"The cost of my medication is a huge burden. I sometimes have to choose between paying for my meds and other essentials."

Another participant added: *"The cost of medication is a huge burden. We need financial support to make it more affordable."*

The financial burden is particularly challenging for those who need to reduce work hours or stop working due to their condition. The high cost of asthma medications adds to the stress and anxiety experienced by patients, further affecting their quality of life.

Some participants discussed the ***challenges in accessing biologic treatments***, which require the patient to meet certain medical criteria before they could be approved for reimbursement and may not be readily available or covered by insurance. Biologics can be highly effective in managing severe asthma, but the barriers to access mean that not all patients can benefit from these treatments. The limited availability and high cost of biologics further contribute to the challenges faced by patients with severe asthma.

Awareness and education

Several participants recounted instances where their symptoms were not taken seriously by doctors or were attributed to other causes. This points to ***awareness and knowledge gaps among medical staff***, which lead to a lack of trust in the medical system among patients and further delays in receiving appropriate care. It was pointed out that female patients may be more likely to be dismissed or not taken seriously, indicating a potential gender bias in treatment:

"You tend to be gaslit more and not listened to by doctors."

Patients also reported insufficient ***awareness and education about severe asthma*** among the general public and employers. This lack of understanding can lead to misunderstandings and patients feeling they need to continuously explain themselves. For example, employers or education providers may not recognise the need for accommodations, and healthcare providers may not be fully aware of the latest treatments and management strategies for severe asthma.

"There is a general lack of awareness about severe asthma. People don't understand how serious it can be."

Social and psychological factors

The focus group found that severe asthma has a ***profound impact on the quality of life*** of patients. It affects their ability to work, engage in social activities, and perform daily tasks without fear of triggering an asthma attack. The constant worry about asthma attacks and the limitations imposed by the condition lead to social isolation and a reduced quality of life. Participants reported feeling anxious, stressed and sometimes lonely which can further exacerbate their asthma symptoms. The opportunity to connect with each other over shared experiences as part of the focus group was welcomed by many. One participant recalled that:

"I've had to leave jobs, change career path... I just don't feel asthma is taken seriously enough."

The *emotional impact* of living with severe asthma is significant. Patients feel isolated and anxious about their health and the unpredictability of asthma attacks. The constant worry about managing their condition and the limitations it imposes on their lives lead to feelings of frustration and helplessness. The emotional toll of severe asthma was highlighted as an important aspect that needs to be addressed to improve the overall well-being of patients.

Remedial measures identified through the Patient Focus Group

The participants not only highlighted currently existing challenges but also brought forth several proposed solutions and policies to address these issues. These solutions aim to improve the quality of care, increase awareness, and provide better support for patients with severe asthma.

Improving standards of care

One of the key solutions proposed by participants is the ***implementation of a standardised approach to asthma care*** across different regions of the country. This would ensure that all patients receive the same level of care regardless of where they live. Standardised care protocols would help reduce disparities in treatment and improve health outcomes for patients with severe asthma. By establishing uniform guidelines for diagnosis, treatment, and follow-up care, healthcare providers can offer consistent and effective care to all patients.

There was a call for ***standardised protocols in emergency departments*** for treating severe asthmatics. Participants emphasised the need for clear guidelines to ensure that they are seen and treated promptly according to their specific needs. Standardised emergency care protocols can help reduce wait times, improve treatment outcomes, and provide a more consistent and reliable experience for patients during asthma attacks.

Improving follow-up care after diagnosis and treatment is essential for managing severe asthma effectively. Participants expressed the need for regular monitoring and support rather than managing asthma on a crisis basis.

"Regular follow-up care is crucial. We need ongoing support to manage our asthma effectively."

By providing ongoing follow-up care, healthcare providers can help patients maintain better control of their asthma, reduce the risk of severe attacks, and improve their overall quality of life.

Access to care also requires improvements, according to participants. This includes ensuring timely referrals to respiratory specialists after a certain number of chest infections and streamlining the process for accessing specialist care. Participants emphasised the need for a more efficient and consistent referral system that does not vary significantly from one patient to another. By improving access to specialist care, patients can receive the appropriate treatment and management for their condition in a timely manner.

Participants were informed of ***integrated hubs*** established by the Health Service Executive (HSE), which are multidisciplinary teams providing specialist care in the community. These hubs offer a range of services, including access to consultants, specialist nurses, physiotherapists, and psychological care. Participants suggested that these integrated hubs could be a good option for those needing specialist care.

"Integrated hubs are a great idea. They provide comprehensive care and support in the community."

By providing comprehensive and coordinated care in the community, integrated hubs can improve access to specialist services and alleviate pressures on emergency departments.

Building knowledge in the health service

Increasing ***awareness and education*** about severe asthma among the public, healthcare professionals, and employers is crucial. Participants highlighted the need for educational campaigns to raise awareness about the seriousness of asthma and the accommodations needed in the workplace. Educating healthcare professionals about symptom recognition, the latest treatments and management strategies for severe asthma can also improve the quality of care provided to patients. By increasing awareness and understanding, patients can receive better support and accommodations in their daily lives.

The ***creation of a severe asthma registry*** was proposed as a way to collect dependable data on the number of people with severe asthma, the medications they are on, and other relevant information. A registry would provide valuable insights into the prevalence and management of severe asthma, helping to inform healthcare policies and treatment strategies. By having access to accurate data, healthcare providers can better understand the needs of patients and develop targeted interventions to improve care.

Supporting patients

The ***high cost of asthma medication*** was another major concern for participants. To alleviate the financial burden, participants proposed several solutions, including lowering the drug payment scheme ceiling and including asthma in the long-term illness scheme. These measures would help reduce the cost of medications and make them more affordable for patients. Financial support for medication is essential to ensuring that patients can manage their asthma effectively without the added stress of financial constraints.

Moreover, the importance of ***patient input in healthcare decisions*** was also emphasised. Participants highlighted the need for healthcare providers to recognise their ability to understand their own bodies and treatment responses. By involving patients in decision-making processes and valuing their input, healthcare providers can develop more personalised and effective treatment plans.

The focus group discussed the need to ***empower patients to share their experiences*** and advocate for change with politicians and the public. By encouraging patients to speak out about their challenges and needs, they can play a crucial role in influencing healthcare policies and raising awareness about severe asthma.

Conclusion

The focus group revealed several challenges faced by patients, as well as potential solutions to improve their care and quality of life. The participants' experiences underscored the significant delays in receiving an accurate diagnosis, often leading to prolonged suffering and inadequate treatment. The lack of standardised care and the financial burden of asthma medications were also highlighted as major concerns. The impact of severe asthma on daily life, including mental health, social relationships, and employment, was described as profound and must be taken into consideration when addressing challenges.

The solutions proposed include improving access to specialist care, providing financial support for asthma medications, and increasing awareness and education about severe asthma among the public and healthcare professionals. The establishment of a severe asthma registry and the implementation of standardised care protocols were also recommended to enhance the management of the condition. The session concluded with a call to action for healthcare policymakers and professionals to address the gaps in severe asthma care and to consider the recommendations made by the focus group participants. By implementing these solutions, the aim is to provide a more consistent, informed, and supportive approach to managing severe asthma, ultimately improving the quality of life for patients.

ROUNDTABLE DISCUSSION

Overview

On 16 August 2024, the Asthma Society of Ireland hosted a roundtable of healthcare professionals, including consultant respiratory physicians, specialist nurses and a pharmacist. The discussion sought to build on and further refine the recommendations made by the patient focus group to improve severe asthma management. The Asthma Society would like to thank in particular the members of its Medical Advisory Group for providing their expertise and time to the roundtable.

A key objective was to identify one priority recommendation with the greatest potential for positive impact on severe asthma patients and related healthcare services.

Key Themes

The discussion underscored the critical importance of understanding the challenges faced by patients with severe asthma. Experts highlighted that severe asthma is often underdiagnosed, misdiagnosed and inadequately treated, which can lead to poor health outcomes and an increased reliance on emergency healthcare services. This not only affects the quality of life for patients but also places a significant strain on healthcare systems.

Additionally, the discussion brought to light the substantial economic burden associated with severe asthma, including the high costs of medications and treatments. Accessibility to these medications remains a significant barrier for many patients, further complicating their management of the condition. The conversation also revealed inconsistencies in the standards of care provided to severe asthma patients.

Moreover, there is a pervasive lack of awareness and education about severe asthma among patients, some healthcare professionals, and the general public. This gap in knowledge can lead to mismanagement of the condition and prevent patients from receiving the comprehensive care and supports they need. To address these issues, the report identifies these critical themes and outlines a series of recommendations derived from the roundtable discussion, aimed at improving diagnosis, treatment, and overall awareness of severe asthma.

Economic Burden and Medication Accessibility

The challenges faced by asthma patients, particularly those with severe asthma, are significant, primarily due to the high costs of medications and the impact of the disease on

their ability to maintain employment. Combination inhalers, which are essential for effective asthma management, represent a substantial financial burden for patients. This issue has been a longstanding concern for organisations like the Asthma Society of Ireland. Experts have highlighted the need for a cost-benefit analysis of fully subsidising asthma medications to demonstrate the broader value of such investments. It was noted by roundtable participants that "the high medication costs primarily relate to combination inhalers and [it] has been an issue for years for [patients and the Asthma Society of Ireland]"

One proposed measure to address these challenges is to include asthma in the long-term illness scheme by amending the Health Act of 1970. This would allow for the subsidisation of asthma medications, in particular combination inhalers, providing much-needed financial relief to patients. There is strong support from pharmacists for this approach, with representatives noting that "in terms of subsidising asthma medications ... there [is] an overwhelming support from pharmacists" as it would specifically target asthma patients without affecting the revenue of community pharmacies, which are already under financial stress.

Another suggestion is to reduce the threshold of the Drugs Payment Scheme. This measure would improve medication adherence and health outcomes among vulnerable populations by making medications more affordable. However, there is concern that lowering the threshold would impact all patients, not just those with asthma, potentially affecting the financial stability of community pharmacies. Community pharmacist representatives expressed this concern noting that "reducing the drugs payment scheme threshold would affect all patients, not just asthma patients, so from a pharmacist's perspective, the long-term illness route or something akin to that would be preferable." Therefore, some experts believe that the long-term illness route or a similar approach would be more beneficial.

It was recognised, however, that there has been no illness added to the LTIS almost 50 years and that it unlikely to change. The Asthma Society's CEO pointed out Sláintecare commitments to review the LTIS, and that for these reasons, the Society must seek alternative recommendations regarding subsidisation of asthma medications, and in particular combination inhalers that are themselves more cost-effective than alternative inhaler treatments at driving down societal costs from asthma exacerbations and hospitalisations.

Additionally, there was a call for continued and increased investment in high-tech biological treatments for severe asthma. These treatments are effective but expensive, and access to them is often hindered by their high costs. The roundtable discussions emphasised that biologic treatments, despite being expensive in nature, are the best treatment for

appropriate severe asthma patients. It was agreed that more patients could benefit from access to biologic treatment and, potentially, patient could benefit from earlier intervention with biologics. However, it was noted that the high-cost burden of these treatments could potentially detract from investment in other solutions to treat severe asthma.

Inconsistencies in Standard of Care

The discussion highlighted significant differences in the quality of care for severe asthma patients across various regions in Ireland. These disparities have resulted in delays in referrals and diagnoses, extended wait times, and difficulties in accessing biological medications. It was noted that patients with severe asthma often face diagnostic challenges, with some focus group patients waiting up to 10 years for a proper diagnosis. Such delays can severely affect their health, family life, social interactions, and employment.

A major issue identified was the absence of standardised care protocols in primary and emergency care settings, which has led to inconsistent outcomes. It was noted that patients expressed frustration over the need for self-advocacy to convince healthcare providers of their condition and the necessary treatments. This issue was particularly pronounced in general practice and emergency department settings, where 86% of patients felt improvements were needed.

The discussions also addressed the need for better access to specialists, shorter waiting lists, and improved follow-up care across all levels of healthcare. Focus group findings presented at the roundtable indicated that patients wanted a standardised set of criteria for GPs to refer patients to specialists, which could enhance the consistency and quality of care.

Roundtable participants stressed the importance of establishing a severe asthma registry. They argued that such a registry is crucial for categorising the patient population, facilitating research, and ensuring appropriate access to biologic treatments. Healthcare experts mentioned that while each hospital has collates its own data, a nationwide registry that integrates with the International Severe Asthma Registry (ISAR), for example, would benefit both patients and healthcare providers.

The roundtable discussion emphasised that introducing a registry would support a coordinated approach to care delivery across all healthcare settings. The registry would also help establish clear guidelines and protocols for managing severe asthma, ensuring that all patients receive timely and appropriate care.

Awareness and Education

Awareness and education for severe asthma are critical components in managing the condition effectively. The roundtable highlighted several key points regarding the challenges and needs for better education and awareness among patients, healthcare providers, and the broader community. A lack of awareness about severe asthma among the public and some healthcare professionals has resulted in misconceptions about the condition's seriousness and impact.

This is particularly exacerbated by the lack of a suitable and universally accepted definition for severe asthma. It was noted that severe asthma is not easy to package and communicate, and there is a need for education not only for patients but also for stakeholders such as those in the Department of Health or the HSE. Participants noted that currently severe asthma is “defined by healthcare utilisation, which varies with healthcare availability and resourcing.” However, participants pointed out that the Global Initiative for Asthma (GINA) are planning to amend the “definition to something that's much more objective.”

Confusion over the meaning of severe asthma was further exemplified by some participants expressing that severe asthma meant something vastly different to clinicians than to the general public, indicating a gap in understanding that needs to be bridged through education.

Consultants, and nurses in particular, emphasised the importance of ongoing patient education, citing, "it's not just a one-off, it has to be repeated, repeated and repeated and really get under the bonnet of [it] or understanding that this is something that could be life-threatening."

The role that the Asthma Society of Ireland, plays in providing education was stressed. However, there are limitations due to funding, which restricts the reach of their educational efforts. It was noted that the Asthma Society conducts 4,000 calls annually, with many being follow-up calls, which are a significant part of the education process.

Remedial measures identified through the Expert Roundtable

Establishment of a Severe Asthma Registry

The establishment of a Severe Asthma Registry is a pivotal step towards enhancing the management and understanding of severe asthma in Ireland. The absence of comprehensive data on severe asthma patients, their treatment patterns, and outcomes is a significant barrier to effective care and resource allocation. A registry would address this gap, enabling informed policymaking and better resource distribution.

A Severe Asthma Registry is essential for several reasons. It will systematically collect and manage data on patients with severe asthma, providing critical insights into disease prevalence, treatment effectiveness, and patient outcomes. This data will be invaluable for research, facilitating studies on severe asthma and supporting clinical trials for new treatments. Moreover, by analysing registry data, healthcare providers can identify care gaps, standardise treatment protocols, and tailor strategies to individual patient needs. The registry will also inform policy decisions and resource allocation, ensuring that healthcare services meet the needs of severe asthma patients. Participation in the International Severe Asthma Registry (ISAR) will further enhance learning and best practices, as emphasised by a participant: "It's probably best practice now to be part of international registries in terms of the learnings that you get from them."

The discussion noted that the registry should be modelled after successful systems like the cancer registry, serving as a critical tool for standardising high-quality care, facilitating research, and ensuring timely access to treatments. Key features should include comprehensive patient data collection, standardised criteria for severe asthma, data quality assurance, privacy and security compliance, accessibility and interoperability with other health systems, and sustainable funding and support.

To realise this initiative, several steps and stakeholder actions are essential. Firstly, stakeholder engagement is crucial, involving healthcare professionals, patient advocacy groups, government agencies, and industry partners in planning. Securing funding for 2 to 3 dedicated personnel and technology is necessary, with an estimated annual cost between €400,000 and €500,000. The development of a business plan that outlines objectives, structure, technology requirements, staffing, budget, and timeline was highlighted as a key step by roundtable participants. Additionally, technology development and pilot testing should be conducted, followed by necessary adjustments with the establishment of data collection protocols and providing training for the 2 to 3 data entry personnel. Lastly, advocacy and awareness efforts should be made to promote the registry and encourage participation and utilisation of data for improved care and research.

By taking these steps, a Severe Asthma Registry will provide valuable insights into the disease and support efforts to improve care for patients with severe asthma. The roundtable emphasised that multi-annual funding and integration with digital health records is necessary to prevent the registry from fading into insignificance over time. Furthermore, participants highlighted the need to urge stakeholders, such as the Department of Health, the HSE, and the incoming clinical leads, to prioritise these recommendations. By focusing on funding, staffing, oversight, multi-annual commitment, and digital integration,

significant strides can be made in the management of severe asthma and improve the quality of life for patients across Ireland.

Investment in Biologic Treatments and Subsidising Combination Inhalers

Investment in biologic treatments for severe asthma is recognised as a significant advancement in improving patient outcomes. Biologics target specific pathways in the immune system, reducing inflammation and asthma symptoms. A participant highlighted the effectiveness of these treatments, stating, "There's been outstanding developments in translational science in recent years that has given us really effective treatments for reducing flare ups of this condition."

Continued investment in high-tech treatments for severe asthma patients is essential to ensure that every suitable patient can access these therapies promptly. This investment would enhance treatment outcomes and reduce the long-term burden on healthcare systems. One healthcare practitioner suggested that a mindset change among healthcare providers to move towards a more objective definition for testing for severe asthma, expected to be introduced by Global Initiative for Asthma (GINA) next year, could double the number of patients on biologics and “reduce the overall cost for the biologics by 60%.” This figure was reached following a trial which proved that switching to “objective measures rather than subjective measurements, you could give twice as many people a biologic for the same cost”.

The excessive cost of biologics poses challenges: "Before committing a patient to a biologic, which is a tremendously expensive medicine, there needs to be certainty that the person indeed has the condition."

Furthermore, it was emphasised by participants that ensuring patient adherence to treatment is crucial for the effectiveness of biologics, as some patients may not take their inhalers as prescribed. Combination inhalers, which are more effective than older generation inhalers, improve adherence and asthma outcomes, lowering costs overall. Participants also stressed the importance of ensuring equitable access to these treatments, particularly for patients who have not responded to traditional therapies. By investing in combination inhalers and biologic treatments and promoting their use among healthcare providers, healthcare systems can improve patient outcomes and reduce the overall burden of severe asthma.

Education

The discussion highlighted the critical role of education supporting severe asthma patients to stay well, with a focus on providing comprehensive education at all touchpoints of the

patient journey, including primary care, pharmacy care, specialist care and care in the community. The Asthma Society of Ireland already provides high-quality education but requires more funding to reach a larger audience. Participants noted, "Education keeps coming up... I think we need to look at the whole patient journey around education and every single touch point." The delivery of education is complex, and time consuming requiring one-on-one tailored information for each patient.

It was noted that The Asthma Society of Ireland conducts thousands of calls with patients annually, with many being follow-up calls, which are crucial for patient education. Participants agreed that, ideally, this level of tailored support would be the norm for adequate patient care.

Roundtable Conclusion

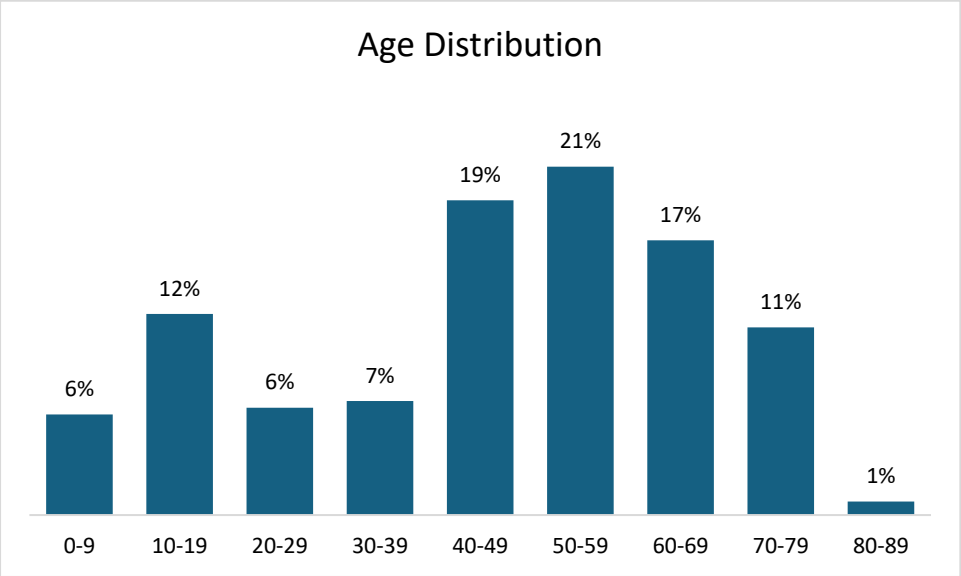
The roundtable discussion provided valuable insights into the current challenges and considerations in managing the condition. The establishment of a severe asthma registry emerged as a critical recommendation to policymakers and political decisionmakers, supported by the need for investment in biologic treatments/subsidisation of combination inhaler treatments and enhanced education and workplace accommodations. These strategic recommendations aim to improve patient care and outcomes in Ireland, addressing the economic, clinical, and social aspects of severe asthma management.

By implementing these recommendations, healthcare systems can enhance the quality of care for severe asthma patients, reduce the burden of the condition, and improve overall health outcomes. The discussion highlighted the importance of collaboration among stakeholders, including healthcare providers, policymakers, and patients, to achieve these goals and ensure that all severe asthma patients receive the care and support they need.

Appendix: demographic background of survey participants

Appending A provides further information on the demographic breakdown of the survey sample. The complete survey questionnaire can be provided upon request.

Age breakdown



Diagnostic details

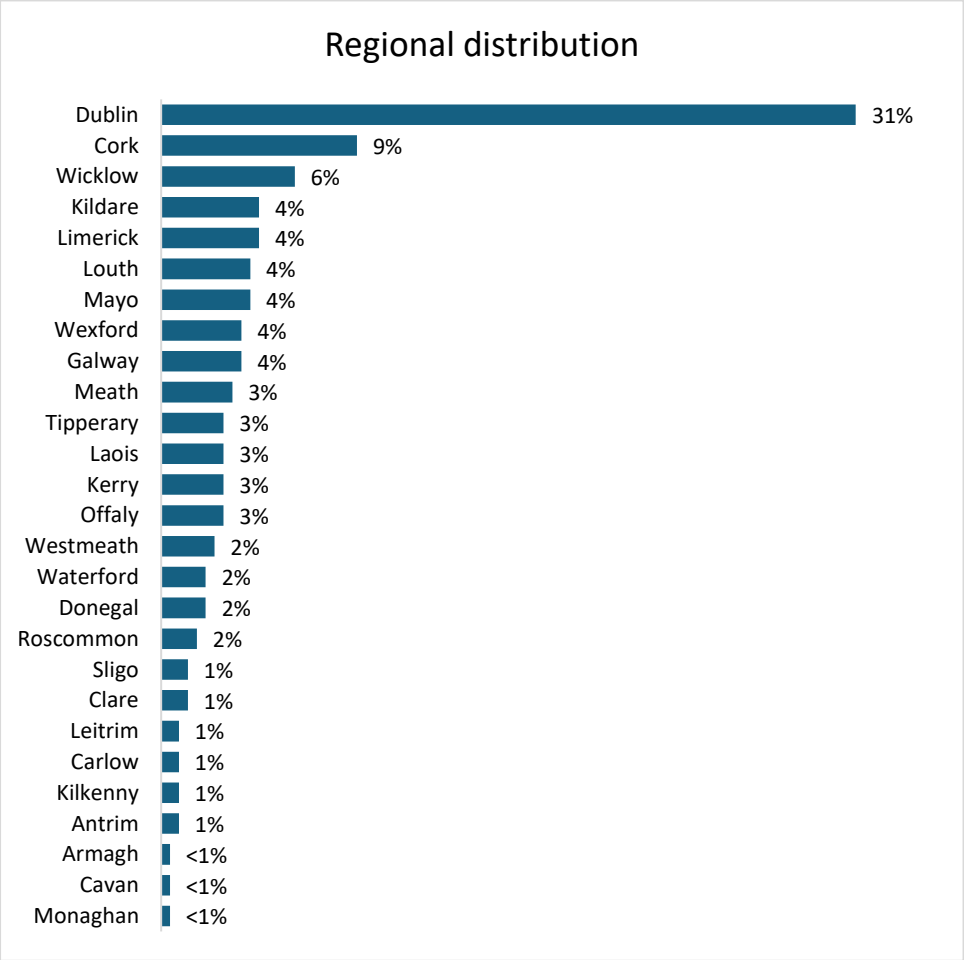
Over nine in ten (91%) respondents have been formally diagnosed with severe asthma. The rest (9%) have not. Of those who remember when the diagnosis was made:

- Only one person (1%) received their diagnosis at birth (at the age 0)
- 21% were diagnosed at the age of 1-5
- 13% were diagnosed at the age of 6-10
- 7% were diagnosed at the age of 11-15
- 5% were diagnosed at the age of 16-20
- 5% were diagnosed at the age of 21-25
- 5% were diagnosed at the age of 26-30
- 3% were diagnosed at the age of 31-35
- 10% were diagnosed at the age of 36-40
- 8% were diagnosed at the age of 41-45
- 8% were diagnosed at the age of 46-50
- 15% were diagnosed over the age of 50

Of those who remember when they first experienced symptoms:

- 2% experienced symptoms at birth (at the age of 0)
- 25% experienced symptoms at the age of 1-5
- 10% experienced symptoms at the age of 6-10
- 7% experienced symptoms at the age of 11-15
- 8% experienced symptoms at the age of 16-20
- 5% experienced symptoms at the age of 21-25
- 9% experienced symptoms at the age of 26-30
- 3% experienced symptoms at the age of 31-35
- 8% experienced symptoms at the age of 36-40
- 7% experienced symptoms at the age of 41-45
- 7% experienced symptoms at the age of 46-50
- 12% experienced symptoms over the age of 50

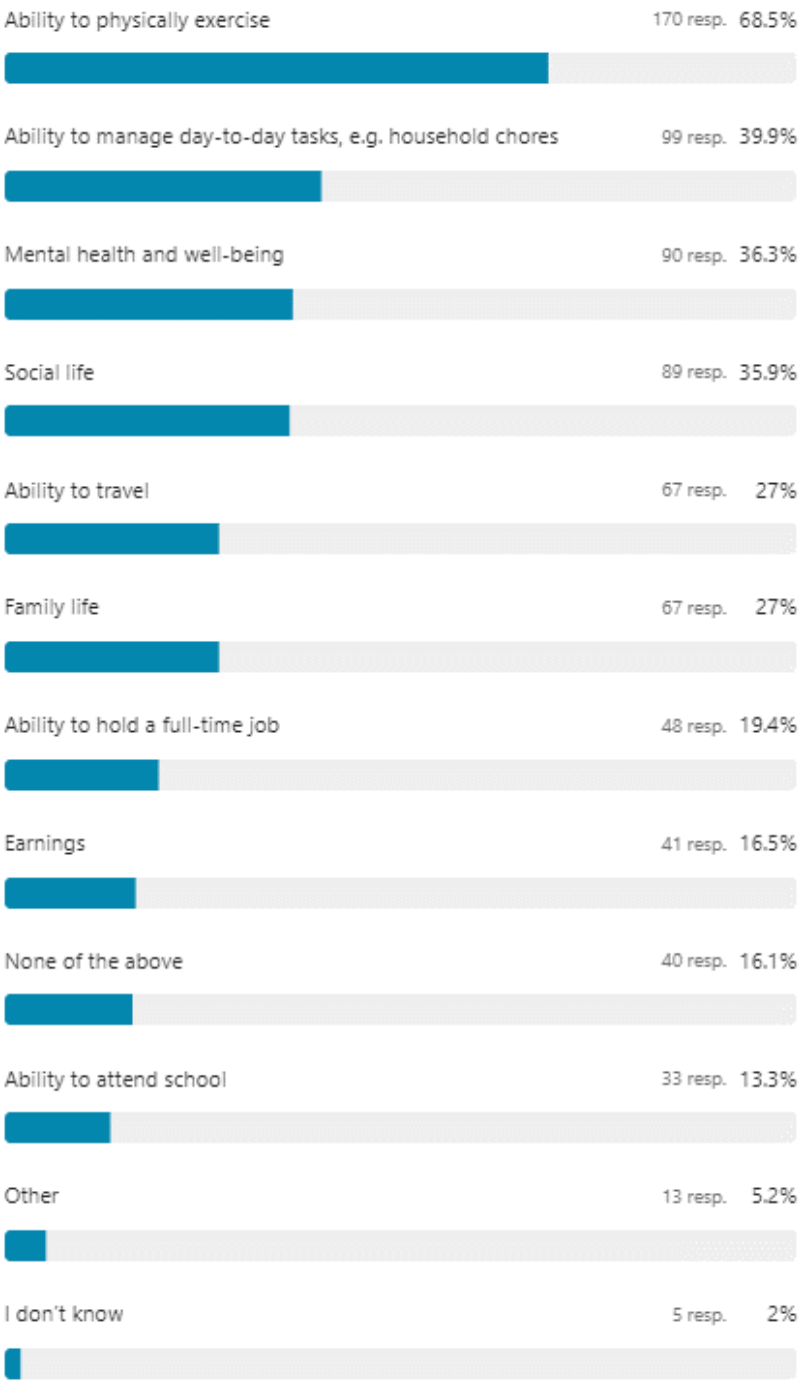
Region breakdown



Impact of severe asthma

Which, if any, of the following areas in your / their life are currently negatively impacted because of severe asthma?

248 out of 273 people answered this question (with multiple choice)



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