

Special report: asthma care in the UK

Improving outcomes and experiences



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BY THE NUMBERS

Asthma in the UK

1 in 20

people with asthma have a severe case of the disease¹

39%

of people with asthma were prescribed excessive reliever medication (blue inhalers) in the year¹ before their asthma-related death²

5.4m

people living with asthma in the UK³

3+

blue (reliever) canisters per year are associated with a two-fold increase in risk of severe asthma attacks⁵

130,000

people with asthma take three or more courses of oral corticosteroids (OCS) per year⁶, which can have life-changing side effects⁷

75,000

hospital admissions per year due to severe attacks in the UK⁸

3.24m

people with asthma do not receive the basic level of care^{ii,iii}, which includes an annual asthma review, written action plan and an inhaler technique check⁴

72 months

is the average time to diagnosis of severe asthma from the original asthma diagnosis⁹

~1,000,000

severe asthma attacks in the UK every year¹⁰

i) Excessive prescribing of blue inhalers is described as more than 12 reliever inhalers in one year. ii) Reliever/rescue inhalers (Short-action beta-agonist (SABA)) - commonly referred to as the "blue inhaler" can provide immediate symptom relief but do not treat the underlying inflammation of asthma. iii) Basic level of care is defined as an annual asthma review, a written action plan and an inhaler technique check with a healthcare professional

Zero tolerance for asthma attacks

Asthma outcomes in the UK are amongst the poorest in Europe¹¹ – now is the time for zero tolerance for asthma attacks, says [Dr Alexander de Giorgio-Miller](#), vice president for medical and scientific affairs at AstraZeneca

With 5.4 million people in the UK living with asthma³, you may suffer from it personally or know someone who has it. Our familiarity with asthma means that many refer to it as “just asthma”. However, asthma is a serious, inflammatory disease requiring regular inhaled anti-inflammatory treatment to reduce symptoms and prevent severe asthma attacks. In the UK, it is estimated that someone with asthma suffers an attack every ten seconds¹². Any severe attack is a terrifying event and can be life-threatening. With approximately 75,000 people hospitalised for severe attacks each year⁸, rates of hospital admission and mortality in the UK are amongst the worst in Europe¹¹.

Fundamentally, asthma is an inflammatory disease and therefore the foundation of care is inhaled corticosteroid (ICS) treatment¹³. ICS-containing “preventer inhalers” (typically brown but come in many colours) reduce inflammation in the airways, preventing symptoms from worsening and reducing the risk of an attack. One of the biggest contributors to the growing burden of asthma attacks is a systematic over-reliance on “rescue” therapies – in particular, the “blue inhaler”.

Despite numerous effective preventer

inhalers available, people with asthma instead primarily seek quick relief from their asthma symptoms by using their blue inhaler¹⁴. Evidence suggests that people who use blue inhalers excessively are at a greater risk of having an asthma attack². Indeed, the use of three or more blue inhalers in a single year is associated with a two-fold increase in the risk of having a severe attack¹⁵. Disappointingly, in the UK, we dispense 15.5 million blue inhalers to asthma patients each year (~three per person on average), which is amongst the highest in the world¹⁶ and suggests a large number of people may be sub-optimally treated. Used alone, blue inhalers possess no anti-inflammatory properties and therefore do not address the cause of the disease, the inflammation^{14,17}.

Another consequence of the over-reliance on blue inhalers beyond the associated attacks, is the over-prescribing of steroid tablets to treat them. Oral corticosteroids (OCS) may be used in short bursts as a life-saving treatment for attacks but frequent use of OCS courses may be an indicator of sub-optimal asthma care^{2,18}. OCS tablets are associated with significant side effects⁶, and even short courses can have a significant impact on patients¹⁹. Side effects can include weight gain, mood changes, and the increased risk of

osteoporosis, hypertension, heart attack, and stroke, amongst others²⁰.

Furthermore, people with severe asthma, a significant form of the disease that is not controlled with high doses of inhaled medication, are frequently treated with OCS⁶. In light of the side-effects associated with OCS and despite numerous “precision” medicines now available to treat severe asthma, only a small proportion of approximately 200,000 people living with severe disease in the UK today are given access to these medicines³.

The over-reliance on rescue treatments in the UK is contributing to poor national asthma outcomes and is increasing the risk of asthma attacks. Furthermore a reliance on frequent OCS courses may be causing unnecessary harm to people with asthma. Given the extraordinary circumstances of recent months and the heightened need to keep high risk people out of hospital, now is the time to seek better outcomes for all people living with asthma.

It is more critical than ever that we all adopt a mindset of zero tolerance for asthma attacks – people with asthma must come to understand the cause of their disease and use the appropriate anti-inflammatory medicines to treat it. Only then, will asthma ever be “just asthma”. ●

Asthma is a chronic inflammatory condition, affecting 5.4 million people in the UK – one of the highest prevalence rates in the world²¹

Asthma outcomes – it’s time for change

Introduction

Despite over 50 years of campaigning for change^{22,23,24,25,26,27}, people with asthma in the UK continue to face significant challenges in the management and treatment of their condition²⁸. Between the early 1990s and 2006, progress was made globally in reducing deaths from asthma, but improvements plateaued by 2012²⁹. At this time, the UK lagged behind most of its main European counterparts, recording the second highest rates of deaths and hospital admissions (see table)¹¹, and recent evidence demonstrates that improvements against these key outcomes have stalled over the past ten years⁷.

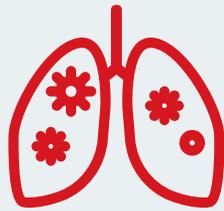
For people with asthma, the goal of treatment is to achieve good asthma control by minimising the risk of asthma attacks and reducing the burden of their symptoms³⁰. Uncontrolled asthma is debilitating for people living with the condition, impacting every area of their lives³.

On average, three people die from an asthma attack every day in the UK³⁰. In 2017, 1,484 people died from an asthma attack in the UK³¹ (latest data available), almost equalling the 1,793 UK road deaths in the same year³².

The Royal College of Physicians’ (RCP) report, The National Review of Asthma Deaths (NRAD), published six years ago, analysed circumstances surrounding

ASTHMA EXPLAINED

- ❑ Asthma is a chronic inflammatory disease with fluctuating levels of inflammation and episodic symptoms⁸
- ❑ Difficult asthma is often the result of poor adherence to treatment, other co-morbidities and/or the wrong diagnosis⁶
- ❑ Severe asthma is a distinct condition, classed as requiring high-intensity treatment to keep it under control³⁰



On average, three people die every day from asthma

¹Basic level of care is defined as an annual asthma review, a written action plan and an inhaler technique check with a healthcare professional

deaths from asthma in 195 people in the UK between February 2012 and January 2013. The Review found that about two-thirds of deaths from asthma are potentially preventable in the UK². The report made 19 recommendations to support an improvement in outcomes and a reduction in death². However, despite acknowledgement of the findings by charities and professional organisations^{33,34,35} and development of materials to help translate the guidance into clinical practice³⁶, only one recommendation has seen implementation so far – the National Asthma and COPD Audit Programme launched in 2018, designed to audit services from across the care pathway to present a vision for improved patient care^{37,38}.

Asthma UK, the largest asthma patient group in the UK, states that optimal control is not being reached in the majority of people with asthma in the

HOSPITAL ADMISSION (2012) AND MORTALITY RATES (2011) OF ASTHMA IN ADULTS ACROSS THE “BIG FIVE” EUROPEAN COUNTRIES¹¹

Country	Hospital admission rate for asthma in adults (2012)	Mortality rate of asthma in adults (2011)
(Age-standardised rate per 100,000, ≥15 years of age)		
France	32.51	1.14
Germany	45.67	1.13
Italy	35.8	0.52
Spain	89.72	1.53
United Kingdom	77.74	1.47



UK, and they are not receiving adequate treatment⁹. In 2018, Asthma UK found that despite system improvements across all areas of basic care¹, 60 per cent of people with asthma are “still not receiving the most basic asthma care”, which includes an asthma review, a written action plan and an inhaler technique check with a healthcare professional⁴. In the same year, a paper commissioned by *The Lancet* reported that people with asthma are still at risk of preventable asthma attacks across all disease severities, with the authors calling for “zero tolerance for asthma attacks”¹⁷. In severe asthma – a distinct condition affecting up to 4 per cent of asthmatics requiring high intensity treatment – especially, Asthma UK has identified there is a “significant unmet need for referral to specialist care”⁶. Furthermore,

There must be zero tolerance for asthma attacks

ASTHMA AND AIR POLLUTION

Public Health England (PHE) says that poor air quality is the largest environmental risk to public health in the UK, contributing to chronic conditions such as asthma. The UK Health Forum and Imperial College London, in collaboration with PHE, developed a modelling framework, which estimates 9,300 cases of asthma in England over an 18-year period could be prevented with a reduction (1 microgram/m³ reduction in fine particles air pollution) in the particulate air pollution⁴⁰.



in England, health services for adults with severe asthma are currently commissioned based on modelled data for an estimated 7,700 people with severe asthma. This is much lower than the estimated real-life population of 200,000⁶ suggesting that services, as they are currently configured, do not have the capacity to effectively treat everyone with severe asthma.

Positive steps are being taken to improve asthma outcomes; respiratory disease is included as an area of clinical focus in a number of NHS strategy initiatives, including NHS RightCare⁴¹, the Long Term Plan⁴², and Getting It Right First Time (GIRFT)⁴³. Additionally, UK clinical groups are working to put the management of asthma in the spotlight, such as the Primary Care Respiratory Society’s “Asthma Right Care” social movement, which is exploring how to challenge the current status quo in asthma outcomes⁴⁴.

But more must be done, and national leadership is key to this. With exacerbating factors such as rising pollution putting people with asthma at higher risk⁴⁵, it is possible that the care and treatment needs of people with asthma will continue to increase, as will the pressures on the health system.

To reverse the stagnation in UK asthma outcomes we must raise awareness of the issues in asthma treatment and care across the public, healthcare professional, and policymaker communities, as well as improve environmental factors. The

literature and real-world experience demonstrate multi-faceted issues in the treatment and management of asthma, and the challenge of implementing clinical guidelines into practice has been widely documented^{4,44,46}. Asthma UK states “a condition of this scale demands national leadership, as we’ve seen with diabetes”⁴. This report summarises the significant issues facing people with asthma and the various recommendations which have been made to address these.



Diagnosis

Asthma is primarily diagnosed and treated in primary care, although there is no universally recognised standard for diagnosis²². The absence of accurate diagnostic testing coupled with limited specialist knowledge can result in incorrect and/or delayed diagnosis thus impacting patient outcomes⁴⁷. This is especially the case for those with severe asthma, as accurate diagnosis is usually only possible via referral to specialist-led centres which have the appropriate expertise and equipment⁶. Unfortunately, due to the limited awareness of severe asthma within non-specialist clinical communities and inadequate data sharing between primary and secondary care³, people can experience long delays (median 72 months from original asthma diagnosis⁹) for their severe asthma diagnosis.

The UK and Global guideline bodies all state that symptoms alone should not be enough to diagnose asthma, and recommend capturing a clinical history supported by objective measurements^{13,18,48}. In primary care, a number of methods and assessments, such as lung function tests, are available to determine the likelihood of asthma but normal results do not exclude asthma and abnormal results do not always mean it is asthma¹³. There is a further optional test, measuring airway inflammation¹³, used where diagnosis is uncertain, but there are concerns over its cost-effectiveness⁴⁹.

In 2017, Asthma UK called for investment into the development of a low-cost, accurate diagnostic test that

improves diagnosis in primary care and identification of new biomarkers³⁶. The National Institute for Health and Care Excellence (NICE) asthma guidelines and quality standard recommends “establishing asthma diagnostic hubs to achieve economies of scale and improve the practicality of implementing the recommendations”.



Asthma treatment and management in primary care

There are several issues facing the asthma patient and healthcare professional in the primary care setting – we explore three common issues.



Basic asthma care

Asthma UK defines basic asthma care as an annual asthma review, a written personalised asthma action plan (PAAP) and an inhaler technique check with a healthcare professional⁴. An annual asthma review aims to achieve optimal outcomes for people with asthma and address any issues with treatment, adherence or symptoms⁵¹. Monitoring of

adherence to preventer treatment (such as a brown inhaler) is particularly important: yet studies have found that average adherence to preventer treatment in asthma varies from 22-63 per cent⁵². In 2014, the National Review of Asthma Deaths (NRAD) identified that non-adherence is associated with increased risk of poor asthma control, and of those who died, 77 per cent did not have a PAAP, an essential component of supported patient self-management, and 43 per cent had not received an annual asthma review⁶.

In 2014, NRAD recommended implementation of basic care for every person with asthma, assessment of asthma control, self-management and education, and monitoring of adherence to preventer medication⁶ which is advocated by NICE¹³, BTS/SIGN⁴⁸, PCRS⁵³ and GINA^{18,ii}. NICE also recommends the use of a validated questionnaire such as The Asthma Control Test™ which measures symptoms, quality of life and reliever use^{13,54}. Despite this, Asthma UK’s 2018 survey findings demonstrate that unfortunately three fifths of people, approximately 3 million people, are “still not receiving this most basic level of care”, highlighting that implementing the recommendations in clinical practice is proving difficult⁴. There is also significant variation in asthma care across the UK, which has been a trend since the Asthma UK surveys began, with the 2018 results showing Wales has the lowest level (32 per cent) of people with asthma receiving basic care⁴.

In the 2018 paper commissioned by *The Lancet*, the authors recommended a change to prevention strategies, such as collecting variables including A&E attendance, number of reliever (blue inhaler) prescriptions and poor symptom control, which could be built into a routine review to reduce risk of an asthma attack¹⁷. NICE has since published new indicators that have been added to the Quality and Outcomes Framework from 2020/21, which includes, in the annual review, a record of the number of asthma attacks⁵⁵.



Reliever therapy overreliance

Asthma is a variable, inflammatory disease¹⁸ – blue inhalers (reliever) do not treat

the underlying inflammation, so the use of brown inhalers (preventer) is crucial to treat the inflammatory component of the condition and to achieve optimal patient outcomes¹⁴. However, people with asthma learn that immediate symptom relief is best achieved with their blue inhaler. This may lead to non-adherence to their preventer treatment¹⁴, leaving them at risk of preventable attacks^{14,56}.

Additionally, using three or more blue inhalers a year is associated with increased A&E visits or hospitalisations⁵⁵ and 12 or more with an increased risk of death¹⁸. Overreliance on blue inhalers also leads over time to bronchial hyperresponsiveness (characterised by easily triggered contraction of the airway)⁵⁷ and tolerance (people with asthma experience less relief from the original dose)⁵⁸. In 2014, NRAD identified excessive prescribing of blue inhalersⁱⁱⁱ in 39 per cent of the 195 deaths analysed, the under-prescribing of brown inhalers^{iv} in 38 per cent of deaths and no brown inhalers prescribed in 14 per cent of deaths².

Multiple Coroner’s reports following the death of an individual from asthma reference the failure by the health service to recognise the risks of future poor outcomes and excessive blue inhaler prescriptions^{59,60,61}. This under-recognition of blue inhaler overreliance has been proven further in clinical practice – asthma experts in both primary and secondary care were interviewed and defined acceptable blue inhaler use as ranging from 0.5 to 12 inhalers per year⁶². The study also found complacency in the perception that overreliance did not represent a marker for risk of asthma death⁵⁴, contrary to statistics.

Following the 2014 review of asthma deaths, NRAD recommended people with asthma who have been prescribed more than 12 blue inhalers in the previous 12 months should be invited for urgent review of their asthma control²

which has since been supported in the BTS/SIGN 2019 guidelines⁴⁸. GINA has taken this a step further – as of 2019 its strategy no longer positions the traditional blue inhaler as the first-line reliever option and reflects the latest evidence to suggest the use of more than three blue inhalers per year is associated with an increased risk of severe asthma attacks, and more than 12 is associated with an increased risk of asthma-related death¹⁸. Additionally, the NHS Business Services Authority respiratory dashboard defines excess reliever prescribing as people with asthma being prescribed six or more blue inhalers in a 12-month period⁶⁴.

Although these updates are promising, this guidance has not currently been upheld in the UK as NICE recommends sole use of blue inhalers in asthma in some instances and does not specify a threshold for overreliance¹³.



Systemic corticosteroids use

Those with difficult or severe asthma, either identified or unidentified, can often be prescribed oral corticosteroids (OCS) to

Emergency care may be required for some attacks

control symptoms and prevent risk of future asthma attacks⁶⁵. However, long-term use of OCS is associated with a risk of debilitating side effects, such as weight gain, bone weakening and mood changes⁷. In 2014, NRAD recommended people with asthma to be referred to a specialist asthma service if they have required more than two courses of systemic corticosteroids in the previous 12 months² which GINA endorses¹⁸.

Despite this, Asthma UK’s 2019 report on severe asthma identifies over 130,000 people with asthma on three or more OCS courses per year with only 23.4 per cent of these people being referred⁶. This is likely a result of the lack of OCS recommendations in UK national guidelines, as the BTS/SIGN guidelines do not provide a threshold of OCS courses, but recommend frequent or continuous use of oral corticosteroids should be under the care of a specialist asthma service⁴⁸ with no mention of frequent or continuous OCS use in the NICE guidelines¹³.



Emergency admissions

For some people, especially those with difficult and severe asthma, asthma attacks require emergency care, and hospital admission^{3,4,31}. Asthma UK estimates that on average, 185 people are admitted to hospital because of asthma attacks every day in the UK³¹. Too often, this is a revolving door; some people have multiple hospitalisations for life threatening asthma attacks which are not viewed collectively, and not flagged for urgent review⁶⁰. This was tragically demonstrated in the Coroner’s report on the death of a 13-year-old girl, who had attended both primary and urgent care services 47 times for her asthma over four years⁶⁰.

A 2018 paper commissioned by *The Lancet* advocates for asthma attacks to be considered as a trigger event that should prompt a thorough re-evaluation

ⁱⁱNational Institute for Health and Care Excellence (NICE); British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN); Primary Care Respiratory Society (PCRS); Global Initiative for Asthma (GINA)

ⁱⁱⁱExcessive prescribing of blue inhalers is described as more than 12 reliever inhalers in one year

^{iv}Under-prescribing of brown inhalers is described as fewer than four out of the recommended 12 preventer inhalers in one year

of asthma management in the patient²⁶, particularly as having an asthma attack puts a person at an increased risk of having another one⁴. Of the deaths analysed in the 2014 NRAD report, 47 per cent had a history of previous hospital admission, and 10 per cent died within 28 days of discharge².

NRAD also recommended that follow-up arrangements must be made after every attendance at an emergency department or out-of-hours service for an asthma attack², and both NICE¹³ and BTS/SIGN guidelines recommend a two-day follow-up period⁴⁸. However, a lack of aligned communications between primary care, emergency care and pharmacy⁶⁶ can result in people falling through the net and not receiving follow-up care. Asthma UK's 2018 survey found that 64 per cent of those admitted did not receive this follow-up within two days and 65 per cent were not told they should have one⁴.



Secondary care and specialist centres

Accurate diagnosis of severe asthma is normally only possible following referral to specialist-led centres which have the appropriate expertise and equipment⁷. Across the asthma treatment pathway, there are multiple opportunities for a person to be referred to specialist care if they are predicted to have severe asthma.

However, people with asthma are often not being referred at the right time, or sometimes, not at all, with analysis from Asthma UK suggesting this is the case for 82 per cent of people with difficult and severe asthma⁷. Furthermore, three quarters of people on three or more courses of OCS have not had an appointment with an asthma specialist⁶. This means that they have had multiple asthma attacks but have still not been referred according to the guidelines.

Potentially one of the most significant reasons for the variable care received is misaligned referral criteria⁶. Currently, there are no statutory guidelines on the management of people with difficult and severe asthma⁶; and there is

variance in recommendations. BTS/SIGN guidelines state over-prescription of inhaled and/or oral steroids and symptoms of acute severe or life-threatening asthma as a criterion for referral⁴⁸, while in 2014, NRAD recommended people with asthma should be referred to a specialist asthma service if they have required more than two courses of systemic corticosteroids in the previous 12 months⁷.

This has contributed to confusion among clinicians about the referral threshold; previous research carried out by Asthma UK of 17 difficult/severe asthma clinicians and nurses from across the UK shows clinician uncertainty about which people should be referred, ranging from two courses of OCS (11 per cent of responses) to continuous courses (15 per cent of responses) being the criteria for referral¹. Compounding this, there is variation in primary care understanding of the wider services offered in secondary/tertiary care, and the importance of these for severe asthma³.

NICE, SIGN and BTS are collaborating to produce UK-wide Joint Guidelines

Wider access to specialists is crucial for asthma care

on Chronic Asthma to be published in 2020⁶⁷, which provides an important opportunity to provide clarity and subsequently increase appropriate and timely referrals. However, key stakeholders such as Asthma UK⁶ and The Taskforce for Lung Health⁶⁸ have highlighted concerns that the criteria under which specialist services are commissioned is based on modelling that does not reflect the real-life patient population.

There is a risk that some hospitals may not have capacity for an increased number of suspected severe asthma referrals^{6,68}. To provide sustainable care for appropriate, increased referrals, Asthma UK recommends a boost to the healthcare workforce would be needed, supported by the Taskforce for Lung Health calling for 100 extra respiratory speciality training posts to be created^{6,69}.



Ambitions for UK asthma outcomes

There are a plethora of guidelines, strategies and reports calling for different recommendations in the treatment and management of asthma. However, asthma outcomes in the UK are stagnating and action must be taken to improve the lives of people with asthma.

The summarised evidence points to clear areas for improvement within the health system, including ensuring every person with asthma receives basic care, clearer referral criteria for primary care clinicians, improved symptom monitoring and support for those over-relying on blue inhalers, and increased communication between primary and secondary care.

Contradictory advice and recommendations must be streamlined, and commissioning of specialist services should be properly resourced. All stakeholders, both in the healthcare and policy community, must focus on and act to improve the key challenges experienced by people with asthma along their treatment and care pathway, in order to start improving these outcomes. ●

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“A right to breathe”

At an event in Westminster, sponsored by AstraZeneca and the All-Party Parliamentary Group on Respiratory Health, experts and policy influencers gathered to discuss asthma awareness and care strategies

Poppy Hadkinson, a television presenter and nutritional therapist, has suffered from severe asthma since she was a child. Her condition has caused her to be hospitalised on numerous occasions, to experience hypoxic fits (convulsions caused by the body’s reduced access to oxygen), to be intubated (where airways are supported with a ventilator), and to be medicated with oral steroids for much of her life.

This is the “stark reality” of severe asthma, she told the audience at a parliamentary reception event earlier this year, sponsored by AstraZeneca and the All-Party Parliamentary

Group on Respiratory Health (APPG). Too often, she said in the company of around 50 guests in Westminster, including a range of clinicians and industry experts, her struggle was still being underestimated. “A phrase you’ll often hear as an asthmatic is that it’s ‘only asthma,’” Hadkinson lamented, before offering in retort: “Is it ‘only breathing?’”

The host of the reception, Jim Shannon, the DUP Member of Parliament for Strangford and the chair of the APPG, agreed that the “mindset around asthma has to change”. To this aim, he explained, the APPG is launching an inquiry into the quality and nature

of asthma care in the UK over the next 18 months. Shannon, whose second-eldest son suffered from asthma during childhood, said that respiratory health represented an area of “consensus”, and stressed that any government, of any party, should view asthma “on a par with all other serious diseases”.

At the end of its inquiry, Shannon said, the APPG wants to have clear recommendations for standards and more uniformity across asthma care, from diagnosis through to treatment, and outpatient support. “The economic argument,” Shannon said, “is in helping people with asthma to enter and stay in the workforce.” More important than



that, however, the MP added, is the “social argument that we need to look at. . . We have to ensure that everyone has a right to breathe, and to a better quality of life.”

The scale of asthma prevalence and cost is significant⁷⁰. According to Asthma UK, around 5.4 million people in this country are currently receiving treatment for the condition³, comprising 1.1 million children (one in 11) and 4.3 million adults (one in 12), at a cost of roughly £1bn a year to the NHS³¹. Every ten seconds someone in the UK has a potentially life-threatening asthma attack, and on average, three people die from asthma every day³. Of all asthma cases in the UK, approximately 200,000 are classed as severe⁶ – the most debilitating form of the condition, which may not respond to usual treatments, and can have a staggering ripple effect across the wider economy and society⁷⁰.

As much as it being a personal issue for those affected, Hadkinson highlighted that asthma also represented a “productivity” issue, in that asthmatics

Asthma is “an emotional rollercoaster”

who are not given adequate support and treatment would not be able to work as much as or in the way that they would like. “I would spend days, sometimes weeks at a time struggling to walk up the stairs of my own home,” she said. “A full week of school and then onto work, was near enough impossible. And, socialising like everyone else did. . . well, needless to say that wasn’t something I had the luxury of.” Thankfully, in the years since her diagnosis – which she described as “an emotional rollercoaster” – Hadkinson has “eventually” been able to access specialist care and pursue a fulfilling career and lifestyle.

Hadkinson warned that the “inconsistency” in asthma care, namely regional disparities in terms of the number of specialists on hand at different NHS Trusts, and delays in diagnoses and access to specialist treatments, for example, must be treated as urgent priorities if UK asthma care is to improve as it needs to. In 2014, The Royal College of Physicians’ National Review of Asthma Deaths (NRAD) report estimated that about two-thirds of all deaths from asthma in the UK could be classed as preventable².

Also speaking at the reception was Professor Andrew Menzies-Gow, who serves as the director of the lung division at Royal Brompton Hospital. Using a short clip from a documentary produced by AstraZeneca, *Breathless – The story of life with severe asthma*, he underscored the importance of early diagnosis, and avoiding a “pile-up in primary care”.

He, too, raised the issue of the lack of awareness around asthma, not just in terms of public perception, but even within the medical community. While



Menzies-Gow did not dispute the role that corticosteroid tablets had to play in treating asthma – indeed, he noted their capacity to provide valued relief to particularly uncomfortable symptoms – he stressed that they should not be too readily given out as a “sticking plaster”, and that greater consideration must be afforded to their potential side effects. For Menzies-Gow, while steroid-based treatments can help to alleviate symptoms, the focus within the medical science community should be on more advanced treatments that actually address the underlying causes of asthma.

Across the board, he said, the health service had to be more alert to the condition. Menzies-Gow called for a more efficient referral process, empowered and streamlined by data, that could help get people with asthma to the specialist knowledge and expertise they need more quickly. “Many life-changing treatments and services do exist now, I am proud to say, but the fact is, at the moment, we aren’t getting people to them quickly

enough. We are trying very hard, though, and it’s a very clear focus for the severe asthma community.”

Although Menzies-Gow admitted that specialist asthma hubs were not as widely in place as some may have hoped, he did point out the progress that has been made in the past ten years: “I think if we look back to a decade ago, we had about four centres – one in London, one in Birmingham, one in Manchester, and one covering the Leicestershire area. That’s all there was, and people were travelling from Truro – that’s about six hours away – to come and see me in London. We are now up to 12 [specialist asthma] centres and

Data can be leveraged to improve care

England is becoming better covered geographically.”

Also on display at the reception were asthma “heat maps” – digitised databases to chart and analyse variance in prevalence and outcomes of asthma across the UK, in addition to prescribing data and referral patterns⁷¹. Funded by AstraZeneca, and developed by the NHS South Central and West Commissioning Support Unit, it is hoped these maps will help identify potential outlying performance to prioritise efforts to tackle unwarranted local variation throughout England.

Ultimately, the event in Westminster was confirmation that, as Poppy Hadkinson put it, it’s “never only asthma”. The energy for change within the asthma patient community must be matched by proactive policymaking. Asthma is not an issue to be swept under the carpet; it is a serious condition that has profound effects on people’s physical and mental wellbeing, as well as a knock-on impact on the UK economy⁷⁰. ●

My life with asthma

Gabriella Perry, a student at the University of South Wales, shares her experiences of living with severe asthma



What has it been like to live with severe asthma?

I was diagnosed with asthma when I was two years old, and with severe asthma when I was seven. By the age of ten, I was being seen by a consultant at a children's hospital, and by 11 or 12, my asthma had become extremely difficult to manage.

In many ways, asthma has been life-limiting for me, because having been an initially energetic child, I suddenly became less capable of joining in with sports and other activities. I had to give up dancing and playing rugby. My attendance at school was patchy, because of constant hospital appointments. I was even kicked out of Sixth Form at one point because of my attendance and that was heartbreaking.

I've also found it hard to get work placements that can accommodate my condition – which often leaves me fatigued or short of breath. While I enjoy studying where I am, going to university in London or another busy city was never an option for me, because the air pollution would make things worse.

What has been extremely frustrating throughout my life has been the lack of awareness attached to asthma, both among the general public, and even within clinical settings. Too often, I've found, asthma is used as an umbrella term that covers all respiratory difficulties. The reality is that each case is unique, and some are very serious, but people don't seem to appreciate that. During one hospital stay, a paediatrician suggested that he would have to stop dealing with me in order to tend to "actually sick children".

What are your views on the current state of asthma medicine and care in the UK?

While things are better now than when I was diagnosed, we still have a long way to go in terms of the level of pastoral support shown to patients. In the early stages of my diagnosis, I was never really told exactly what was wrong with me. That made me feel very vulnerable.

There is a tendency, in my experience, to over-medicate asthma patients. While oral corticosteroids can provide short-term relief to severe asthma's more uncomfortable symptoms, they also carry some adverse side effects, including weight gain and mood swings, that are not always fully articulated to patients. It's a Catch-22, because I am grateful for the relief they provide, but I've been stuck on them for over ten years.

What are your hopes for the future of asthma care, in terms of treatment and perception?

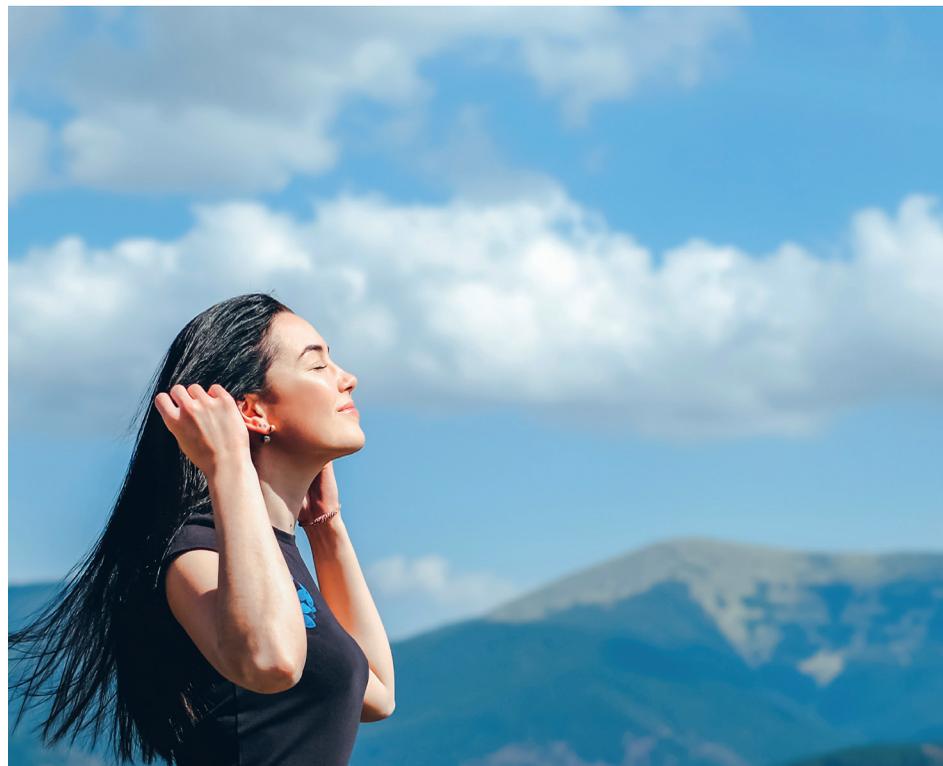
Asthma care in the UK could definitely stand to be more coordinated. Various doctors and healthcare staff having access to the same patient information, in real time, would be a good place to start.

I've had a pretty disjointed experience between the doctors I see closer to home and those that I see when at university. I would also encourage further research into the expansion of biologics [precision treatments that target a specific antibody or cell involved in asthma and are usually delivered by parenteral injection].

As for improving people's perception, that can only come through training and education. Asthma isn't "just asthma"; it is a serious respiratory condition that affects millions of people's lives. ●

Radical change in asthma policy requires a shift in public perception, says **Monica Fletcher**, honorary research fellow at The Usher Institute, University of Edinburgh, and knowledge exchange lead at the Asthma UK Centre for Applied Research

Understanding asthma as a social issue



There are many reasons why asthma may not be treated as seriously as it should be by healthcare professionals and often by patients themselves. This is not helped by well-intentioned current national and international guidelines, that according to the methods they use, classify the majority (between 50-75 per cent) of asthma cases as mild. Evidence shows us that patients are poor perceivers of their own condition and many overestimate their level of control and therefore inappropriately tolerate regular symptoms.

We also know, according to the National Review of Asthma Deaths in the UK, that patients with ostensibly mild cases can die. It is also important to recognise that about 200,000 of the 5.4 million people with asthma in the UK live with a severe life-threatening and disabling disease, on a daily basis.

On a positive note, there have been

many advances in the way asthma can be diagnosed and treated over recent decades. There is a greater understanding of the underlying mechanisms of the disease, improvements in diagnosis and we have a range of therapies to treat asthma across the disease severity spectrum. So why have outcomes not improved, and has complacency set in and what can be done? It is probably

The UK can learn from the example set by Finland

time to rethink our approach and to wholesale shift mindsets. We need to move away from concentrating on individual practitioners and patients and their behaviours, and on to whole systems thinking.

It is only when we do this that we will see game-changing improvements in asthma care and patient outcomes. For such a change to occur a political drive to treat asthma as a priority health and wider social issue is needed. This prioritisation is necessary at both a national and local level. A review of seven national European asthma programmes aimed at reducing asthma mortality and morbidity, concluded that national- or regional-wide programmes are more effective than conventional treatment guidelines. The authors also suggested that the success of these programmes relies on the commitment of stakeholders at all levels.

One of the most well-known and

successful national programmes in Europe is the Finnish National Asthma Programme, the results from which are certainly impressive showing reductions in morbidity, mortality and treatment costs. Not only did the Ministry of Social Affairs and Health in Finland recognise asthma as an important public health issue, it designed – with a whole range of experts and patients – a national programme for the prevention and alleviation of asthma-related problems.

So why was the programme successful and what can we learn? At the heart of their strategy was the acceptance that asthma was a community problem – a public health issue – and therefore to achieve a broad commitment and reallocation of resources, government action was essential. Central to the success of the Finnish Programme was the recognition that primary care practitioners – physicians, nurses and pharmacists – were pivotable and investment was needed in capacity building, including a national training programme for front-line generalists. So national steer is vital, but so is the recognition that no one single intervention will make the changes that are necessary.

Poor health outcomes in patients with asthma have been attributed to gaps between evidence-based recommendations and practice, particularly in primary care, where most asthma patients are seen. The use of evidence-based clinical guidelines to guide healthcare professionals in their day to day practice are known to be helpful, particularly to those working in primary care. In the UK the British Thoracic Society's national guidelines are respected and updated.

However, it is not the guidelines per se that will bring about change, but the recognition that the dissemination and implementation of what is written in the guidelines is what matters. Studies suggest that evidence-based care is implemented in only about half of all medical interactions. The reasons for this are complex, but they occur at the

patient, provider and system level. In one study, although most physicians were familiar with the key asthma guideline recommendations, these were not followed due to perceived time constraints and resource limitations.

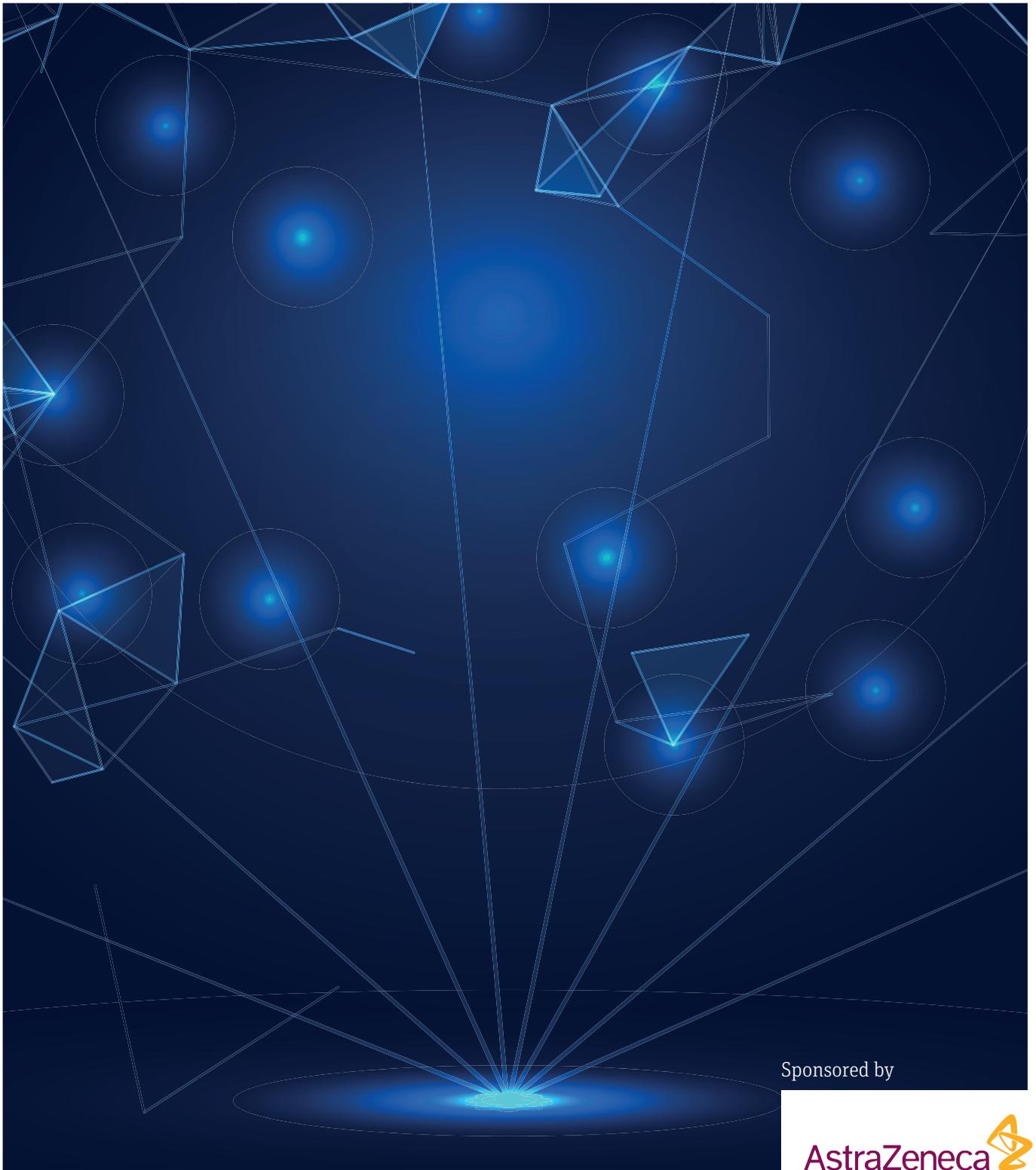
Adoption of innovation in healthcare has historically been a long and complex process. It has been estimated on average it takes 17 years to incorporate research findings into practice. Currently, the rate of healthcare innovation exceeds the rate of implementation and evidence suggests that the gap between science and implementation is growing. Some of the obstacles include budgetary restrictions, multiple decision makers, layers of bureaucracy and lack of time.

So, what could make a real difference? National policies which stimulate the importance of asthma to healthcare professionals and patients and invest in primary care services are paramount. Some healthcare systems have invested in reward for performance schemes to stimulate improvements and although this is dependent on the type of scheme, those which target quality asthma outcomes rather than basic fee for service do appear to have some degree of success. Linking these schemes to evidence-based guidelines also aids the implementation of the recommendations.

Investing in the organisation and infrastructure of the primary care practice, both with systems such as digitalised electronic patient records and staffing, have also been shown to improve asthma outcomes and bring about change.

So, if we are committed to bringing about future improvements in asthma care and raising the expectations of patients and healthcare professionals, it needs to be recognised that no single intervention will make a difference.

The current issues span across individual patients and healthcare systems, so a coordinated multifaceted approach which puts the patient in the centre and supports a public awareness campaign is the most viable way forward. ●



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