Transforming asthma care in the UK

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ASTHMA+ LUNG UK

FIGHTING BACK

Contents

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Foreword

Asthma is serious. It can have a devastating impact on people's lives and tragically four people still die every day from an asthma attack in the UK.

This is our ninth edition of the annual asthma survey, and sadly one of our most shocking. It reveals the stark levels of basic asthma care, treatment and support millions of people with asthma are experiencing.

Only a third of people with asthma who responded received the most basic level of care last year. The lowest since 2015. With current treatments, the vast majority of people with asthma should be able to live their lives with their asthma well-managed. Yet, almost half told us they do not. We are calling on policy makers to change this and join our fight for everyone's right to breathe by transforming asthma care.

We know that those in the poorest areas are seven times more likely to die from a lung condition,[1] and our survey found that people living in these areas are also more likely to be living with uncontrolled symptoms.

Over half of people with asthma told us they didn't think their asthma is taken seriously. One in five have faced discrimination because of it. It's clear a renewed effort is needed by policy makers to make sure asthma is taken seriously and that it's prioritised on par with other long-term health conditions.

Unlike many other health conditions, asthma can be lifelong. Many people live with it through childhood, and some develop it as a result of key life stages such as menopause. By prioritising action on asthma, there is a significant opportunity for policy makers to improve wellbeing and health across the life course, reducing the burden on the NHS and most importantly, improving quality of life for millions of people.

The UK continues to lag behind other European countries on lung health, but it's not too late to turn this around. By tripling respiratory research, prioritising lung health policy and listening to the millions with lung conditions, the UK could transform these outcomes and be an asthma pioneer.

The voices of people with asthma must be heard at the very top, change is possible, and we know what works. It is time now for politicians to listen and join the fight back.

Sarah Woolnough
Chief Executive, Asthma + Lung UK

Executive summary

The COVID-19 pandemic is having a lasting impact on all parts of the health service. Unsurprisingly, asthma care has taken a big hit. Poor access to care, outdated treatment guidelines and an ineffective care pathway has left the UK with some of the worst asthma outcomes in Europe. This report is the ninth edition of the Annual Asthma Survey, but our first as Asthma + Lung UK.

It sets out the changes needed to transform asthma care and treatment, to help ensure millions of people's right to breathe.

Lung health outcomes in the UK are dismal

Asthma deaths have increased by a quarter (26%) over the last decade[2] and we have one of the worst asthma death rates in Europe.[3] Yet, we know that two thirds of asthma deaths are preventable with better basic care.

Women are worst impacted. They are almost twice as likely to die from an asthma attack than men.[4] We need more research into the role of sex hormones to understand why this is and will be launching a campaign to raise awareness and fund more research in spring 2022.

In 2022 we have innovative and life-changing treatments which are available on the NHS, but, across the UK, the blue reliever inhaler remains the mainstay of asthma treatment despite calls for its removal as sole treatment in the over 12s due to safety concerns.[5]

The UK ranks second from bottom when compared to similar European countries for uptake of life-changing biologic drugs.[6] For too long we have lagged behind other countries. Now is the time for the policy makers to ensure we are world leaders in asthma treatment, care, and research.

Worst levels of basic asthma care in six years

Our survey found that only 30% of people with asthma received basic care last year. The lowest since 2015. This equates to around 3.8 million people with asthma not getting even the most basic elements of care. The COVID-19 pandemic forced a move to remote care, but we don't yet have the technology or skills in primary care to be delivering good quality basic care remotely. This has meant a huge reduction in access to basic asthma care.

People with uncontrolled asthma are being failed by the system

Uncontrolled asthma – that is, having frequent symptoms that interfere with everyday life, requiring multiple relievers or oral steroids – can have a devastating impact on every part of someone's life. Almost half (48%) of people with asthma have uncontrolled symptoms that require oral steroids or multiple reliever inhalers every year. This is being fuelled by the lack of basic care, poor access to tests such as **Fractional Exhaled Nitric Oxide (FeNO)** and spirometry and not enough research into different types of asthma and how they should be treated.

Despite evidence that poor inhaler technique increases the likelihood of asthma attacks, we found just 27% of people with uncontrolled asthma had their inhaler technique checked last year. We need to move towards pathways that make sure those most at risk of uncontrolled asthma can be identified, have their treatment optimised and be referred to a specialist for life-changing biologic drugs.

Misunderstanding about asthma is leaving people exposed

Our survey found that the vast majority of people with asthma still use a separate reliever inhaler, with one in five people using six or more inhalers in the last year. Almost 90% of people are at risk of being over reliant on their reliever inhaler. This reinforces wider evidence that reliever inhalers are being over relied upon, leaving many people with asthma unprotected because reliever inhalers do not provide adequate protection.

It's time for asthma to get the attention it deserves

People with asthma are not currently being equipped with adequate tools, such as digital apps, to understand their condition, self-manage or remain adherent to their treatments. And what is available, is largely not fit for purpose. There is a huge potential for the UK to become a pioneer in asthma treatment, technology, and research to radically change outcomes for people with asthma.

Our five-point plan

We're calling on policy makers across the UK to implement the following recommendations:

1. **Health services must ensure access to basic care for everyone with asthma**. This should include testing, developing and adopting new ways to diagnose the condition and help people manage their own health. Good access to basic care and better technology, such as digital apps, is essential to help people with asthma manage their own condition effectively.

2. **Health services need to implement pathways that identify those with uncontrolled asthma who are most at risk of a life-threatening asthma attack**. By doing this, we can ensure those who need it get the treatment they need as soon as possible including referral for specialist assessments and access to life-changing biologic drugs, where appropriate. Adoption of the Accelerated Access Collaborative's uncontrolled asthma pathway offers a huge opportunity for policy makers across the UK to do just this.

3. **Treatment guidelines should be amended to reduce the role of reliever inhalers in care** and embrace new treatments such as biologics, in order to improve outcomes for millions with asthma.

4. **Policy makers need to ensure everyone with suspected asthma gets the timely and accurate diagnosis they deserve**. This must include improving access to current diagnostic tests (including FeNO and spirometry) and funding research to develop more accurate and at-home diagnostic tests for the future. Without a proper diagnosis, people with asthma can't be treated effectively and will continue to cycle through the system without the right care and support.

5. **Policy makers should ensure that lung health is a priority in all plans to tackle health disparities, given its significant role in fuelling poor health outcomes across the UK**. This should include funding more research into the role of sex hormones, prioritizing prevention and changing the way asthma data is collected to record ethnicity and income. And funding targeted breathlessness awareness campaigns to the communities that need it most.

About this survey

The survey was conducted by Asthma + Lung UK from September 2021 to January 2022. It was online, and responses were encouraged via both paid and organic social media promotion, emails to our supporter base and promotion on our website. After data cleaning (removing duplicate and incomplete responses), we received 8,300 responses. Of this number, 215 were completed by people under 18, or by those who care for them. This number means we have not conducted extensive analysis here of the data for children. Survey questions are available in Appendix 1, and a full breakdown of the demographics or the survey respondents, as well as data tables for this report and references, is available in Appendix 2.

Chapter 1: Making it known that asthma is serious

Asthma is serious. It can have a devastating impact on people's lives and tragically four people still die every day from an asthma attack in the UK.[7] This chapter sets out the impact that asthma can have on everyday life and how asthma is still not taken seriously by the public, people with asthma, the NHS and the government. It also shows how women and those on the lowest incomes are worst impacted. It argues that asthma must be made a priority to tackle health disparities and taken more seriously through increased research and awareness campaigns.

Lung health is everyone's problem but it's not being taken seriously

Our survey found over half of people with asthma don't think that their asthma is taken seriously. More than one in five have faced discrimination because of their asthma. This is despite 5.4 million people being affected by asthma.

Millions are living in fear of their next asthma attack

According to our survey results, almost half (48%) of people with asthma have uncontrolled asthma symptoms that require oral steroids (which can cause devastating side effects such as bone damage and weight gain) or multiple reliever inhalers every year (figure 1 shows this breakdown). Many people with asthma therefore live in constant fear of their next asthma attack. And we know that too often people are relying on their reliever inhaler, which is putting them at increased risk of a life-threatening asthma attack.[8]

Figure 1: Percentage of people with asthma needing reliever inhalers and oral steroids

The poorest people are affected the most

Uncontrolled asthma, or sometimes referred to as 'difficult' asthma, is caused by a range of factors, often underpinned by a lack of basic care. These factors include poor adherence, other untreated health conditions, poor mental health, smoking, life-style factors and even the wrong diagnosis altogether. Once again, the poorest are hit hardest. Our survey shows 54% from our lowest household income bracket (below £20,000 a year) have uncontrolled asthma symptoms, compared to 40% from the highest income bracket (above £70,000 a year).[9]

Women are more likely to die and have uncontrolled symptoms

Our recent analysis shows that women are almost twice as likely to die from an asthma attack than men.[10] Our survey also shows that women are more likely to need unscheduled healthcare and to have taken oral steroids in the last year to treat an asthma attack. Evidence suggests that sex hormones may play an important role as well as gender-based health inequalities, but this a severely under researched area.[11]

We need change

Policy makers need to ensure:

- Investment into an awareness raising campaign to increase public and healthcare professional awareness of what asthma is and how serious it can be.
- Provision of a large-scale funding call to investigate the influence of sex differences on adult asthma. Without this vital research, women will continue to be unfairly impacted by asthma.
- Lung health is made a priority in plans to tackle health disparities across government, in order to level up asthma outcomes across the UK.

Fiona's story

Fiona Doyle, 38, a nursery schoolteacher from East Finchley, has been hospitalised three times in the past ten years because of her asthma and worries about the impact her condition has on her eight-year-old daughter Ciara.

"I was diagnosed with asthma as a child after periods of wheezing and shortness of breath. It was just a part of my life – something that didn't affect me day to day or that I worried too much about.

The turning point came when I was 25, when I'd come down with both pneumonia and swine flu at the same time and that led to a life-threatening asthma attack. I was in hospital for nearly two weeks, hooked up to machines and with doctors so concerned about me they were considering putting me in an induced coma. With hindsight if I had been more diligent with taking my medication and been more on top of spotting the signs of an asthma attack, I may not have ended up in hospital. But as crazy as it sounds, after I made a full recovery from this terrifying attack, I admit I fell back into my old mindset of not taking my condition seriously.

Having my daughter, Ciara, was the wake-up call I needed to get on top of my asthma. Ciara and I are joined at the hip. When I was hospitalised in 2015 with another asthma attack, it was quite traumatic for her. She didn't really understand what was going on or why I wasn't at home. I don't want her to see me in intensive care, rigged up to monitors with tubes up my nose and needles in my arms.

I now take my asthma more seriously and attend regular asthma reviews with my GP. Everyone should be entitled to an annual review – they're an essential part of keeping me well and I find them a really helpful reminder about how to manage my symptoms. I've learnt that asthma doesn't come and go, you must manage it. I take my condition far more seriously now that I am a mother. I have someone else who depends on me to be healthy and that's more than enough of an incentive to care for myself and manage my asthma properly. Some people think asthma is just a mild condition but it's put me in hospital and kept me away from my daughter – everyone should take it seriously."

Chapter 2: Fighting for the right to basic asthma care

We're fighting for everyone's right to basic asthma care, including a written asthma action plan, inhaler technique check and annual review. Our survey found the lowest levels of asthma basic care in the last six years. This chapter sets out the current state of asthma care and recommends urgent action to increase access to basic care, faster identification and treatment of people with uncontrolled asthma and better technology to improve remote care.

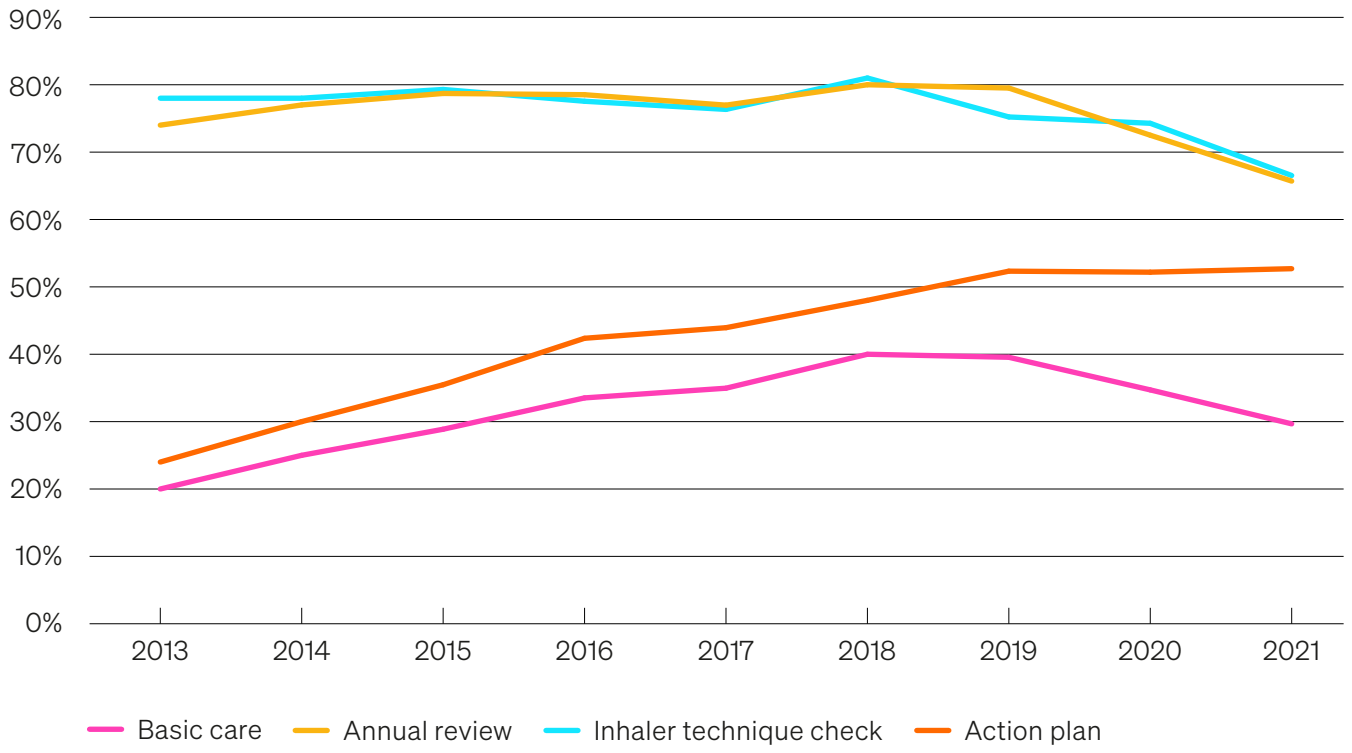
The pandemic has hit basic asthma care hard

Our survey has shown that only 30% of people with asthma received basic care last year. The lowest since 2015 (figure 2). This is equivalent to around 3.8 million people with asthma not getting the fundamental basics needed to help them manage their condition.

"The components of basic care are opportunities to help people with asthma to understand their condition, to know how to keep their asthma under control and know when to seek help. Without good access to basic care, people with asthma can't be expected to know how to self-manage their condition well."

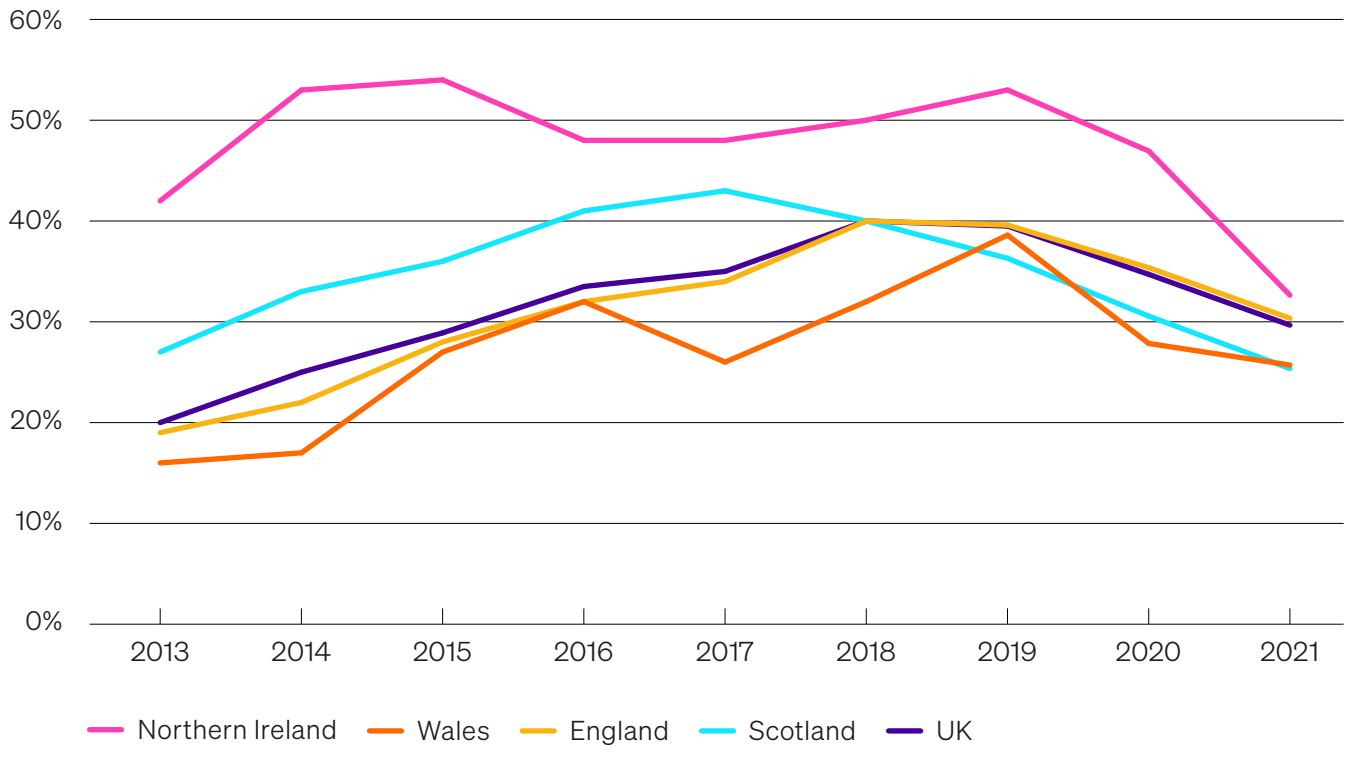
Dr. Andy Whittamore, GP

Figure 2: Access to basic care from 2013 to 2021



Basic care levels have fallen across the UK. The biggest fall was in Northern Ireland, which is down 14% compared to last year and now stands at 33%. For the first time, Scotland has the worst level of care at just 25%, closely followed by Wales at 26% and England at 30% (Figure 3).

Figure 3: Access to basic care by nation 2013–2021



The move to remote care left people behind

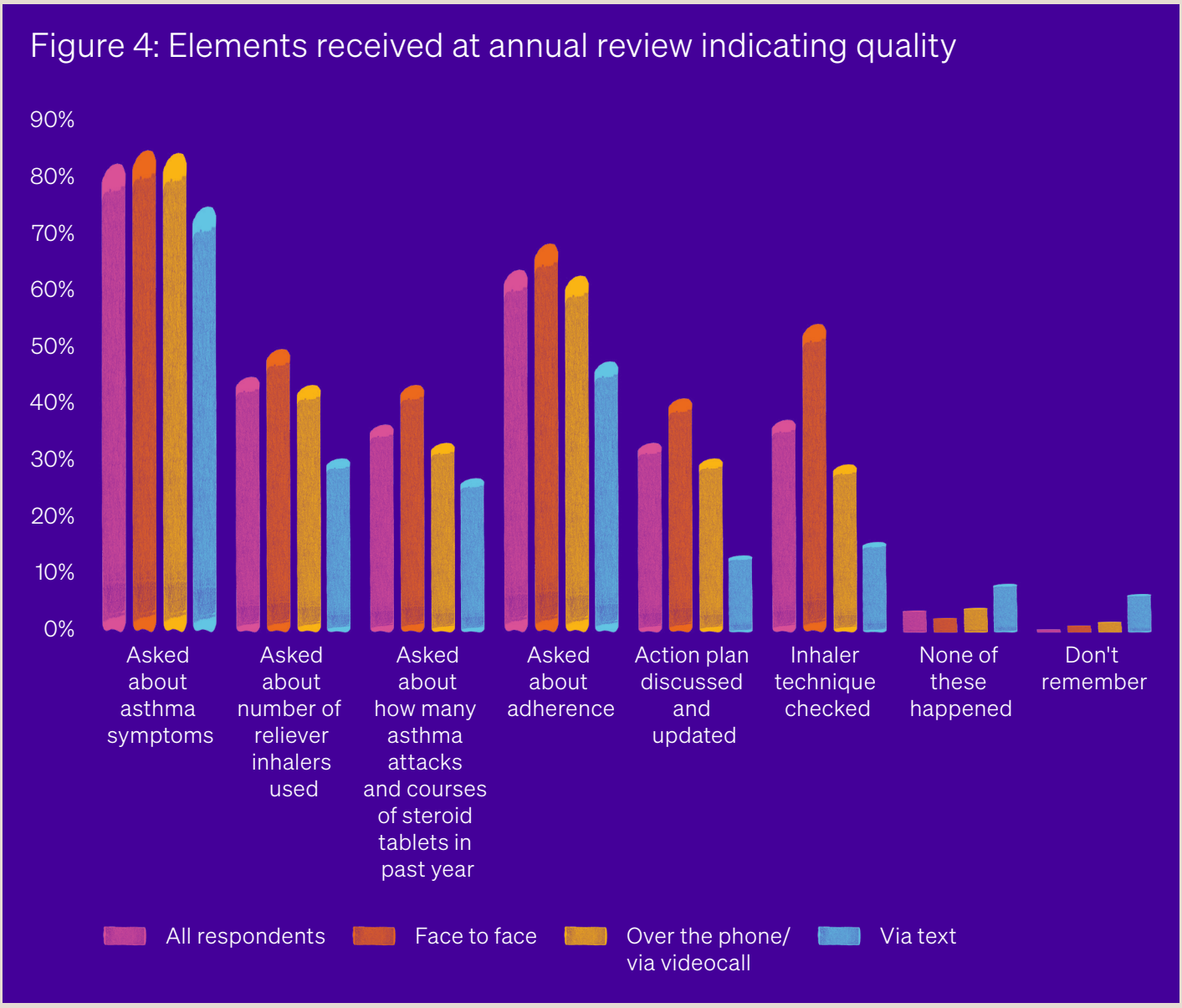
The COVID-19 pandemic drastically sped up the move to remote care. This should have been an opportunity to increase access to basic care. Instead, it has become one of the biggest barriers to access.

Our survey respondents stated they were more likely to receive a better-quality annual review if it is conducted face to face compared with one done remotely (figure 4 shows the different elements of what makes a good quality annual review and how this compares by mode). Inhaler technique checks can be done remotely with the right resources and training (the Taskforce for Lung Health has created a **helpful resource**), but worryingly they are now at the lowest they have ever been since we started this survey in 2013.

Diagnostic tests have also been hit hard by the pandemic. Spirometry has still not restarted in most of primary care and despite investment into increasing uptake of FeNO and creating Community Diagnostic Centres (CDCs), proper diagnosis of asthma is not happening across the UK.

There has however been an increase in provision of written asthma action plans, which is now incentivised by the Quality Outcome Framework (QOF) in England. This increase may have occurred because action plans are more easily adapted for remote provision and as a result of payment incentives in England, however the quality of this provision is unclear. For example, we don't know if they are being co-written with people with asthma (which they should be) or to what extent they are being used. Overall, our survey has shown that we don't yet have the technology or skills in primary care to be delivering good quality basic care remotely. This has meant the care people with asthma received last year has severely suffered.

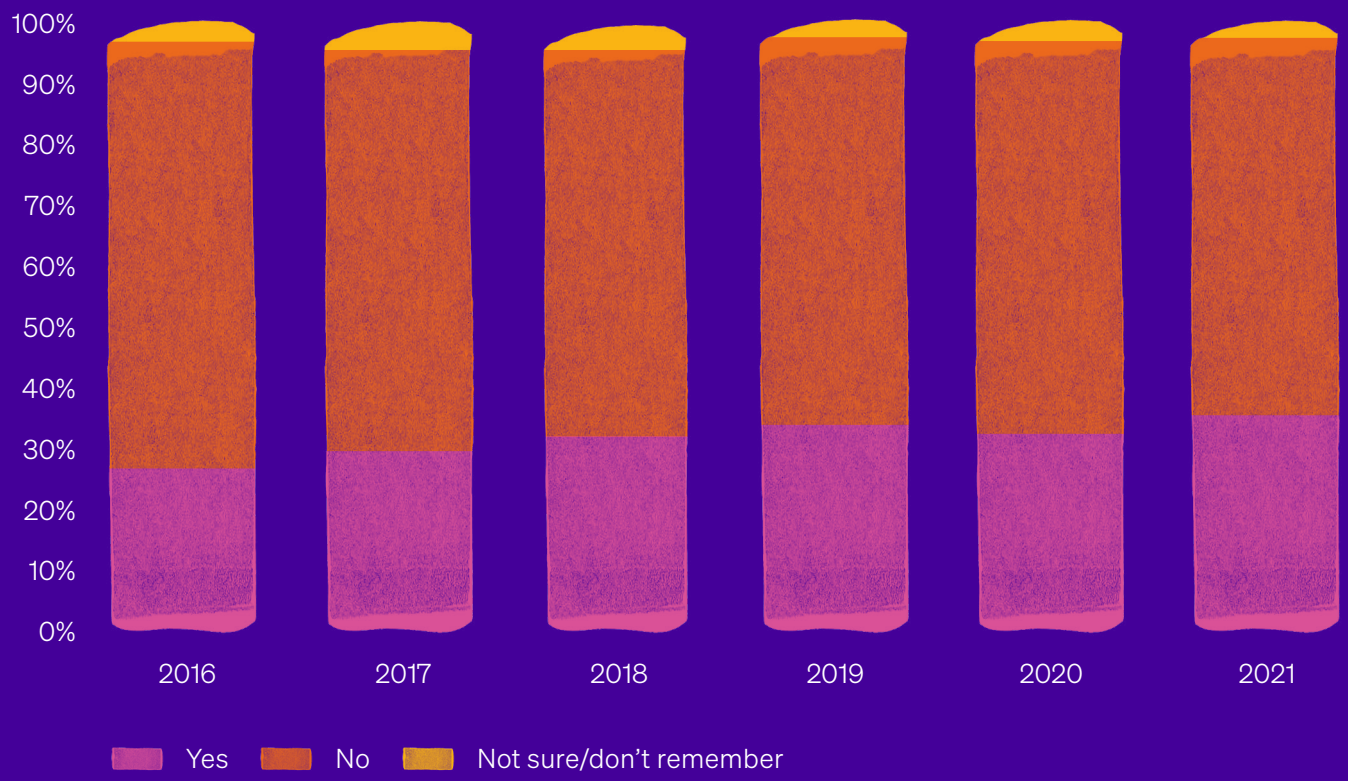
Figure 4: Elements received at annual review indicating quality



Follow up for emergency care is also lacking

Although we have seen some improvement, our survey has shown that 62% of people who received emergency or unscheduled care did not get a follow-up within 2 working days as recommended by the National Institute of Health and Care Excellence (NICE) clinical guidelines (figure 5). In fact, 42% said they did not feel supported after receiving emergency care. This follow-up care is crucial in preventing future asthma attacks through proper assessment. It is an opportunity to deliver basic care and restate the seriousness of asthma and the need to take treatment regularly to prevent asthma attacks.

Figure 5: Follow-up after emergency care within 2 working days 2016 to 2021



Treating uncontrolled asthma should be simple

If we tackled uncontrolled asthma, a huge difference could be made to asthma outcomes across the UK. Those with uncontrolled asthma (defined in this report as needing oral steroids or six or more relievers in the last 12 months) should be proactively identified, have their asthma diagnosis confirmed and receive a structured assessment. This allows the root cause of their asthma symptoms to be identified and their treatment tailored to prevent future asthma attacks. It is recommended by NICE guidelines that two diagnostic tests, spirometry and FeNO, should be used to confirm diagnosis.[12] However, only 15% of people we surveyed had ever even heard of a FeNO test. It is crucial that there is funding available so people with asthma can access these diagnostic tests locally.

An approach has been developed called SIMPLES to review a person with uncontrolled asthma once diagnosis is confirmed that should be adopted across the UK. This includes[13]:

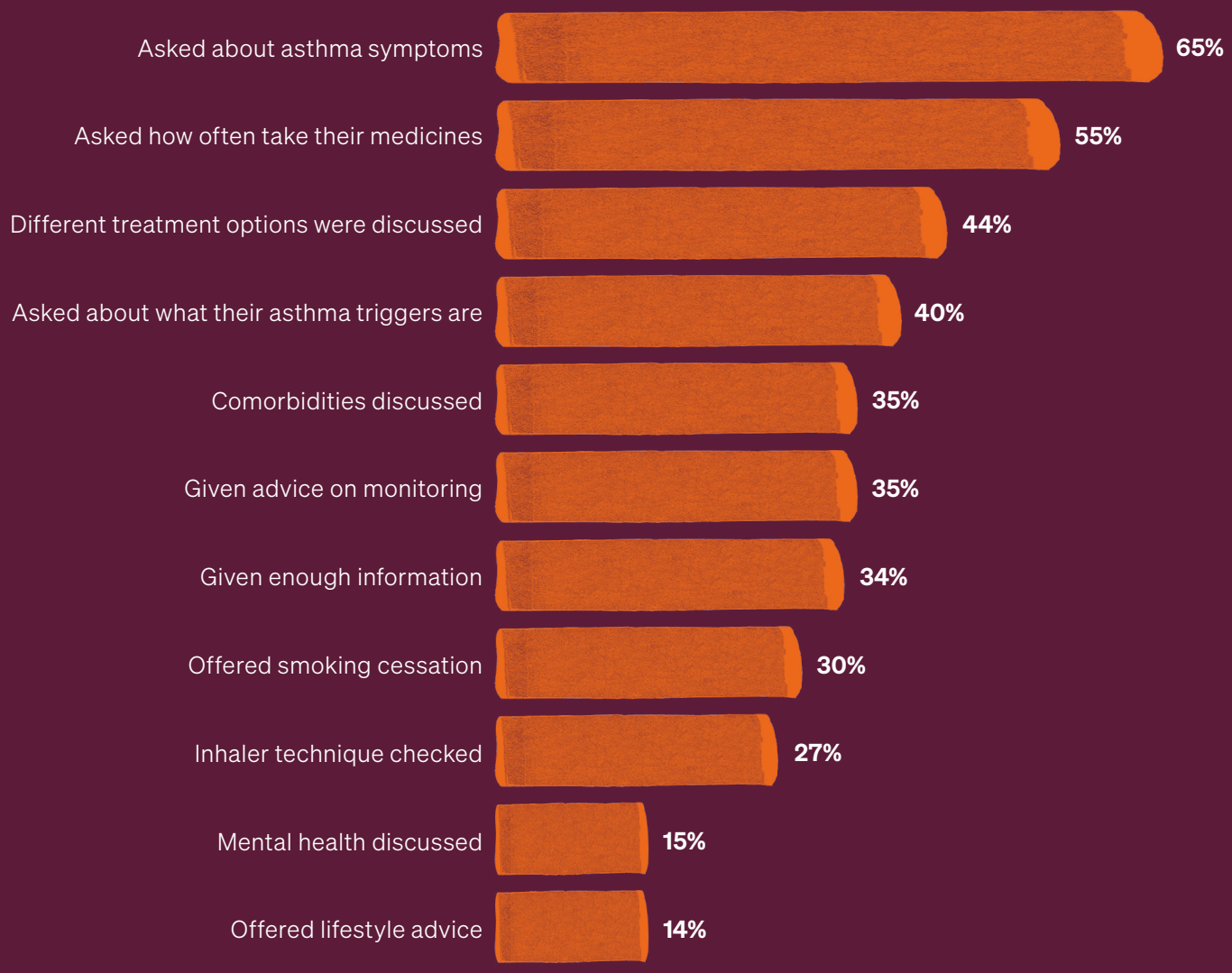
- Support to stop smoking
- Inhaler technique (being shown how to use their inhaler by a trained healthcare professional)
- Monitoring (assessing symptoms and monitoring peak flow)
- Pharmacotherapy (including increasing inhaled corticosteroids and addressing adherence)
- Lifestyle (advice on diet, exercise, alcohol and weight maintenance, as well addressing and treating comorbidities)
- Education (understanding of the condition and written asthma action plan in place)
- Support (structured reviews)

Multiple opportunities are being missed to transform people's lives

We found that in the last year most people with uncontrolled asthma (figure 6) didn't get the support they deserve and need:

- More than one in three weren't even asked about their asthma symptoms.
- Less than a third of people who smoke were offered support to quit.
- Just 27% had their inhaler technique checked.
- Two thirds didn't believe they had been given enough information to understand their condition or their treatments and similar numbers weren't given the tools to help them monitor their symptoms.
- Less than half had different treatment options discussed with them or had their inhaler changed (such as to a stronger dose preventer).
- Hardly anyone (15%) was given lifestyle advice or asked how their mental health might be impacting their asthma.

Figure 6: Elements of SIMPLES received by people with uncontrolled asthma in the last year



Fuelling the UK's dismal track record on lung health

The lack of care and support for the estimated 2.51 million people with uncontrolled asthma is fuelling some of the worst asthma outcomes in Europe. It is time to prioritise people with asthma. Health services across the UK need to be more proactive. Early identification and treatment optimisation through structured assessment, such as SIMPLES, could be lifesaving. This will also enable faster identification of people with severe asthma who need to be referred to a specialist for access to life-changing biologic treatments.

We need change

Policy makers need to ensure:

- Urgent action to improve remote care, increase access to basic care and address the backlog created by the COVID-19 pandemic.
- More proactive identification and treatment of people with uncontrolled or difficult asthma through structured assessment in primary care and appropriate referral to specialist asthma services.
- Restarting of diagnostic tests in primary care and the funding available to ensure easy and timely access to diagnostics locally. We also need investment in research into the development of more accurate and at-home diagnostic tests for the future.

Louise's story

Louise Horwood, 31, from Lincolnshire, has had asthma since she was a child, but it developed into severe asthma in her early 20s. She's now struggling to hold down her job as she battles life-threatening asthma attacks and regular doses of oral steroids, which have serious side effects. She says:

"I had my first asthma attack in my early twenties at work – one moment I was joking and laughing with colleagues and the next thing I knew I was gasping for breath with an ambulance on its way. At the time I hoped it was a one-off, but that was the moment my life started to go completely downhill."

Now Louise, a veterinary receptionist, has been taking oral steroids consistently for almost three years. These drugs are used to treat severe asthma and can be life-saving, but they also come with serious side effects. Louise has experienced weight gain and 'moon face', putting on three stone in the past year. She continues:

"Repeated steroids have terrible side effects and have weakened my bones. In September I stood awkwardly on a stone on my driveway, and because my bones are so fragile I ended up breaking my ankle and had to wear a walking boot. These side effects are devastating, but if I don't take the steroids my asthma symptoms quickly flare up, causing me to struggle to breathe, to cough and wheeze.

"Trying to hold down my job and live my life as normally as possible is nearly impossible. Before I was diagnosed with severe asthma, I was an active, happy person who enjoyed the outdoors, spending time with my dog and my horse, and seeing my friends regularly. Now I'm clinging on to my part-time job and am too scared to leave the house in case I have an asthma attack. I live with my mum and on my bad days she is basically my carer."

Like many people living with severe asthma, Louise has been disappointed by the care she's received from healthcare professionals, which she describes as patchy. Louise had good care when she lived in the south but since she moved up north she says her GP didn't seem "clued up" on asthma advise and told her off for over-using her inhaler when she believed she was simply following her respiratory team's advice.

Chapter 3: Transforming asthma treatments, together

Over the last few decades, there has been a huge increase in the treatments available for people with asthma. Yet too many people still depend on their blue reliever inhalers, and many are taking medications that hold back their lives through their side effects, such as oral steroids. This chapter finds that asthma treatment in the UK is outdated and ineffective, that policy makers need to set out new pathways to make sure everyone with asthma is getting the treatment and care they need and deserve.

People aren't getting the treatments they need or deserve

We now have combinations of inhaled drugs which are easy to use and very effective for most people with asthma, and we have truly life-changing biologic treatments for severe asthma. We have also seen huge advances in technology which could provide the basis for much more tailored digital self-management tools if they are carefully tailored towards people with asthma's behaviours.[14]

Yet, despite these advances, the reliever inhaler remains the mainstay of asthma treatment in the UK, and we rank second from the bottom in uptake of biologics when compared to similar European countries.[15] As a result, many people are left struggling unnecessarily on oral steroids, which have nasty side effects including weight gain and osteoporosis.[16]

Likewise, most existing digital tools for self-management, such as apps, are not fit for purpose and the current NHS infrastructure has been slow to adopt new innovation that could be transformative.

Jo's story

Jo Beecroft, 41, spent much of her 30s being rushed to hospital after being diagnosed with severe asthma in 2014 following an unexpected and very frightening asthma attack at her work Christmas party.

Asthma affected every aspect of Jo's life, but now she feels like a new woman after being given biologic drugs. Biologic drugs work by stopping the body processes that cause lung inflammation, and can truly be a game-changer for people with the severest form of asthma. Before being given a new lease of life by biologic drugs, Jo was instead being prescribed regular doses of oral steroids to manage her attacks, but these had debilitating side effects:

"I wouldn't wish the side effects I experienced from oral steroids on my worst enemy. I would be on steroids for less than a week and put on half a stone in weight, and the changes in my mood were so intense and horrible I'm surprised my husband stuck by me. I'd wake up each morning and not know what Jo I would be that day – irritable, teary, angry, moody. The depressive episodes were unbearable."

Jo, a project manager from Bristol, struggled on with her severe asthma for five years, being rushed to hospital from a friend's wedding after experiencing an asthma attack and being jokingly nicknamed 'sick note' at her work because of the amount of time she was needing to take off. Her social life grinded to a halt and she had a backpack at home ready to go with a change of clothes, phone charger, toiletries and a book in preparation for a sudden trip to hospital.

Life changed when Jo was put on biologic drugs in December 2019:

"Biologic drugs have given me my life back. I noticed a huge improvement almost immediately and haven't needed to take steroids since. I can now exercise and have regained my independence and social life. I find it so upsetting that there are many people who are still in the same boat I was in several years ago, and I think it's vital that anyone who is eligible for these drugs can access them as they've truly changed my life."

The problem with reliever inhalers

Reliever inhalers are lifesaving in an asthma attack, but they don't treat the underlying causes of asthma symptoms. It is estimated that 20% of people with asthma aren't prescribed a preventer inhaler, which means over a million people with asthma solely rely on a reliever inhaler for treating their condition.[17] We know that many people with asthma also don't take their preventer medication regularly and instead rely on their reliever.

More than a third of people are high risk of being over-reliant

The UK has a huge problem with overuse and overreliance on reliever inhalers. Most people we surveyed have a separate reliever inhaler (94%) and more than one in five (21%) used six or more relievers in the last year, even though people should at most be using one or two a year. Using the **validated reliever reliance questionnaire**, we assessed the risk of overreliance on reliever inhalers in the general asthma population.

Alarmingly, we found that more than a third of people are considered at 'high risk' of being over reliant on their reliever inhaler and more than half are medium risk. We also found:

- Almost a quarter of people said that their reliever inhaler is the only asthma treatment they can rely on
- 18% said they prefer to rely on their reliever inhaler rather than their preventer
- More than half said they don't worry about their asthma if they have their reliever

This is even though the standard blue reliever inhaler does not treat the underlying causes of asthma. A regular preventer inhaler dampens down the inflammation that causes asthma symptoms and increases the risk of life-threatening asthma attacks.

This is putting lives at risk

Overuse of reliever inhalers is associated with increased risk of asthma attacks, hospital admissions and even death.[18] Often, people with asthma are being encouraged to treat their symptoms with their reliever inhaler rather than to address the root causes of these symptoms.

Every single day, people's lives are being put at risk. Many are unaware of the rationale behind the treatments that they are given, and many healthcare professionals do not adequately monitor or assess patients who appear to be overusing their reliever or underusing their preventer therapies. Since relievers give instant relief to symptoms, it is often perceived as more effective than preventer medication.[19] In fact, there is evidence to suggest that some people develop a complex behavioural relationship with their reliever and this if often referred to as 'overreliance'.[20] The quotes below show how many people incorrectly view their inhalers. Although someone should have a reliever on them all the time, they should hardly be used because the preventer inhaler is working quietly in the background.

"This is like my little miniature child. Like it's just part of who I am. It comes with me everywhere [describing reliever inhaler]."

"Because the blue one [reliever inhaler] is going to save my life. The purple one is... I don't know, the preventer or whatever, so it prevents the attacks. The blue is the cure. It's like that's the holy grail of my life, the blue. The purple one, I don't really have the same attachment to it."

A bold step forward in asthma treatment

The current treatment pathway is simply not working. The misunderstanding about which asthma treatments are most important is leaving people with asthma unprotected and exposed to deadly asthma attacks. For decades, blue reliever inhalers have been given as first line treatment for asthma, but we now have safer combination inhalers that can both relieve symptoms and treat the underlying causes of asthma (known as maintenance and reliever therapies or MART).[21]

Despite **our calls for more research**, there are still not adequate treatments for the substantial numbers of people who respond poorly to inhaled steroids or for whom biologic treatments don't work.

The UK, with its track record in developing asthma treatments has an opportunity to lead the world in developing new asthma treatments and testing new technology to radically improve outcomes for people with asthma.

We need change

Policy makers need to ensure:

Treatment guidelines are changed through the NICE/BTS/SIGN joint asthma guideline:

- There needs to be clear guidance showing that repeated steroid tablet use is a failure of asthma management, prompting urgent action and appropriate referral to a specialist
- Treatment guidelines should reflect the evidence showing the dangers of reliever inhalers prescribed without preventative treatment or as first line treatment, so that reliever inhalers are no longer over relied upon.
- There should be greater emphasis on the prescribing of maintenance and reliever therapies as an alternative to reliever inhalers.

Increased access to biologic treatments:

- Governments must recommit to bringing access to biologics for people with severe asthma in line with other European countries.
- Health services must radically rethink the asthma pathway so that people with suspected severe asthma are identified, referred, and put on biologic treatments faster.[22]

Investment in more research:

- Governments must invest in more research into better treatments for people with asthma who don't respond to existing treatments.

Adoption of technology:

- Health services need to test and adopt new diagnostic and self-management technologies making them available to everyone who needs them.

Chapter 4: Demanding a new way forward

For years, the asthma pathway has been confusing and inadequate for people with asthma and healthcare professionals alike. It has meant poor access to life-changing treatments and contributed to some of the worst asthma outcomes in Europe. This chapter sets out how we can transform asthma care if governments across the UK implement Asthma + Lung UK's five-point plan.

A new pathway for transformation

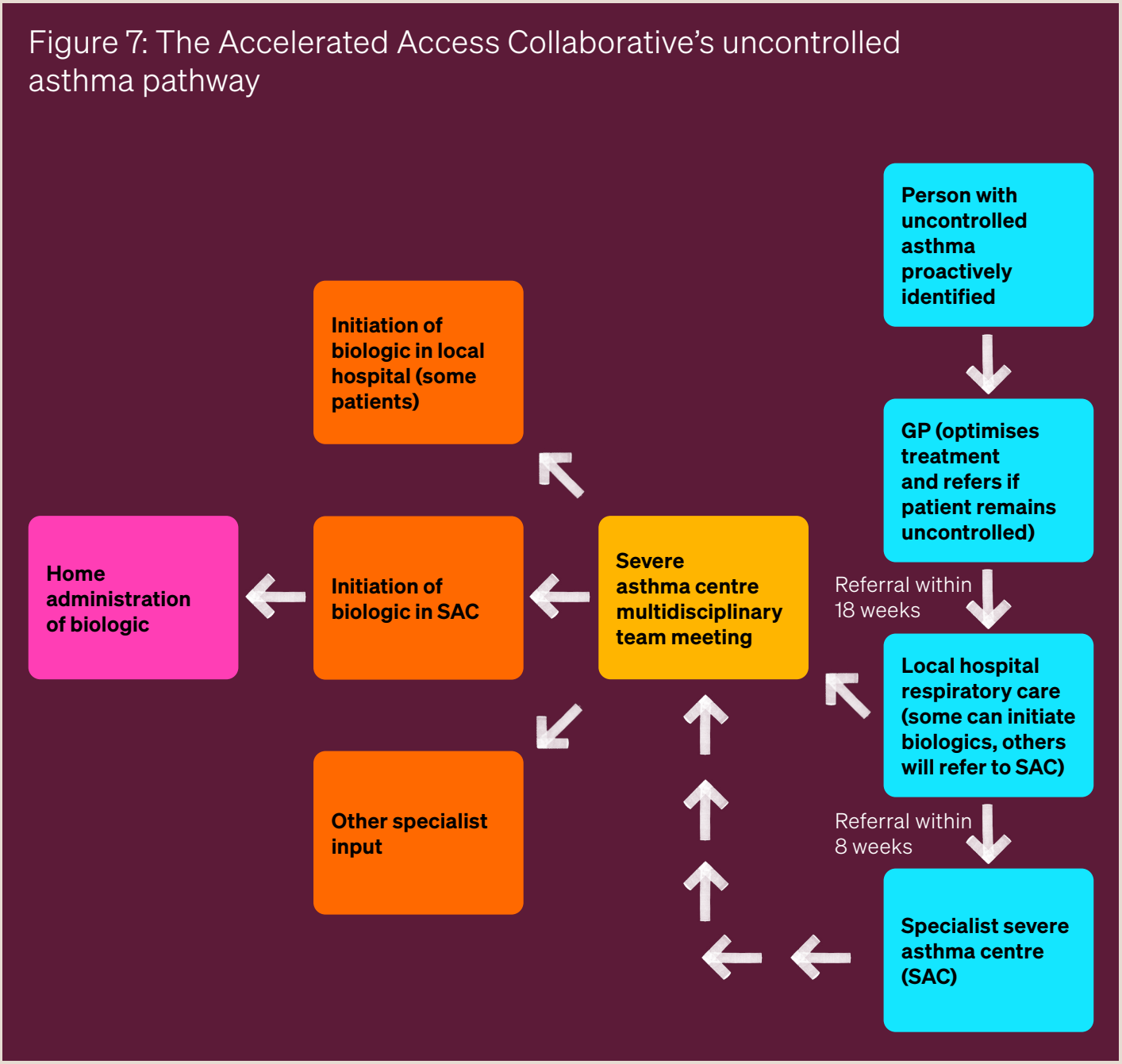
The Accelerated Access Collaborative* has created an asthma pathway for England which has the potential to transform adult asthma care and treatment if implemented (figure 7).

Through risk stratification and proactive identification, the new pathway identifies those with uncontrolled asthma and optimises their treatment through structured assessment such as the SIMPLES approach. It advocates timely referral to a specialist for anyone with persistent poor asthma control and presents solutions to increase capacity in specialist centres to get more people onto biologics faster. It has the potential to address many of the problems highlighted in this report, but for this to happen it needs to be adopted regionally and supported by pipeline technology and innovation. At a local level, there are already good examples of risk stratification happening, such as in **Portsdown Group Practice**.

Where applicable, we also want to see elements of this pathway implemented across Scotland, Wales and Northern Ireland and adopted for children and young people. There are huge opportunities to learn from England's experience and transform lives across the UK.

* The NHS Accelerated Access Collaborative runs Rapid Uptake Products (RUP) programmes to support stronger adoption and spread of proven innovations. It identifies and supports products with NICE approval that support the NHS Long Term Plan's key clinical priorities but have lower than expected uptake to date. Asthma biologics and FeNO were accepted onto the programme in 2021.

Figure 7: The Accelerated Access Collaborative's uncontrolled asthma pathway



Innovative and life-changing drugs are available, but only if people can access them

We need to move away from the reliever inhaler as the mainstay of asthma treatment and look to more effective and safer treatment options. We welcome the incentives for England introduced in April 2022 that aim to increase the prescribing of preventative treatment and reduce the prescribing of relievers. However, this must be accompanied by proper treatment optimisation and education, such as SIMPLES, to ensure people with asthma aren't denied the treatment they need and are fully supported.

We're demanding a new way forward

We are calling on governments across the UK to implement Asthma + Lung UK's five-point plan to transform asthma care by 2027:

Our five-point plan

We're calling on policy makers across the UK to implement the following recommendations:

1. **Health services must ensure access to basic care for everyone with asthma**. This should include testing, developing and adopting new ways to diagnose the condition and help people manage their own health. Good access to basic care and better technology, such as digital apps, is essential to help people with asthma manage their own condition effectively.

2. **Health services need to implement pathways that identify those with uncontrolled asthma who are most at risk of a life-threatening asthma attack**. By doing this, we can ensure those who need it get the treatment they need as soon as possible including referral for specialist assessments and access to life-changing biologic drugs, where appropriate. Adoption of the Accelerated Access Collaborative's uncontrolled asthma pathway offers a huge opportunity for policy makers across the UK to do just this.

3. **Treatment guidelines across the UK need to be amended to reduce the role of reliever inhalers in care** and embrace new treatments such as biologics to improve outcomes for millions with asthma.

4. **Policy makers need to ensure everyone with suspected asthma gets the timely and accurate diagnosis they deserve**. This must include improving access to current diagnostic tests (including FeNO and spirometry) and funding research to develop more accurate and at-home diagnostic tests for the future. Without a proper diagnosis, people with asthma can't be treated effectively and will continue to cycle through the system without the right care and support.

5. **Policy makers should ensure that lung health is a priority in all plans to tackle health disparities, given its significant role in fuelling poor health outcomes across the UK**. This should include funding more research into the role of sex hormones, as well changing the way asthma data is collected to record ethnicity and income. And funding targeted breathlessness awareness campaigns to the communities that need it most.

Concluding remarks

It is time the voices of people with asthma are heard at the very top. The UK must start taking asthma seriously. Millions aren't receiving basic care. And our survey found this got worse last year.

We have one of the worst asthma death rates in Europe and access to life-changing treatments remains stubbornly low. In some areas more research is needed, for instance we don't understand the role that sex hormones play or how to treat asthma that does not respond to inhaled therapies or biologics, but in many others, we already know what works.

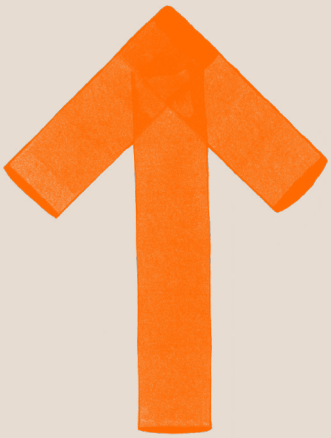
People with asthma are our loved ones, our leaders and our children. A better life with asthma is entirely possible for everyone, with bold improvements to treatment, care and support. As well as by targeting investment in lung health research, that still lags far behind other condition areas.

Our vision is for a world where everyone breathes with healthy lungs. A world where no one has to unnecessarily fight for breath because their treatment, care or support wasn't fit for purpose. Where no one with asthma ends up unnecessarily hospitalised, and where innovation is put at the heart of lung health research to transform the condition for future generations.

We're calling on politicians to take stock and listen. To hear the stories and experiences of the thousands of people with asthma who responded to this year's survey and take urgent action.

Are you ready for the challenge? Help us fight for breath today:

AsthmaAndLung.org.uk



Appendices

Appendix 1: Survey questions

1. Where do you live?
    a. England
    b. Northern Ireland
    c. Scotland
    d. Wales

2. Which region do you live in [English answers]?
    a. East Midlands
    b. East of England
    c. London
    d. North East
    e. North West
    f. South East
    g. South West
    h. West Midlands
    i. Yorkshire and the Humber

3. What is your gender?
    a. Male
    b. Female
    c. Other

4. What is your age?
    [numerical value]

5. Please tell us the total annual income of your household (before tax and deductions, but including benefits/allowances)?
    a. Below £20,000
    b. £20,000–£30,000
    c. £30,001–£40,000
    d. £40,001–£70,000
    e. Above £70,000
    f. Rather not say

6. In the last 4 weeks have you/your child had any usual asthma symptoms such as cough, wheeze, chest tightness or shortness of breath **during the day**, more than twice a week?
    a. Yes
    b. No
    c. Don't remember

7. In the last four weeks, have you or your child been woken up during the night because of your/their asthma?
    a. Yes
    b. No
    c. Don't remember

8. In the last four weeks have you or your child needed to use your/their reliever inhaler more than twice a week?
    a. Yes
    b. No
    c. Don't remember

9. In the last four weeks, has you or your child's asthma interfered with usual daily activities, for example performing work/housework or going to school/activities?

    a. Yes
    b. No
    c. Don't remember

10. Do(es) you/your child currently have a written action plan for managing your/their asthma to help understand when symptoms are getting worse and what to do about it?

    a. Yes
    b. No

11. Have you/child had a planned review or planned check-up (sometimes called your annual review) of your asthma with your doctor or nurse in the last year?

    a. Yes – face to face
    b. Yes – over the phone
    c. Yes – online (i.e. via videocall, online or text)
    d. No
    e. Not sure

12. How would you prefer to have your annual asthma review?

    a. Face to face
    b. Over the phone or via videocall
    c. Online or by text only)
    d. Not sure

13. Thinking of your/child's last planned asthma review (sometimes called your annual review), which of the following happened?
    Tick all that apply

    a. I was asked about my asthma symptoms (e.g. if your asthma wakes you at night or interferes with your usual activities)
    b. I was asked how many reliever inhalers I have used in the last year
    c. I was asked about how many asthma attacks and courses of steroid tablets I have had in the last year
    d. I was asked about how often I take my preventer inhaler and if I ever miss puffs
    e. My written asthma action plan was discussed and updated
    f. The doctor/nurse made sure I could use all my inhalers correctly
    g. I can't remember
    h. None of the above

14. Did your/child's doctor or nurse help you make sure you could correctly use ALL your current types of inhaler before you started using them?

    a. Yes
    b. No
    c. Do not remember

15. Have you/your child received emergency/ unplanned care at a hospital or out-of-hours centre for your asthma in the past year?

    a. Yes
    b. No
    c. Don't remember

16. The last time you/your child received emergency/ unplanned or out-of-hours centre, did you have a follow up appointment for your asthma within 2 working days?

    a. Yes, I had a face to face appointment with the doctor/nurse
    b. Yes, I had a telephone appointment with the doctor/nurse
    c. No, but I had one within 2 weeks
    d. No
    e. I'm not sure /I can't remember

17. Which of the following statements apply to you?
    Select all that apply

    a. I have previously taken oral steroid tablets (e.g prednisolone)/had a steroid injection for my asthma, but not in the last year
    b. I have had 1 course of oral steroid tablets (e.g prednisolone)/steroid injection in the last year
    c. I have had 2 courses of oral steroid tablets (e.g prednisolone) /steroid injections in the last year
    d. I have had 3 or more courses of oral steroid tablets (e.g prednisolone) /steroid injections in the last year

e. I take oral steroid tablets (e.g prednisolone) everyday

f. In the past, I have taken steroid tablets (e.g prednisolone) everyday

g. None of the above

18. [for those who have had 2 or more OCS courses in past year] Have you ever spoken with your GP/ nurse about being referred or have you been referred for your asthma to a specialist doctor or nurse in a hospital?

a. I have discussed referral, but not been referred

b. I have discussed referral and been referred

c. I have never discussed referral

d. Not sure

19. Do you have a separate blue reliever inhaler?

a. Yes

b. No

c. Not sure

20. Using my blue reliever inhaler to treat symptoms is the best way to keep on top of my asthma

a. Strongly disagree

b. Disagree

c. Uncertain

d. Agree

e. Strongly agree

21. I don't worry about my asthma when I have my blue reliever inhaler around

a. Strongly disagree

b. Disagree

c. Uncertain

d. Agree

e. Strongly agree

22. My blue reliever inhaler is the only asthma treatment I can really rely on

a. Strongly disagree

b. Disagree

c. Uncertain

d. Agree

e. Strongly agree

23. The benefits of using my blue reliever inhaler easily outweigh any risks

a. Strongly disagree

b. Disagree

c. Uncertain

d. Agree

e. Strongly agree

24. I prefer to rely on my blue reliever inhaler than my steroid preventer inhaler

a. Strongly disagree

b. Disagree

c. Uncertain

d. Agree

e. Strongly agree

25. Have you been offered support to quit smoking in the last year?

a. I don't smoke

b. Yes

c. No

d. Not sure

26. Have you had your inhaler technique checked by a healthcare professional, such as a nurse, doctor or pharmacist, in the last year?

a. Yes

b. No

c. Not sure

27. Have you ever been given advice on how to monitor your asthma e.g. peak flow diary, monitoring of asthma symptoms?

a. Yes

b. No

c. Not sure

28. Has your GP/nurse discussed changing the dose of your inhaler or different treatment options with you (such as a new type of inhaler) in the last year?

a. Yes

b. No

a. Not sure

29. Has your GP/nurse/pharmacist asked how often you take your medicines in the last year?

    a. Yes
    b. No
    c. Not sure

30. [if yes to above] Has your GP/nurse/pharmacist offered support to help you take your medicines as prescribed in the last year?

    a. No, I don't need support
    b. No
    c. Yes
    d. Not sure

31. How many times in the last year have you experienced ALL of these symptoms during an episode of asthma?

    - Your blue reliever wasn't helping OR you needed to use it more than every four hours
    - You were wheezing a lot OR had a very tight chest OR were coughing a lot
    - You were breathless and found it difficult to walk OR talk
    - Your breathing was getting faster and it felt like you couldn't get your breath in properly

    Type a number (e.g. 0, 1, 2...) below.

32. When out of the house, how often do you carry a blue reliever inhaler with you?

    a. At all times
    b. Most of the time
    c. Some of the time
    d. Occasionally
    e. Never
    f. I don't have a blue reliever inhaler

33. Have you ever felt that there is a stigma attached to living with asthma? *By 'stigma', we mean other people having a negative opinion of your asthma.*

    a. Yes
    b. No
    c. Don't know

34. Do you feel that people take your asthma seriously?
    a. Yes
    b. No
    c. Don't know

35. Do you feel you have faced any stigma or discrimination due to having asthma?

    a. Yes
    b. No

Appendix 2: Data tables

Table 1: Provision of basic care elements, by nation

	England	Northern Ireland	Scotland	Wales	UK
Yes	2062	79	195	127	2463
No	4733	163	574	367	5837
All respondents	**6795**	**242**	**769**	**494**	**8300**
Yes	30.3%	32.6%	25.4%	25.7%	29.7%
No	69.7%	67.4%	74.6%	74.3%	70.3%

Table 2: Do you feel people take your asthma seriously?

	Number of respondents	Percentage
Yes	2739	33.3%
No	4191	51.0%
Don't know	1287	15.7%
All respondents	**8217**	

Table 3: Trends in basic care elements provision, by nation 2013–2021

	Basic care	Annual review	Inhaler technique check	Action plan
2013	20.0%	74.0%	78.0%	24.0%
2014	25.0%	77.0%	78.0%	30.0%
2015	28.9%	78.7%	79.3%	35.5%
2016	33.5%	78.5%	77.6%	42.4%
2017	35.0%	77.0%	76.3%	43.9%
2018	40.0%	80.0%	81.0%	48.0%
2019	39.5%	79.5%	75.2%	52.3%
2020	34.7%	72.5%	74.3%	52.2%
2021	29.7%	65.7%	66.5%	52.7%

Table 4: Prevalence of difficult asthma in survey respondents

	England	Northern Ireland	Scotland	Wales	UK
Yes	3256	100	399	249	4004
No	3539	142	370	245	4296
Grand Total	**6795**	**242**	**769**	**494**	**8300**
Yes	47.9%	41.3%	51.9%	50.4%	48.2%
No	52.1%	58.7%	48.1%	49.6%	51.8%

Table 5: Respondents having a separate blue inhaler

	Number of respondents	Percentage
Yes	7553	93.5%
No	29	0.4%
Don't know	494	6.1%
Grand Total	**8076**	

Table 6: Number of reliever inhalers in past 12 months

Number of inhalers	Number of respondents	Percentage
0 or 1	2011	26.7%
2 or 3	2475	32.9%
4 or 5	1132	15.0%
6 or more	1563	20.8%
Not sure	348	4.6%
Grand Total	**7529**	

Table 7: Reliever reliance scores

Score	Number of respondents	Percentage
5	42	0.7%
6	61	1.0%
7	78	1.2%
8	120	1.9%
9	209	3.3%
10	289	4.6%
11	351	5.6%
12	466	7.4%
13	472	7.5%
14	452	7.2%
15	576	9.2%
16	513	8.2%
17	584	9.3%
18	495	7.9%
19	463	7.4%
20	322	5.1%
21	268	4.3%
22	160	2.6%
23	149	2.4%
24	73	1.2%
25	127	2.0%
	6270	

Table 8: Respondents by nation*

Nation	Number of respondents	Percentage
England	6795	81.9%
Northern Ireland	242	2.9%
Scotland	769	9.3%
Wales	494	6.0%
UK	**8300**	

* Based on questions and methodology used **here**.

Table 9: Respondents by sex

Sex	Number of respondents	Percentage
Male	1551	18.7%
Female	6720	81.0%
Other	29	0.3%
All respondents	**8300**	

Table 10: Respondents by age

Age band	Number of respondents	Percentage
0–10	116	1.4%
11–20	158	1.9%
21–30	556	6.7%
31–40	977	11.8%
41–50	1660	20.0%
51–60	2109	25.4%
61–70	1840	22.2%
71–80	763	9.2%
80+	71	0.9%
Outliers/blanks	50	0.6%
Overall	**8300**	

Table 11: Prevalence of difficult asthma among survey respondents, by nation

	England	Northern Ireland	Scotland	Wales	UK
Yes	3256	100	399	249	4004
No	3539	142	370	245	4296
Respondents	**6795**	**242**	**769**	**494**	**8300**
Yes	47.9%	41.3%	51.9%	50.4%	48.2%
No	52.1%	58.7%	48.1%	49.6%	51.8%

Table 12: Number of courses of oral steroids taken in past 12 months

Number of courses	Number of respondents	Percentage
0 courses	4705	56.7%
1 course	1165	14.0%
2 courses	766	9.2%
More than 2 courses	1068	12.9%
I take them everyday	320	3.9%
I don't remember	103	1.2%
All	**8300**	

Table 13: Asthma control level by household income

Household income	Controlled	Partly controlled	Uncontrolled	All
Below £20,000	244	656	1074	1974
£20,00–£30,000	232	593	707	1532
£30,001–£40,000	189	382	427	998
£40,001–£70,000	262	549	585	1396
Above £70,000	136	237	246	619
Rather not say	309	620	801	1730
All	**1372**	**3037**	**3840**	**8249**
Below £20,000	12.4%	33.2%	54.4%	100.0%
£20,000–£30,000	15.1%	38.7%	46.1%	100.0%
£30,001–£40,000	18.9%	38.3%	42.8%	100.0%
£40,001–£70,000	18.8%	39.3%	41.9%	100.0%
Above £70,000	22.0%	38.3%	39.7%	100.0%
Rather not say	17.9%	35.8%	46.3%	100.0%
All	16.6%	36.8%	46.6%	100.0%

Table 14: Use of emergency care, by sex

	Yes	No	Don't remember	Grand Total
Male	177	1369	5	1551
Female	1164	5532	24	6720
Other	5	23	1	29
Grand Total	**1346**	**6924**	**30**	**8300**
Male	11.4%	88.3%	0.3%	100.0%
Female	17.3%	82.3%	0.4%	100.0%
Other	17.2%	79.3%	3.4%	100.0%
Grand Total	**16.2%**	**83.4%**	**0.4%**	**100.0%**

Table 15: Use of oral steroids, by sex

Number of courses	Male	Female	Other	All	Male	Female	Other	All
0 courses	955	3730	20	4705	66.4%	56.0%	74.1%	57.9%
1 course	170	991	4	1165	11.8%	14.9%	14.8%	14.3%
2 courses	106	658	2	766	7.4%	9.9%	7.4%	9.4%
More than 2 courses	119	948	1	1068	8.3%	14.2%	3.7%	13.1%
I take them everyday	69	251	0	320	4.8%	3.8%	0.0%	3.9%
I don't remember	19	84	0	103	1.3%	1.3%	0.0%	1.3%
All	1438	6662	27	8127				

Table 16: Basic care trends 2013–2021, by nation

	2013	2014	2015	2016	2017	2018	2019	2020	2021
Northern Ireland	42%	53%	54%	48%	48%	50%	53%	47%	33%
Wales	16%	17%	27%	32%	26%	32%	39%	28%	26%
England	19%	22%	28%	32%	34%	40%	40%	35%	30%
Scotland	27%	33%	36%	41%	43%	40%	36%	31%	25%
UK	20%	25%	29%	34%	35%	40%	40%	35%	30%

Table 17: Elements of an annual asthma review provided, by method of provision

	All respondents	Percentage for all respondents	Face to face number of respondents	Over the phone/ via videocall number of respondents	Via text number of respondents	Face to face percentages	Over the phone/ via videocall percentages	Via text percentages
Asked about asthma symptoms	4512	82.7%	1645	2692	255	85.1%	84.7%	75.2%
Asked about number of reliever inhalers used	2457	45.1%	964	1389	104	49.8%	43.7%	30.7%
Asked about how many asthma attacks and courses of steroid tablets in past year	1998	36.6%	847	1059	92	43.8%	33.3%	27.1%
Asked about adherence	3490	64.0%	1326	2002	162	68.6%	63.0%	47.8%
Action plan discussed and updated	1797	33.0%	807	942	48	41.7%	29.6%	14.2%
Inhaler technique checked	2047	37.5%	1052	941	54	54.4%	29.6%	15.9%
None of these happened	206	3.8%	46	131	29	2.4%	4.1%	8.6%
Don't remember	24	0.4%	22	60	22	1.1%	1.9%	6.5%
All respondents	5453		1934	3180	339			

Table 18: Trends in receiving a follow-up within two working days after receiving emergency asthma care, 2016–2021

Received follow up care?	2016	2017	2018	2019	2020	2021
Yes	27%	30%	32%	34%	33%	36%
No	70%	66%	64%	64%	65%	62%
Not sure/don't remember	3%	4%	4%	3%	3%	2%

Table 19: Have you ever heard of FeNO (fractional exhaled nitrous oxide)?

Heard of FeNO?	Number of respondents	Percentage
Yes	1183	14.7%
Not sure	350	4.4%
No	6496	80.9%
All respondents	**8029**	

Table 20: Provision of SIMPLES elements

SIMPLES element	All people with asthma number	All people with asthma percentage	People with difficult asthma number	People with difficult asthma percentage
I have been asked about my asthma symptoms (e.g. if they interfere with daily activities, how often I use my reliever inhaler, if they cause waking at night etc)	4999	61.8%	2618	65.4%
I have had my inhaler technique checked (e.g. I showed someone how I use my inhalers and they gave me advice)	1908	23.6%	1084	27.1%
Changing the dose of my inhaler or different treatment options were discussed with me (e.g a new type of inhaler or medicine)	2834	35.1%	1770	44.2%
I have been asked how often I take or use my medicines	4159	51.5%	2218	55.4%
I have been offered lifestyle advice that may help my asthma e.g. diet, exercise, weight loss etc.	944	11.7%	578	14.4%
I have been asked about what my asthma triggers are	2862	35.4%	1593	39.8%
Other health conditions that might affect my asthma have been discussed or mentioned e.g. hayfever, sleep apnoea, reflux etc.	2320	28.7%	1421	35.5%
I have been asked about my mental health (e.g. around anxiety) and how it might impact my asthma	871	10.8%	595	14.9%
I have been given advice on how to monitor my asthma (e.g. peak flow diary)	2396	29.6%	1415	35.3%
I have been given enough information to understand my asthma and how my medicines work	2709	33.5%	1369	34.2%
	8083		**4004**	

Table 21: Respondents thoughts on whether their blue inhaler is the only treatment they can rely on

Answer	Number of respondents	Percentage
Strongly agree	497	7.6%
Agree	1007	15.4%
Uncertain	1827	28.0%
Disagree	1841	28.2%
Strongly disagree	1347	20.7%
All respondents	**6519**	

Table 22: Respondents thoughts on whether they prefer to rely on their reliever inhaler than their preventer inhaler

Answer	Number of respondents	Percentage
Strongly agree	478	7.4%
Agree	659	10.2%
Uncertain	1759	27.1%
Disagree	1426	22.0%
Strongly disagree	2165	33.4%
All respondents	**6487**	

Table 23: Respondents thoughts on whether they don't worry about their asthma if they have their reliever with them

Answer	Number of respondents	Percentage
Strongly agree	1383	20.7%
Agree	2549	38.1%
Uncertain	1257	18.8%
Disagree	1174	17.5%
Strongly disagree	328	4.9%
All respondents	**6691**	

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