

ASTHMA CARE Due to COVID-19 expect delays

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# ASTHMA CARE IN A CRISIS

ANNUAL ASTHMA SURVEY 2020

We work to stop asthma attacks and, ultimately, cure asthma by funding world leading research and scientists, campaigning for change and supporting people with asthma to reduce their risk of a potentially life threatening asthma attack.

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## FOREWORD



Our Annual Asthma Survey is an important moment each year to take stock and reflect on how all those with asthma are dealing with their condition and experiencing care and support. In this, our eighth edition, carried out in the midst of COVID-19, the findings are as vital as ever to paint a picture of the state of play for those with asthma and to assist policymakers in the recovery and re-build of services.

Pre-pandemic, the provision of basic asthma care was not where it needed to be. There was significant variation across age and socio-economic groups in terms of access to good care, and subsequently outcomes. If you had a lower household income, your asthma care was often worse, and young adults fared particularly poorly in provision of basic asthma care. COVID-19

has understandably placed an enormous burden on the NHS and services have been severely disrupted. Fewer people with asthma had access to basic care over the past year when compared to 2019, and the quality of remote care, where offered, was sometimes a poor alternative to face-to-face.

Where do we go from here? Policymakers should absolutely aim to 'build back better'. We must bank the best of the innovation that's sprung up over the past year. At times, remote care can be an excellent alternative to face-to-face and increase access to asthma checks. We should as a matter of urgency research what works optimally for different groups, pulling on the best technology available. Stratifying those with uncontrolled asthma and offering urgent face-to-face reviews is of paramount importance as part of this approach.

We must also be ambitious in encouraging people back into the system. Many of those with underlying lung conditions have understandably had a particularly tough year and remain anxious about accessing NHS care. We must re-double efforts to welcome people back to NHS services, stressing the vital importance of timely diagnosis, management and support after an exacerbation to improve quality of life and clinical outcomes for all those living with asthma.

The COVID-19 pandemic has exposed the deep inequalities in society and health outcomes that we've known about for many years in the respiratory field. We urge policymakers and those delivering asthma care to strive to offer basic care to *all* with asthma, and to apply the best available evidence to tackle known inequalities.

We at Asthma UK are determined to play our part too. Our helplines, information and support seek to equip those with asthma to take their condition seriously. Our research finds new ways to understand and treat the disease. We will continue to be a constructive partner to those delivering care. For the 5.4 million people living with asthma across the UK, 2020 was a difficult year. Let's collectively work to deliver urgent and much-needed improvements in asthma care, so that we can reflect on good progress in a year's time.

### Sarah Woolnough

Chief Executive, Asthma UK

# EXECUTIVE SUMMARY

Asthma UK conducted the eighth edition of the Annual Asthma Survey in summer 2020, and received over 12,000 responses. This is the report of the key findings.

The period covered by the survey was unlike any of the previous years, and the presence of the COVID-19 pandemic presented very different and very difficult challenges for the NHS and for people with asthma. Our survey found out that basic asthma care levels – comprising an annual asthma review, an inhaler technique check and a written asthma action plan – have dropped by nearly five percentage points, and to their lowest levels since 2016. With only 34.7% of respondents receiving these crucial elements of care, an estimated 3.53 million people with asthma were not receiving this care. This downward trend was present across all nations in the UK. Levels of uncontrolled asthma remain an area of great concern. We found 40.1% of respondents had uncontrolled asthma (equivalent to 2.17m people with asthma in the UK), with only 20.5% having fully controlled asthma. Uncontrolled asthma means a greater disruption in everyday activities, and being at a higher risk of an asthma attack.

Levels of asthma care provision remaining anywhere near what we are used to seeing is testament to the efforts of NHS staff during an incredibly challenging time. Staff have had to deal with personal difficulties as well as professional ones. Many staff have been diverted from respiratory care to focus on COVID-19, and staff have had to adapt to new ways of working. This has included conducting care remotely. Routine care, such as annual asthma reviews and post-unscheduled care follow-up appointments, have increasingly been conducted remotely, either via the telephone, on a video call or via text message. However, our research found that the quality of care provided remotely did not always match that provided in a face-to-face setting, and that people with asthma did not always think that they received the same quality of care remotely. There is plenty to learn about the rapid deployment of remote care, and we expect it to be a feature of asthma care in the years to come.

We also found that the relationship that people with asthma have with using NHS services has changed. During the pandemic, people with asthma have been reticent about using both primary care and secondary care services, mostly due to fears of catching coronavirus and fears of being a perceived burden on a stretched system. Coming out of the pandemic, the NHS needs to rebuild confidence in people with asthma that services are safe and available to use.

In our recovery from the pandemic, there is a temptation to call for things to return to how they were before the pandemic. Previous editions of this report have drawn attention to the persistent gaps in care provision that people with asthma face, and we need to aim higher than restoring care to the levels seen in February 2020. We need a renewed and sustained effort to improve basic asthma care, and this needs to start with addressing uncontrolled asthma. People with uncontrolled asthma need to be prioritised for face-to-face reviews, when it is safe for them to take place. The NHS is facing a backlog of asthma care to address over the next few years, and will need to prioritise those most at risk.

# KEY FINDINGS AND RECOMMENDATIONS

We found that:



Basic asthma care levels have dropped for the first time in the eight years we have run this survey.



An estimated 3.53 million people with asthma did not receive basic asthma care.



Keeping control of asthma is a persistent challenge, with 2.17 million estimated to have uncontrolled asthma in the UK. This

is especially acute for younger people and for those on lower incomes.



Asthma care has partially adapted to be conducted remotely to face the challenge of COVID, but people with

asthma still value face-to-face appointments for their annual reviews.

We recommend that:



A national effort is needed to improve basic asthma care for everyone.



People with uncontrolled asthma should be prioritised for a face-to-face review.



A renewed drive to ensure that emergency care follow-up happens within two working days after emergency care is a peeded

received is needed.



Confidence in using NHS services needs to be rebuilt among people with asthma.

# INTRODUCTION

This is the report of the eighth Annual Asthma Survey, and it is reporting on a year like no other. The COVID-19 pandemic has presented unprecedented challenges for the NHS and for people with asthma, and this report offers a snapshot of how routine asthma care has had to adapt to face these challenges. The pandemic has been an incredibly difficult time for people with asthma, and disruption to their routine asthma care has been one key challenge. Those with severe asthma were advised to shield, and a further group of people with asthma did so based on their own judgement. NHS staff and services have had to adapt to these circumstances, with face-to-face consultations for routine care being unavailable for much of the past year. People with asthma have told us they have been reluctant to use routine health care (such as going to a GP appointment, or using emergency care services) due to a perception they might be a burden, or due to concern about COVID. When designing the survey on which this report is based, we expected the findings to be different to previous years, due to these circumstances.

The disruption in care faced during the pandemic will likely have a lasting impact on asthma care. We know there is already a significant backlog in care that the NHS will have to plan for, and this will affect people with asthma for the coming years. The crisis has accelerated some innovation in how care has been delivered, and has shone a light on where care could be better. These findings have told us how people with asthma have encountered care over the past year, and will help Asthma UK continue to campaign for better asthma care, and support people with asthma through this very difficult time.

### **About this survey**

The survey was conducted by the Asthma UK and British Lung Foundation Partnership from August 2020 to December 2020. 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 12,145 responses. Survey questions are available in Appendix B, and a full breakdown of the demographics of the survey respondents, as well as data tables for this report and references, is available in Appendix C.

## HOW HAS ROUTINE ASTHMA CARE COPED DURING THE PANDEMIC?

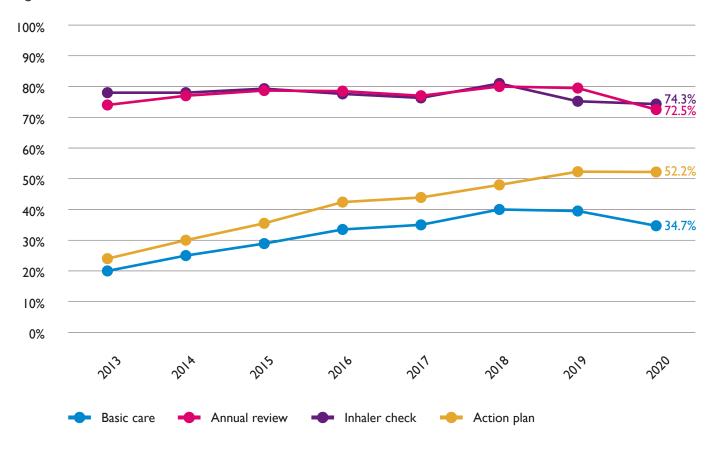
This section will cover the Annual Asthma Survey findings on basic asthma care, follow-up care and asthma control levels, and analyse how the pandemic has had an impact on them.

### Basic asthma care levels have dropped

Every year, we ask survey respondents whether they have received three key elements of basic asthma care. These are:

- Attending an annual asthma review
- Having an inhaler technique check
- Having a written asthma action plan.

If a respondent tells us they have received all three of the above, they have received basic asthma care. This is a key measure in understanding the level of asthma care received across the UK, and allows us to understand the variation in care across the country. In general, we have seen an upward trend in basic asthma care over the years, largely driven by increased rates of written asthma action plans. This year, somewhat understandably, there has been a modest drop in levels of basic asthma care provision.



### Figure 1: Basic care trends, 2013–2020

In 2020, 34.7% of people with asthma received their essential basic care. This is down from 39.5% in 2019, and is the lowest level since 2016. This means that an estimated 3.53 million (of the 5.4 million) people with asthma are not receiving this care. It is important to remember that there were significant gaps in asthma care before the pandemic that needed addressing, and that returning to the levels of care provided before the pandemic will still leave a large proportion of people with asthma not receiving the care they need.

Among the overall level of basic asthma care, there are notable differences. Previous surveys have analysed the variation in asthma care across the UK, with particular attention to age-based differences in 2018<sup>i</sup> and income-based differences in 2019<sup>ii</sup>. As shown in Figure 2, this year, all nations experienced a drop in basic care levels.

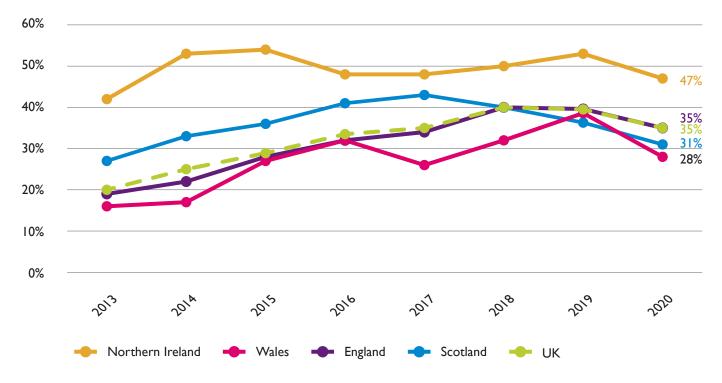


Figure 2: Basic care trends across the UK, 2013-2020

The lowest level of basic care was found in Wales, with only 28% receiving all three elements. This is disappointing, after basic care levels in Wales had shown improvements in 2018 and 2019. Basic care in Scotland is now at its lowest level since 2013, with the last year continuing the downward trend of the previous two years. Basic care levels in Northern Ireland have dropped six percentage points from 2019, and are now also the lowest since 2013. The challenge for the NHS will be to restore basic care levels to those seen previously.

As well as inequalities in basic asthma care provision by location, this year's data also showed differing care levels depending on age. Just over a quarter (28.6%) of those aged 18–29 received basic asthma care, compared to 48.7% of those aged 17 or under. It is disappointing to note that this is a pattern that we have seen in previous years, and indicates that inequalities in basic asthma care provision are persistent.



Figure 3: Basic asthma care levels, by age

These results show that there are persistent inequalities in receiving basic asthma care, both across the UK and between different age groups. Despite the rise in care being conducted remotely during the pandemic, there is a significant proportion of people with asthma who are not accessing their basic asthma care.

**Policy recommendation**: There needs to be a national effort to improve basic asthma care for everyone. Basic care is the foundation of asthma care, and the routine asthma review must reach all people with asthma.

### There is still a strong link between asthma control levels, age and income

In 2020's *The Great Asthma Divide* report<sup>iii</sup>, the link between poor asthma control, higher levels of asthma attacks and subsequent hospital admissions was outlined. COVID has disproportionately affected those on a lower income – in terms of both mortality and economic impact<sup>iv</sup>. We asked again about levels of asthma control in this survey<sup>1</sup>. Asking about levels of asthma control allows us to understand the proportion of people who regularly suffer from asthma symptoms. Uncontrolled asthma has a devastating impact on quality of life, including disruptions to everyday activities and interrupted sleep; no one should have uncontrolled asthma. This year, 40.1% of respondents had uncontrolled asthma (equivalent to 2.17m people with asthma in the UK), with only 20.5% having fully controlled asthma. This is slightly better than the 2019 survey results, where 46.8% had uncontrolled asthma, and 18% fully controlled asthma. This may be due to several factors, including a lower level of exposure to viruses in lockdown and better adherence due to taking asthma more seriously because of the pandemic<sup>v</sup>. However, it is simply unacceptable that most people with asthma continue to suffer needlessly with uncontrolled symptoms. People with asthma and health services must take the condition more seriously, and people with controlled asthma still need their basic care.

<sup>1</sup> When we asked about asthma control, we asked about the presence of usual asthma symptoms, being woken up in the night by asthma, using a reliever inhaler more than twice a week and asthma interfering in daily activities.

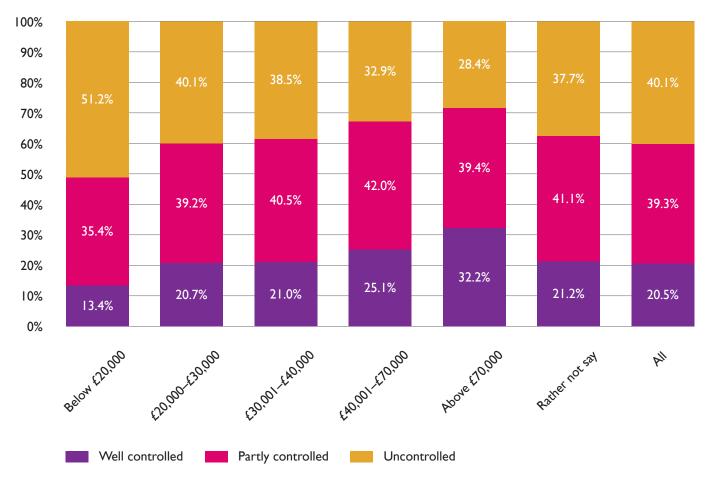


Figure 4: Asthma control levels, by household income

This year, the same pattern of people on lower incomes suffering from worse asthma control was present. Over half (51.2%) of people with a household income of below  $\pounds$ 20,000 suffered from uncontrolled asthma, compared to 28.4% of those in the highest income bracket (household income over  $\pounds$ 70,000). Our previous research has shown that 50.1% of people with lung conditions saw their income drop due to the COVID pandemic<sup>vi</sup>, and there may be further economic challenges ahead that could exacerbate this problem.

There is a further cause for concern in the age-based differences in asthma control levels. Figure 5 shows that children (those aged 17 or under) have the highest levels of asthma control, with 36.8% having well controlled asthma. However, for adults with asthma, there is an age gradient. Younger adults have poorer controlled asthma than older adults. Poor asthma control means more interruption in one's daily life, and a higher risk of asthma attacks. A lower proportion of those with uncontrolled asthma had a face-to-face annual asthma review (40.1%) than those with controlled asthma (48.7%). This means that 59.2% of people with uncontrolled asthma either had a remote review, or no review at all. This is an estimated 1.28 million people in the UK<sup>vii</sup>. This highlights the scale of the issue, and people with uncontrolled asthma should be prioritised for a face-to-face review, when it is safe for them to do so.

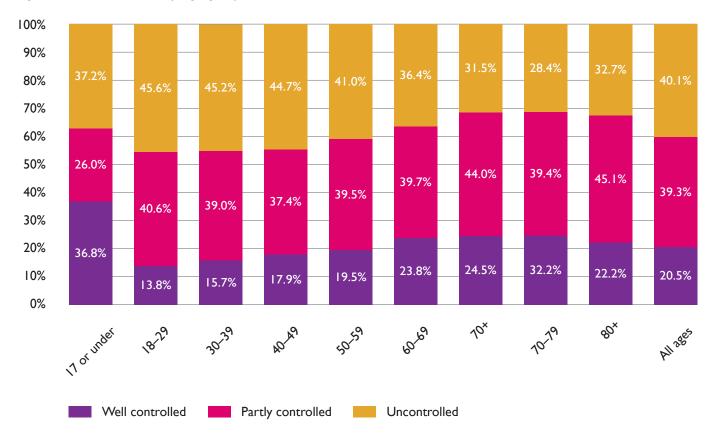


Figure 5: Asthma control by age group

Poor asthma control still affects a significant proportion (40.1%) of people with asthma. For many people with asthma, life during the pandemic has meant a reduction in exposure to many common asthma triggers, with lower pollution levels and lower levels of colds and flu. However, asthma symptoms and the resulting disruption in people's lives are still present. Without addressing this, it will be hard to improve asthma outcomes.

**Policy recommendation**: People with uncontrolled asthma should be prioritised for offering a face-to-face review where they can have their medication optimised, inhaler technique checked and be issued with a written asthma action plan.

### How has asthma follow-up care been affected?

Every year, there are around 75,000 emergency admissions for asthma in the UK<sup>viii</sup>. Every emergency hospital admission for an asthma attack should, according to clinical guidelines<sup>ix</sup>, receive a follow-up appointment within two working days. This is an important step in recovering after emergency admission, and avoiding readmission to hospital. We have asked about whether respondents who had an emergency admission or used unscheduled care (such as an out-of-hours GP) in the past year had received this important appointment, and we have seen little improvement. In the *Great Asthma Divide* report<sup>x</sup>, we called for better joining up of data between primary and secondary care to help facilitate improved rates of follow-up appointments. In 2020, 33% had a follow-up appointment, compared to 34% in 2019. While maintaining this level of care during unprecedented circumstances is worthy of note, this is still a level far below what we need to see. These crucial appointments need to be prioritised by both clinicians and people with asthma.

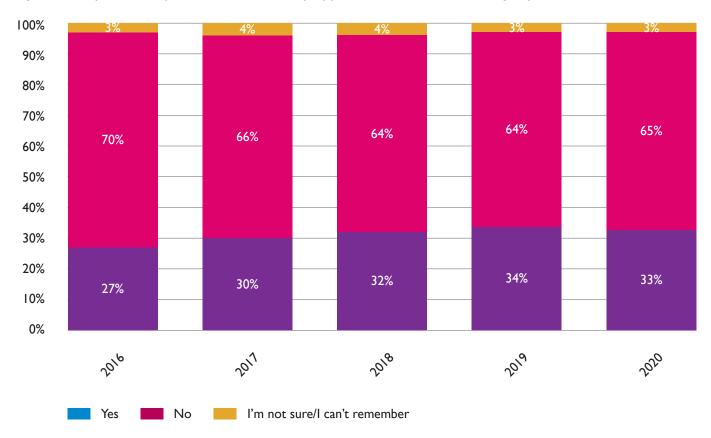


Figure 6: Did you have a post-admission follow up-appointment within two working days?

We asked people by what method they had their post-admission follow-up appointment, and there was a marked increase in telephone appointments, with 13.9% of all people admitted (and 42.7% of all follow-up appointments) in 2020 having a telephone appointment for their follow-up, compared to 3.6% (and 10.7% of all follow-up appointments) in 2019. Although the levels of follow-up care within two working days have remained at similar levels, the proportion not receiving a follow-up appointment at all has increased from 43.9% to 47.9%, which is concerning.

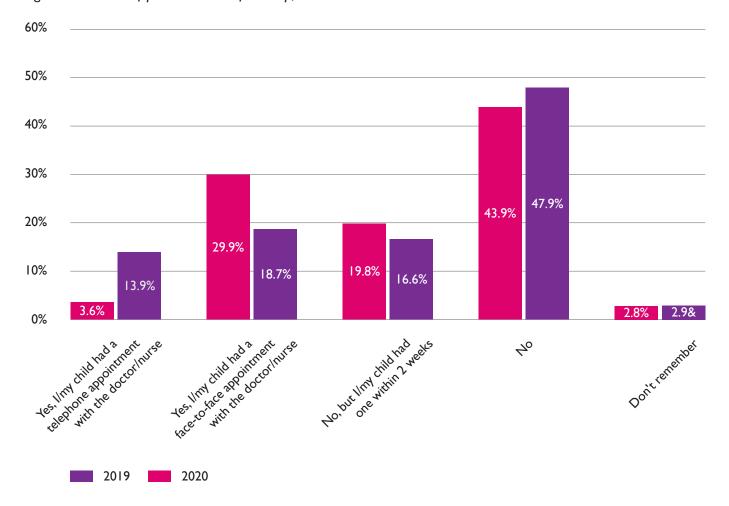


Figure 7: Method of post-admission follow-up, 2019-20

This shift to telephone appointments, while maintaining the same level of follow-up care as before the pandemic, shows that this could be a change that could stick post-pandemic. They have the potential to act as a triage for GPs to find out who needs a face-to-face appointment to discuss their admission and ongoing asthma management. It may also prove to be more convenient for people who are recovering from a hospital admission, rather than a face-to-face appointment, and may help improve the levels of follow-up care.

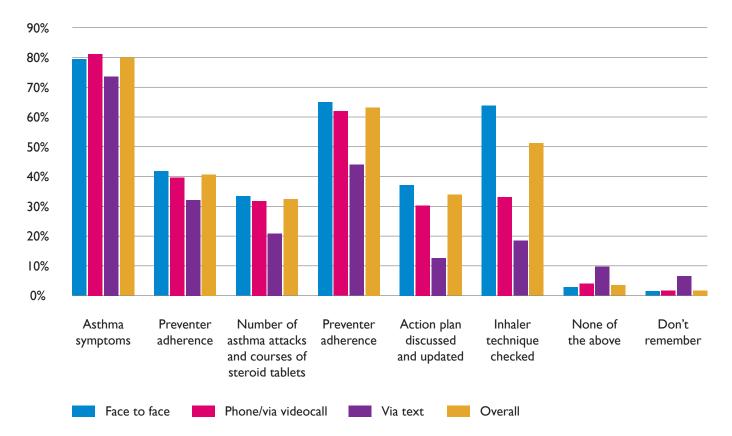
**Policy recommendation**: A renewed drive to ensure the emergency care follow-up happens within two working days after emergency care is received is needed. Ensuring awareness of the importance of this follow-up and being able to make fast-track appointments with GPs – with the potential to do this appointment remotely – are needed.

# WHAT CHANGES TO CARE HAVE WE SEEN?

Maintaining levels of basic asthma care to near normal levels during the past year is, in many ways, a remarkable achievement. The NHS worked rapidly to adjust how asthma care was provided, and these changes, such as conducting more care remotely, are reflected in the data. However, there have been some differing outcomes based on how the asthma care was delivered. We asked the 74.3% of people who received an annual asthma review what care they received in their asthma review, and by what method they received this important appointment<sup>2</sup>. Many elements, such as a discussion of asthma symptoms and a discussion about the amount of reliever inhalers prescribed, do not exhibit significant variation. However, as seen in Figure 8, there is considerable variation in the provision of inhaler technique checks by how the annual asthma review was conducted<sup>3</sup>. For those who had a face-to-face consultation, 63.9% had an inhaler technique check conducted, compared to 33.1% who had an annual review done on the phone or via videocall, and just 18.4% of those who had their review done via text message. This variation is why it is particularly important for people with uncontrolled asthma are offered the chance to be seen in a face-to-face appointment, and this is where there is the most evidence for successful inhaler technique checks<sup>xi</sup>. Only 12.3% of people who had a text message annual review discussed and updated their asthma action plan, compared to 37.2% who had a face-to-face appointment. This suggests that although doing routine asthma care remotely has helped keep basic care levels somewhere near what we are used to seeing, it is not always providing the same level of asthma care. There is also variation in the quality of care by method of remote care, with care needed in getting the format right, as well as making sure the person with asthma feel safe and comfortable in discussing their health<sup>xii</sup>. However, there will be variation within each medium of care delivery. Further work will be needed to understand these more granular differences in care, and how to best support healthcare professionals in delivering the same quality of care across different media.

<sup>2 60.3% (5,310</sup> respondents) of those who had an annual reviews had theirs conducted face to face, 36.6% (3,219 respondents) had theirs conducted over the phone or via videocall, and 2.3% (277 respondents) had theirs conducted via text.

<sup>3</sup> People with asthma can receive inhaler technique checks on other occasions, such as with a pharmacist, or during another asthma appointment. They may also have updated their written asthma action plan at another point, such as after an exacerbation.



### Figure 8: Elements of asthma review, by medium

### Disruptions in care have had an impact on people's asthma

During the past year, we have conducted a series of surveys on how people with asthma have coped with living through the pandemic. This has included asking questions about how they have accessed routine care for their asthma, and how it has changed. This research enhances the findings already discussed (and provides a slightly more up-to-date dataset), and will be discussed from this point.

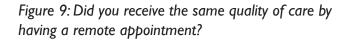
The COVID-19 pandemic caused unprecedented disruption in care across the NHS, and it was no different for people with asthma. As well as primary care appointments being conducted remotely, hospital appointments were also disrupted. However, the picture is more complex than simply replacing face-to-face appointments with remote care. People with asthma have had their regular care cancelled, and have had to adapt to the changing circumstances. Over half (57.2%) of people with asthma had a GP appointment conducted over the phone (and 18% had a hospital appointment conducted over the phone). The pandemic has necessitated an acceleration of efforts to conduct care remotely.

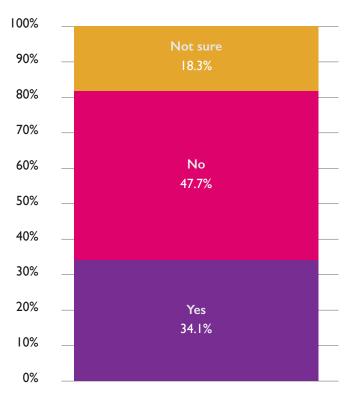
Interruption in care	Percentage of respondents affected		
GP appointment conducted over the phone	57.2%		
Delayed or avoided using my GP	27.5%		
Regular care (e.g. an annual review) for my lung condition at the GP has been cancelled	22.7%		
Hospital appointment conducted over the phone	18.0%		
I have not been able to get a GP appointment when I tried to book	11.0%		
Delayed or avoided using hospital outpatients	7.6%		
Delayed or avoided using emergency care (ambulance or A&E)	6.7%		
Regular care for my lung condition at the hospital has been cancelled	4.4%		
GP appointment conducted via video consultation	3.2%		
Hospital appointment conducted via video consultation	3.1%		
Other [free text]	2.2%		
None of the above	14.1%		

Table 1: Changes in regular asthma care experienced by people with asthma, October 2020 – March 2021

The Annual Asthma Survey data showed that remote annual asthma reviews have not always provided the same level of care as face-to-face appointments. When we asked people with asthma who received a remote appointment (by phone and/or by video, for both GP and hospital appointments) if they had received the same level of care, the results showed a mixed picture.

As Figure 9 indicates, nearly half (47.7%) of people with asthma felt the care they received remotely was not of the same quality as a face-to-face appointment. This should be a cause for concern, given the volume of remote appointments conducted, and the potential for this to become a longer term way of conducting care. While the headline figures may show nearly three quarters of people with asthma having an annual asthma review, this shows the importance of understanding feedback from people with asthma on their experience of receiving care for their asthma. People with asthma also told us they would prefer a face-to-face appointment for their annual review. We asked those who had an annual asthma review whether they preferred to have a face-to-face. telephone or text message review, and over three quarters (76.7%) told us that face to face was their preference. When asked for the main reason behind their preference, three quarters (74.9%) of those wanting a face-to-face appointment said it was because they felt more comfortable discussing their asthma in this setting.





Significant numbers of people with asthma have also been avoiding or delaying receiving care from their GP (27.5%), at hospital for an outpatient appointment (7.6%) and even emergency care (6.7%)<sup>4,xiii,xiv</sup>. This should be a wake-up call. When we asked why people with asthma have delayed or avoided essential care, 60.1% of people with asthma told us it was because they 'didn't want to over burden health services', with 61.4% telling us they didn't think it was safe to use health services. There have been significant and largely unavoidable disruptions to NHS care over the past year, but this suggests that there is an underlying unmet need that these adaptations have not addressed. The relationship between people with asthma and the NHS services they are used to using has changed during the pandemic, and confidence needs to be built that people with asthma won't feel like a burden, or feel unsafe, when accessing asthma care.

There are several impacts of this reticence of people with asthma to use NHS services. We asked those who had delayed or avoided care whether this decision had had an impact on their asthma symptoms, and 36.5% of people told us that it did. This is 11.7% of all people with asthma, and, if applied to the asthma population of 5.4 million<sup>xv</sup>, would mean delaying and avoiding care has had a negative impact on the asthma of an estimated 631,800 people in the UK. This data covers winter 2020/21, but our research showed similar behaviour and results in the first months (March–July 2020) of the pandemic<sup>xvi</sup>, so avoiding care – and the subsequent negative impact – has been happening for longer than this period.

Delaying and avoiding care (as well as care being cancelled) has had a negative impact on people's asthma. Coupled with concerns about the variable quality of remote care, it is little surprise that we have seen a drop in basic asthma care levels, and persisting poor levels of asthma control. Once again, we must stress that changes in asthma care were inevitable given the scale of the challenge faced, but understanding the impact and the fallout of these changes is essential to improving care for people with asthma. However, the changes forced by the pandemic mean that there are now more ways to access care than before, which we hope will improve access to care. The necessary speed of this change means there is still work to be done in making sure the quality of care replicates what people with asthma are used to with face-to-face care.

**Policy recommendation**: Confidence in using NHS services needs to be rebuilt among people with asthma. A communications campaign will help people with asthma start to use NHS services as they did pre-pandemic.

<sup>4</sup> This is reflecting in statistics on NHS activity for asthma. Public Health England's *Syndromic Surveillance Summaries* indicate GP appointments for asthma during the coronavirus pandemic have been around 60% of usual levels. Further research also indicates a drop in emergency admissions for asthma in Scotland and Wales.

### WHAT CHANGES DO WE NEED TO SEE IN THE FUTURE?

The pandemic has had an enormous toll on people with asthma. Not just in the worry and anxiety associated with living through a time where a respiratory pandemic dominates, but also in their relationship with NHS care for their asthma. The pandemic has made people with asthma less sure about accessing NHS care, and this has had an impact on outcomes. These changes are likely to have a long-term impact in asthma care, and several steps need to be taken to ensure asthma care is not only restored to the levels we saw before the pandemic, but it improves upon those levels. As discussed in the report of the previous edition of this survey, basic asthma care levels were stagnating before the pandemic, and there was acute health inequality in asthma outcomes<sup>xvii</sup>. These recommendations aim to improve basic asthma care levels, and to improve levels of asthma control.

# Basic care and follow-up appointment levels must be improved

The pandemic has necessitated the increase of routine asthma care done remotely. In 2020, we called for investment in technology to allow digital asthma reviews<sup>xviii</sup>, and the pandemic has accelerated this capability. This rapid change has been crucial in maintaining basic care levels at similar levels to previous years. However, patient experience of this change has been mixed, with 47.7% of those who have had a remote appointment telling us they did not think they received the same quality of care, and levels of inhaler technique checks being lower in remote asthma review appointments than in face-to-face appointments. There is also some evidence that the majority of those who have shielded during the pandemic have valued the option to have remote GP or hospital care<sup>xix</sup>. Face-to-face care also remains of huge importance to GPs\*\*. However, the convenience of remote care will appeal to some. It has the potential to improve

access to care for people who do not wish to attend a face-to-face appointment. Post-pandemic, improving patient choice in appointment method is desirable. Further research is also needed into what appointments would be best conducted remotely and which need a face-to-face appointment, and which methods are most clinically appropriate for the intervention needed. For instance, checking inhaler technique<sup>5,xxi</sup>, changing prescriptions and conducting diagnostic tests may be best done face to face – but a phone call (or video call) may be desirable in some circumstances, and increase access to care. People with asthma also told us that face-toface annual reviews were their preference. Indeed, a higher proportion of those with uncontrolled asthma (80.1%) told us they preferred a face-to-face appointment, compared to those with controlled asthma (72.1%). Remote care is likely to stay, and the NHS needs to work out how to make this care safe, high quality and providing an excellent patient experience. People with uncontrolled asthma should be prioritised for a face-to-face review where they can have their medication optimised, inhaler technique checked and be issued with a written asthma action plan. Remote appointments have helped maintain levels of post-admission follow-up appointments. However, with only 33.5% having a follow-up within two working days, the importance of this appointment needs to be restated.

# Better data can help improve asthma control

The data presented in this report on asthma control levels should be a wake-up call. The uneven identification of people with asthma who were advised to shield in 2020, and of who was eligible for the COVID vaccine in 2021, highlighted the importance of GP practices being able to stratify their asthma list by severity and clinical need. We

<sup>5</sup> The Taskforce for Lung Health has produced a position paper on best practice for providing remote inhaler technique checks.

know that 40.1% of survey respondents have uncontrolled asthma, which means that their symptoms are present regularly, and their lives are disrupted by their asthma. Addressing these levels will need improved use of data in identifying which people are in urgent need of a review. It will also need improved data infrastructure, including better coding and the joining up of data<sup>xxii</sup>. We also welcome the introduction of enhanced Quality and Outcomes Framework (QOF) indicators in England, which will help with this identification. Data will be collected on the level of asthma control, the number of exacerbations, whether an inhaler technique check was conducted and the presence of a written asthma action plan<sup>xxiii</sup>. Being able to systematically identify those with uncontrolled asthma who are most in need of an intervention (such as a face-to-face annual review) will help efforts to reach people with asthma who have been avoiding care during the pandemic, and help improve levels of asthma control.

# Confidence needs to be rebuilt in people with asthma in NHS care

In our September 2020 report Recovery and reset for respiratory<sup>xxiv</sup>, we noted the changed relationship between people with lung conditions and NHS services. The subsequent data from this research has further underlined this - people with asthma have been reticent, for very understandable reasons, to use NHS services in the way they did before the pandemic. In this report, we called for NHS England and the devolved administrations to launch a communications campaign to tell people with lung conditions that NHS services were open, and to access them if they were having an exacerbation. Since this report's publication, we have not seen such a campaign, and we restate this call. The experiences of people with asthma during winter 2020/21 have made it more urgent. A concerted effort is needed to rebuild confidence in people with asthma that the threat of coronavirus within NHS services is no longer present, and that there is enough capacity in the NHS for people with asthma to access the care they need (and are entitled to) without feeling like a burden. While

we expect forms of remote care to stay after the pandemic, more support will be needed for people with asthma to navigate remote consultations and changes to their care, along with support and training for healthcare professionals in conducting this care.

### A looming challenge

This report has also noted the impact of delayed care on people with asthma. Over the next couple of years, the NHS will have to address a looming backlog, including what can be quantified, such as numbers on a waiting list, and the harder-to-estimate number of people who have avoided care, and may look to address their asthma when they are comfortable it is safe for them to do so. Both of these problems show deleterious effects on asthma symptoms. To meet this challenge, a plan is needed to address this backlog and ensure that people with asthma are not faced with long waits for the care they need. Before the pandemic, there was an unmet need for referrals for people with severe asthma, with only 18% of adults with possible difficult and severe asthma getting referred for specialist treatment in line with clinical guidelines<sup>xxy</sup>. We know that an estimated 3,399 people with lung conditions have missed out on referrals each week during the pandemic in England<sup>xxvi</sup>, with a significant proportion of this group being people with asthma. People with asthma should not be at the back of the gueue for the care they need, and the NHS needs to plan to address the backlog.

This section has offered some solutions for the coming year to improve basic asthma care. Improving basic asthma care and levels of asthma control proved a huge challenge in the years before COVID, and the past year will provide an added challenge. It will need a concerted effort from people with asthma, healthcare professionals and clinical leaders to deliver these calls.

# CONCLUSIONS

This has been an incredibly difficult year for people with asthma. As well coping with the threat of COVID-19, the anxiety and the mental health challenges of living under lockdown and the economic impact of the past year, people with asthma have also had their care disrupted. Despite this disruption, asthma care has maintained levels close to what we have seen in previous years. Regrettably, this was not good enough then, and it is not good enough now. Both healthcare professionals and people with asthma have reacted to the disruption by adapting quickly. The past year has necessitated changes in care delivery, and although introduced at pace in challenging circumstances, there is much to learn about how this can inform future care delivery. Despite concern about replicating the quality of face-to-face care, people with asthma have had to embrace having care done remotely. However, basic asthma care

levels have dropped by five percentage points. This means that an estimated 3.53 million people with asthma in the UK are not receiving basic asthma care. From 2013 (the first year of this survey) to 2018, we saw sustained, if modest, increases in the levels of basic asthma care, with a stagnation last year. People with asthma deserve to receive this most basic level of care. Next year's survey will still cover care during COVID restrictions, but we hope to see improvements in these basic care levels as the NHS and people with asthma move forward. Learnings from the enforced changes in care since March 2020, and the recovery after the pandemic, offer a chance to reimagine how asthma is managed, and how people with asthma interact with NHS services. We also hope to see those most at risk of an asthma attack seen face to face, and that everyone receives good quality basic care, either remotely or face to face.

This research was conducted and analysed by, and the report was written by Andrew Cumella, Senior Analyst at the Asthma UK and British Lung Foundation Partnership.

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# APPENDIX B: SURVEY QUESTIONS

These are the questions from the Annual Asthma Survey used to gain the survey results used in this report.

- I. Where do you live?
  - a. England
  - b. Northern Ireland
  - c. Scotland
  - d. Wales
- 2. What is your gender?
  - a. Male
  - b. Female
  - c. Other
- 3. Are you, or the person you are completing the survey for:
  - a. 17 or under
  - b. 18–29
  - c. 30–39
  - d. 40–49
  - e. 50–59
  - f. 60–69
  - g. 70–79
  - h. 80+
- 4. 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

- 5. In the last four 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
- 6. 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
- 7. 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
- 8. In the last four weeks, has your 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
- 9. 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

- 10. 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
- 11. 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
- 12. For what reasons would you prefer to have your annual asthma review at this setting?
  - a. It is more convenient for me
  - b. I think it is safer
  - c. I feel more comfortable discussing my asthma in this setting
  - d. Other
- 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 two 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 two weeks
  - d. No
  - e. I'm not sure/l can't remember

The following questions were asked as part of a survey to understand how people with asthma had been coping with coronavirus, and included questions on disruption to care. Findings from these questions were included in the report.

- I. Since the start of October, has any of the following happened to you?
  - a. My regular care for my lung condition at the GP has been cancelled
  - b. My regular care for my lung condition at the hospital has been cancelled
  - c. I had a GP appointment conducted over the phone
  - d. I had a GP appointment conducted via video consultation
  - e. I had a hospital appointment conducted over the phone
  - f. I had a hospital appointment conducted via video consultation
  - g. I have delayed or avoided using my GP
  - h. I have delayed or avoided using hospital outpatients
  - i. I have delayed or avoided using emergency care (ambulance or A&E)
  - j. I have not been able to get a GP appointment when I tried to book
  - k. None of the above
- 2. Why did you delay or avoid using health services?
  - a. I didn't want to overburden health services
  - b. I didn't think it was safe for me to go to (for example) the GP or to A&E
  - c. I wasn't able to get there

- 3. Do you think you received the same quality of care for your lung condition by having a remote appointment?
  - a. Yes
  - b. No
  - c. Not sure

# APPENDIX C: DATA TABLES

These are the data tables showing the results behind the report.

### Table 1: Location of respondents

Nation	Number of respondents	Percentage of total
England	10023	85.5%
Northern Ireland	245	2.0%
Scotland	1227	10.1%
Wales	650	5.4%
Overall	12145	

### Table 2: Sex of respondents

Sex	Number of respondents	Percentage
Female	10008	82.4%
Male	2110	17.4%
Other	27	0.2%
All respondents	12145	

### Table 3: Age of respondents

Age band	Number of respondents	Percentage
17 or under	304	2.5%
18–29	643	5.3%
30–39	1189	9.8%
40–49	2452	20.2%
50–59	3279	27.0%
60–69	2892	23.8%
70–79	1233	10.2%
80+	153	1.3%
All respondents	12145	

# Table 4: Annual household income of surveyrespondents

Annual household income	Number of respondents	Percentage
Below £20,000	2933	24.3%
£20,000-£30,000	2246	18.6%
£30,001-£40,000	1560	12.9%
£40,001-£70,000	1956	16.2%
Above £70,000	805	6.7%
Rather not say	2555	21.2%
All respondents	12055	

Table 5: Suffering from usual asthma symptoms (such as cough, wheeze, chest tightness or shortness of breath during the day) more than twice a week

	Number of respondents	Percentage
Yes	8515	70.1%
No	3550	29.2%
Don't remember	80	0.7%
All respondents	12145	

Table 6: Being woken up during the night because of their asthma in the past four weeks

	Number of respondents	Percentage
Yes	4095	33.7%
No	7733	63.7%
Don't remember	317	2.6%
All respondents	12145	

# Table 7: Needed to use reliever inhaler more than twice a week, in the last four weeks

	Number of respondents	Percentage
Yes	7197	59.3%
No	4676	38.5%
Don't remember	92	0.8%
l don't have a reliever inhaler	180	1.5%
All respondents	12145	

Table 8: Asthma interference with usual daily activities, for example performing work/housework or going to school/activities, in the last four weeks

	Number of respondents	Percentage
Yes	7197	59.3%
No	4676	38.5%
Don't remember	92	0.8%
l don't have a reliever inhaler	180	1.5%
All respondents	12145	

Table 9: Levels of asthma control, by household income level

Asthma control level	Below £20,000	£20,000- £30,000	£30,001– £40,000	£40,001- £70,000	Above £70,000	Rather not say	All
Well controlled	392	465	328	491	259	542	2477
Partly controlled	1039	880	632	821	317	1051	4740
Uncontrolled	1502	901	600	644	229	962	4838
All respondents	2933	2246	1560	1956	805	2555	12055
Well controlled	13.4%	20.7%	21.0%	25.1%	32.2%	21.2%	20.5%
Partly controlled	35.4%	39.2%	40.5%	42.0%	39.4%	41.1%	39.3%
Uncontrolled	51.2%	40.1%	38.5%	32.9%	28.4%	37.7%	40.1%

### Table 10: Levels of asthma control, by age

Asthma control level	l7 or under	18–29	30–39	40–49	50–59	60–69	70+	70–79	80+	All ages
Well controlled	112	89	187	438	639	689	339	305	34	2493
Partly controlled	79	261	464	918	1296	1149	610	541	69	4777
Uncontrolled	113	293	538	1096	1344	1054	437	387	50	4875
All respondents	304	643	1189	2452	3279	2892	1386	1233	153	12145
Well controlled	36.8%	13.8%	15.7%	17.9%	19.5%	23.8%	24.5%	24.7%	22.2%	20.5%
Partly controlled	26.0%	40.6%	39.0%	37.4%	39.5%	39.7%	44.0%	43.9%	45.1%	39.3%
Uncontrolled	37.2%	45.6%	45.2%	44.7%	41.0%	36.4%	31.5%	31.4%	32.7%	40.1%

Table 11: Do you currently have a written action plan for managing your asthma, to help understand when symptoms are getting worse and what to do about it?

Asthma action plan?	ction plan? Respondents		
Yes	6337	52.2%	
No	5808	47.8%	
All respondents	12145		

Table 12: Have you 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?

Annual review?	Respondents	Percentage
Yes – it was done face to face	5310	43.7%
Yes – it was done via text	277	2.3%
Yes – it was done over the phone/via videocall	3219	26.5%
No	3080	25.4%
Not sure	259	2.1%
All respondents	12145	

Table 13: How would you prefer to have your annual asthma review?

Medium for annual review	Respondents	Percentage
Face to face	6710	76.7%
Not sure	319	3.6%
Over the phone/ via videocall	1570	17.9%
Via text	154	1.8%
All respondents	8753	

	Respondents	Percentage
Preferred a face-to-face review	6614	
I feel more comfortable discussing my asthma in this setting	4952	74.9%
I think it is safer	789	11.9%
It is more convenient	562	8.5%
Other [free text]	311	4.7%
Not sure	176	
I feel more comfortable discussing my /their asthma in this setting	51	29.0%
l think it is safer	47	26.7%
It is more convenient	72	40.9%
Other [free text]	106	60.2%
Preferred a review over the phone/via videocall	1550	
I feel more comfortable discussing my/their asthma in this setting	71	4.6%
l think it is safer	584	37.7%
lt is more convenient	857	55.3%
Other [free text]	38	2.5%
Preferred a review via text	149	
I feel more comfortable discussing my asthma in this setting	13	8.7%
I feel more comfortable discussing their asthma in this setting	3	2.0%
l think it is safer	27	18.1%
It is more convenient	102	68.5%
Other [free text]	4	2.7%
All respondents	8130	

Table 14: For what reasons would you prefer to have your annual asthma review at this setting?

Table 14: Thinking of your last planned asthma review (sometimes called your annual review), which of the following happened?

Element of asthma review	Respondents	Percentage
Asthma symptoms	7035	79.9%
Number of reliever inhalers	3586	40.7%
Number of asthma attacks and courses of steroid tablets	2856	32.4%
Preventer adherence	5567	63.2%
Action plan discussed and updated	2985	33.9%
Inhaler technique checked	4509	51.2%
None of the above	306	3.5%
Don't remember	152	1.7%
Total	8806	

	Face to face	Phone/via videocall	Via text	Overall	Face to face	Phone/via videocall	Via text	Overall
Asthma symptoms	4217	2614	204	7035	79.4%	81.2%	73.6%	79.9%
Number of reliever inhalers	2218	1279	89	3586	41.8%	39.7%	32.1%	40.7%
Number of asthma attacks and courses of steroid tablets	1773	1025	58	2856	33.4%	31.8%	20.9%	32.4%
Preventer adherence	3453	1992	122	5567	65.0%	61.9%	44.0%	63.2%
Action plan discussed and updated	1976	974	35	2985	37.2%	30.3%	12.6%	33.9%
Inhaler technique checked	3393	1065	51	4509	63.9%	33.1%	18.4%	51.2%
None of the above	147	132	27	306	2.8%	4.1%	9.7%	3.5%
Don't remember	82	52	18	152	I.5%	1.6%	6.5%	1.7%
Total	5310	3219	277	8806	100.0%	100.0%	100.0%	100.0%

Table 15: Elements of	asthma review, b	y medium it was	conducted
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Table 16: Did your doctor or nurse help you make sure you could correctly use ALL your current types of inhaler before you started using them?

Asthma action plan?	Respondents	Percentage
Yes	9020	74.3%
No	2368	19.5%
Don't remember	755	6.2%
Total	12143	

Table 17: Basic asthma care trends, 2013–2020

	Basic care	Annual review	Inhaler 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%

### Table 18: Basic asthma care trends 2013–2020, by nation

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

Table 19: Basic asthma care levels, by age

	Yes	No	Total respondents	Yes	No
17 or under	148	156	304	48.7%	51.3%
18–29	184	459	643	28.6%	71.4%
30–39	380	809	1189	32.0%	68.0%
40–49	809	1643	2452	33.0%	67.0%
50–59	1126	2153	3279	34.3%	65.7%
60–69	1053	1839	2892	36.4%	63.6%
70+	516	870	1386	37.2%	62.8%
70–79	470	763	1233	38.1%	61.9%
80+	46	107	153	30.1%	69.9%
All ages	4216	7929	12145	34.7%	65.3%

Table 20: Receiving a follow-up appointment within two working days of using emergency care discharge trends, 2016–2020

	2016	2017	2018	2019	2020
Yes	27%	30%	32%	34%	33%
No	70%	66%	64%	64%	65%
I'm not sure/I can't remember	3%	4%	4%	3%	3%

Table 21: Receiving a follow-up appointment within two working days of using emergency care discharge trends, by method 2019–2020

	Respondents (2020)	Percentage 2020	Percentage 2019
Yes, I/my child had a telephone appointment with the doctor/nurse	297	13.9%	3.6%
Yes, I/my child had a face-to-face appointment with the doctor/nurse	399	18.7%	29.9%
No, but I/my child had one within 2 weeks	355	16.6%	19.8%
No	1021	47.9%	43.9%
Don't remember	61	2.9%	2.8%

The following data is from a COVID-19 survey, run by the Asthma UK and British Lung Foundation Partnership in March 2021. Although the survey ran under both brands and thus covered all people with lung conditions, the results below are only for people with asthma.

Table 22: Since the start of October [2020], has any of the following happened to you?

Disruption	Respondents	Percentage
Regular care (e.g. an annual review) for my lung condition at the GP has been cancelled	823	22.7%
Regular care for my lung condition at the hospital has been cancelled	161	4.4%
GP appointment conducted over the phone	2074	57.2%
GP appointment conducted via video consultation	117	3.2%
Hospital appointment conducted over the phone	654	18.0%
Hospital appointment conducted via video consultation	114	3.1%
Delayed or avoided using my GP	996	27.5%
Delayed or avoided using hospital outpatients	277	7.6%
Delayed or avoided using emergency care (ambulance or A&E)	243	6.7%
I have not been able to get a GP appointment when I tried to book	398	11.0%
None of the above	513	14.1%
Other [free text]	78	2.2%
Total	3627	

Table 23: Why did you delay or avoid using health services?

	Respondents	Percentage
I didn't want to overburden health services	682	60.1%
I didn't think it was safe for me to go to (for example) the GP or to A&E	696	61.4%
I wasn't able to get there	57	5.0%
Other [free text]	57	5.0%
Total	1134	

Table 24: Do you think you received the same quality of care for your lung condition by having a remote appointment?

	Respondents	Percentage
Yes	276	34.1%
No	386	47.7%
Not sure	148	18.3%
All respondents	810	

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