The reality of asthma care in the UK

Annual Asthma Survey 2018 report

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Foreword

In 2014 the National Review of Asthma Deaths (NRAD) showed that two thirds of deaths from asthma could be prevented with better basic care[1]. In this report we find three out of five people are not receiving critical elements of routine asthma care in the UK, as outlined in the recently published NICE guidelines. With current treatments, the vast majority of people should be able to live their lives with their asthma well-managed, yet the vast majority do not. Four out of ten find it interferes with their daily lives.

Tragically this picture of poor asthma is even more marked in the 18-29 age group – at the very point people are starting their working life, their asthma is holding them back. Where there is local leadership some modest gains have been made, and Asthma UK's relentless focus on written asthma action plans has seen significant increases. However, asthma affects one in every 11 people and a condition of this scale demands national leadership, as we've seen with diabetes. What is so frustrating is that some very simple changes could be utterly transformational.

Surely in 2019 it is not beyond the NHS to be able to send simple text reminders for routine asthma reviews or ensure systems talk to each other to secure the all-important asthma attack follow up – a potentially life-saving opportunity, as currently more than one in seven reattends hospital within two weeks[2]. For the young high risk groups we need to be designing services around the way they live – digital-first, rather than constantly expecting them to fit with an old world model or receive no care.

Kay Boycott
Chief Executive, Asthma UK

Executive summary

In the 2017 report of the Annual Asthma Survey, we saw little improvement in the proportion of people with asthma getting the basic care they deserve[3]. This year we have seen modest improvement across all areas of basic care. However, three fifths of people with asthma in the UK (which equates to ~3.24m people) are still not receiving the most basic level of care. It is simply not good enough. Other measures we use in this report – such as provision of follow-up care after an emergency admission – remain dangerously low, and rates of uncontrolled asthma have seen very little improvement. The UK has made a start, but we have a long way to go.

Whilst we are pleased to see some modest improvements, we are aware there is still much more to do in improving basic care and improving asthma control through self-management. Deaths from asthma remain stubbornly high in the UK, and above the European average[4]. This year, we learned more about the stark disparity in care between age groups and across the UK. Those aged 18-29 are more than twice as likely to receive emergency care than those aged over 60, and only one third are receiving basic care, compared with almost half of under 18s. It is likely current models of care are not fully delivering for this age group. Attitudes and lifestyles in this generation are different to older groups, who are currently driving most NHS activity. If we are to see any improvements, we need to consider how their relative comfort with digital, on-demand, collaborative customer experiences in other sectors might be at odds with the traditional routine asthma review, and how healthcare is currently delivered in the UK. Similarly, we are still seeing a 'postcode lottery' of basic care across the UK, with Wales and London faring worst. Where you live should not be detrimental to the care you receive, and more needs to be done both nationally and regionally to improve basic care. In this report we explore the policy solutions required to address these problems, and propose that more engaging digital solutions are needed if we are to continue to see more people with asthma get the care they deserve.

Once again, we see how poorly implemented the two-day follow-up after emergency care is. If you receive emergency care, it is critical that you receive a follow-up appointment with your GP within two working days. We found that 64% do not receive this follow-up and 65% were not even told they should have one. We know having an asthma attack puts you at increased risk of having another one, so this follow-up care, required by the clinical guidelines set out by the National Institute of Health and Care Excellence (NICE) and the British Thoracic Society (BTS), is an important preventative measure in stopping future asthma attacks and trips to A&E[5,6]. We found that many people are managing their asthma attacks alone, and that the average number of asthma attacks a year could be four times greater than previously estimated. We continue to encourage data sharing between primary and secondary care as it ensures GPs are aware of such hospital admissions and enables follow-ups to occur seamlessly, preventing asthma attacks and improving the lives of people with asthma.

The Annual Asthma Survey attracted 10,064 responses this year (over 2,000 more than the previous year). It has provided us with great insight into care received across the UK, but particularly into under-served groups and areas. This report is for clinicians, service providers and policy makers who have the opportunity to improve asthma care. A full list of survey questions, data tables and methodology can be found in the appendix.

We would like to thank those who completed the survey for their contributions.

Key health advice for people with asthma

1. Demand your basic care. It's important to keep and use a written asthma action plan, have your inhaler technique checked (or check it yourself) regularly and receive your annual review. We have 'how to' videos for many different inhalers[7] on our website, and you can download a written asthma action plan here[8].

2. If your asthma symptoms are causing problems, such as interfering with daily activities or interrupting your sleep, the best way to address this is to arrange an asthma review with your doctor or asthma nurse.

3. If you're experiencing frequent symptoms or your asthma isn't well managed (and is interfering with daily activities or interrupting your sleep), we recommend you give our 12-week support programme a go to help you manage your asthma better[9].

4. Message one of our Asthma UK expert nurses on 07378 606 728 on WhatsApp for advice on your asthma. More information about our WhatsApp service is available here. You can also call an asthma nurse specialist on 0300 222 5800 (Monday to Friday, 9am to 5pm).

5. If you do have to attend A&E or receive out of hours care, make sure you demand your follow-up with your GP, even if you aren't told to do so. If there is no availability for an urgent appointment within two working days, then ask for a phone call, so your GP can assess if you need to be seen face-to-face.

6. If you're experiencing frequent asthma attacks, such as two a year (as seen in the survey results), arrange an asthma review with your GP.

7. If you manage an asthma attack yourself, always follow up with your GP afterwards. An asthma attack isn't something you should deal with alone, and could be an indicator that your medicine needs to be changed or you need more specialised care.

Key policy recommendations

1. There needs to be a national effort to improve basic care for everyone. We've seen some improvement, but the overall picture is just not good enough. Basic care is the cornerstone of the asthma guidelines, and the routine asthma review must reach many more people[10]. We want to see services redesigned where necessary in order to drive uptake.

2. There needs to be national efforts to ensure everybody with asthma gets a written asthma action plan, as we know there is strong evidence that this prevents hospital admissions[11].

3. We want to see text message reminders for asthma attack follow-up appointments and asthma reviews mandated. This is an easy and simple tech solution that is proven to work, but we know not all practices are using it[12].

4. There needs to be a drive to ensure the asthma attack follow-up happens within two working days after emergency care is received. Most people are still not receiving this and it is a critical preventative measure in stopping future asthma attacks and trips to A&E. Ensuring awareness of the importance of this follow-up and making fast track appointments available at GP surgeries should be driven by commissioners and planners, particularly in areas of high emergency care use for asthma.

5. We encourage investment in digital technology to improve data collection and data sharing, and to promote a behavioural shift towards preventative and co-ordinated care. Patient data and records in primary and secondary care must be linked to allow asthma attacks to be better recorded, managed and prevented.

6. Moving forward, asthma care pathways should consider the needs of the 18-29s and their changing attitudes and lifestyles, as current models of care are not fully delivering for this group.

7. We want to see a real world trial of asthma digital health solutions, such as 'smart' inhalers, and support given to providers of such solutions to access the NHS. New technologies and connected data offer an opportunity to transform asthma care, prevent asthma attacks, improve efficiency and allow better use of resources within the NHS[13].

8. We also want to see an end to unfair prescription charges for all people with asthma in England. It is unfair that other long-term conditions do not have to pay, when people with asthma do. We know from 2016's survey that 64% said it impacted on their life and finances[14].

Findings

Three out of five still don't receive basic asthma care

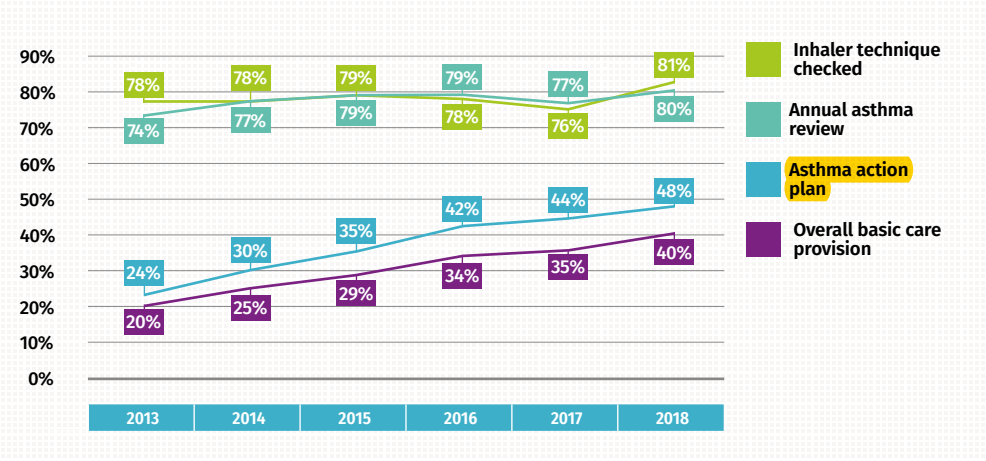
Everyone with asthma should receive all elements of basic asthma care. The provision of basic care helps stop asthma attacks, keeps people with asthma out of hospital, and ultimately saves lives. This year we have seen some improvement across all areas of basic care, however three fifths of people with asthma in the UK, which equates to ~3.24m people, are still not receiving the most basic level of care. It's simply not good enough.

To find out the level of basic care received in 2018, we asked the same questions we've asked since 2013. We asked whether the following three elements of basic care had been received, as set out in the BTS clinical guidelines and endorsed by NICE:[15]

- an annual asthma review
- a written asthma action plan
- an inhaler technique check with a healthcare professional.

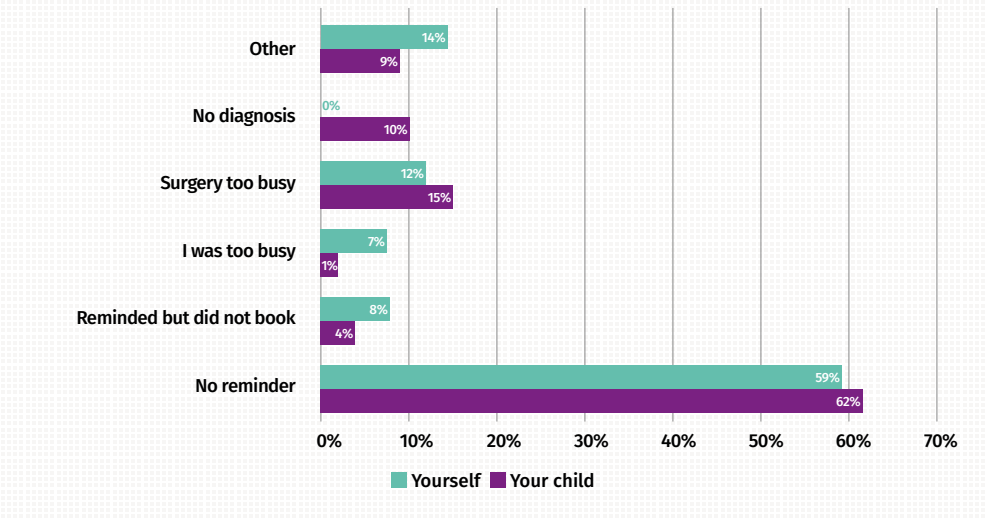
A negative answer to any of these three questions means basic care for asthma is not being met. This year basic care levels were met for 40% of respondents. This is an increase of 5% from 2017 (35%) and figure 1 shows basic care levels have doubled since 2013 (20% to 40%). Annual review attendance increased by 3% with an overall increase of 6% from 2013. Having their inhaler technique checked has mostly tracked the same path as annual reviews, remaining stable across the years, but with an overall increase of 3% from 2013. Action plan use was up by 4% from 2017 and has doubled since 2013 (24% to 48%).

Figure 1: *Trend in basic care level 2013 to 2018*



For the first time, we asked those who did not attend their annual review the reason why. Figure 2 shows the breakdown of answers. Notably, 59% (947/1606) of those answering for themselves said they did not receive a text/call reminder for their annual review, and this was similar for those answering on behalf of their child, although numbers were small (115). The second most common reason was that the surgery was too busy, and it was not possible to book an appointment (12%, 190/1606).

Figure 2: *Reasons for not attending an annual review*



We also asked those not attending if they were aware they should have an annual review, 39% (684/1754) of these respondents did not know they should be receiving an annual check-up for their asthma.

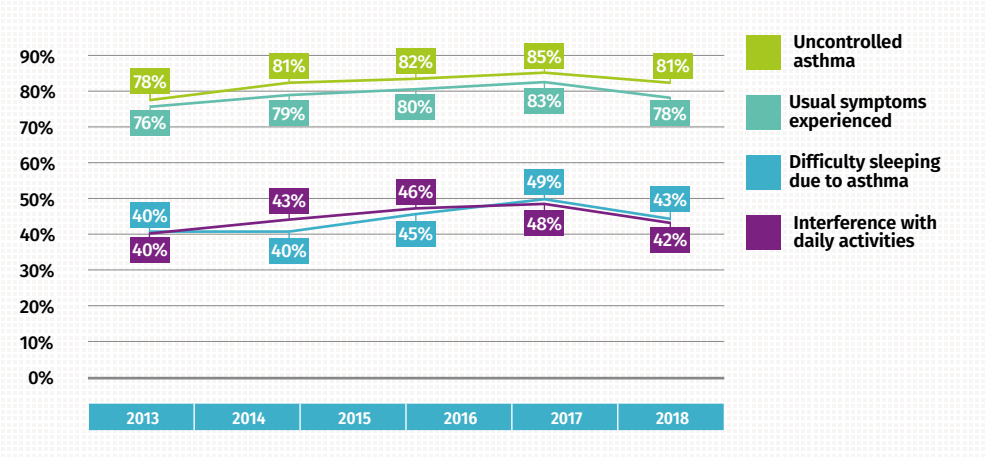
Poorly controlled asthma

Each year, we ask about the level of asthma control. This is a good measure to help gauge how asthma affects people's lives. We ask three questions used by the Royal College of Physicians (RCP), that ask whether, in the past four weeks:[16]

- you, or your child, have experienced trouble sleeping due to your/their asthma
- you, or your child, have experienced usual asthma symptoms, such as cough, wheeze, shortness of breath or chest tightness during the day.
- your, or your child's, usual daily activities, such as performing work/housework, going to school or other activities were interfered with due to asthma

This year 81% of respondents reported having uncontrolled asthma (one or more of the above). Since 2014, reporting of uncontrolled asthma has increased by 3% (figure 3), but we have seen a decrease of 4% this year.

Figure 3: *Trend in uncontrolled asthma, 2014 to 2018*



What do we think about it?

The results have shown three fifths of people with asthma, which equates to ~3.24m people with asthma in the UK, are not receiving basic asthma care. This is simply not good enough. There needs to be a national effort to make sure everyone gets the care they're entitled to. People with asthma should receive basic asthma care and surgeries should have sufficient resources available and a workforce strategy in place to be able to offer timely appointments. Text message reminders for annual reviews and critical asthma attack follow-up appointments are an easy digital solution that can get more people the care they deserve, but our results have shown not all practices are using it[17].

There is potential for those who don't need to see a GP more urgently and frequently to have online reviews, allowing people with well-controlled asthma to stay at home, freeing up resources and reducing waiting times. However, they have not yet been assessed to see if they are effective, and evaluation of online reviews for people with asthma with different needs should be prioritised. Alarmingly, 81% are still reporting their asthma as uncontrolled and we've seen little improvement since 2013. Action is needed to ensure that people with asthma are managing their condition as well as they can and minimising the impact of asthma on their everyday lives.

"[I didn't attend my annual asthma review, because] the GP surgery does not offer asthma reviews they only see me during a flare up, because they are too busy".

Survey respondent

What can you do about it?

Getting better care is a joint effort between you and your GP. The basic care measures outlined here are what you should be receiving on the NHS, but there's a lot you can do to make sure you get the right care:

- If you don't already have a written asthma action plan then download one from our website[18]. Print it out and put it on your fridge or save a digital version and keep it on your phone, so it's always with you.
- If you're worried about your inhaler technique or haven't had it checked in a while, ask your pharmacist or GP to check it for you. You can also visit our website[19] which has videos for many different inhalers.
- If you don't receive your annual review reminder, demand one from your GP practice.
- If your asthma symptoms are causing problems, such as interfering with daily activities or interrupting your sleep, the best way to address this is to arrange an asthma review with your doctor or asthma nurse.

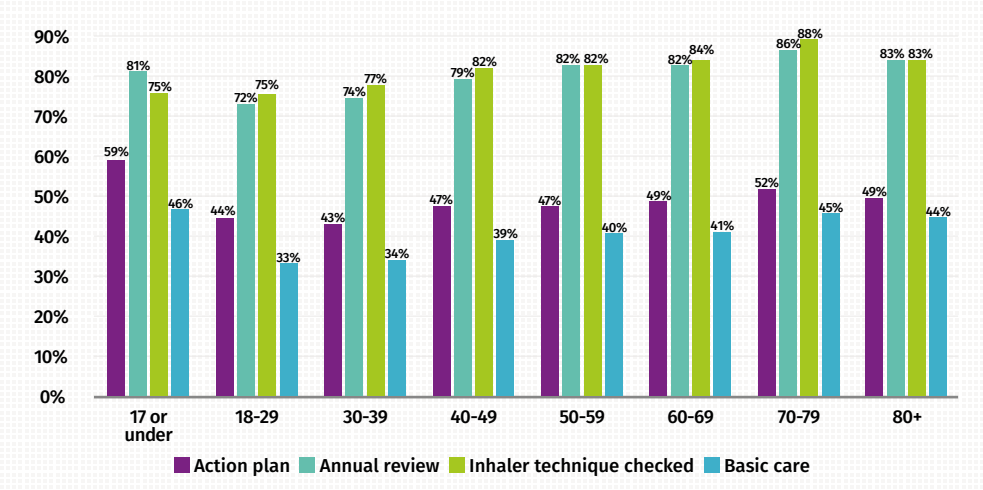
What do we want to happen?

- Everyone with asthma should receive the basic level of care as outlined above. We want to see text message reminders for annual reviews and follow-up appointments mandated. This is an easy and simple tech solution that's proven to work[20], but we know not all practices are using it. It's up to NHS England, the Care Quality Commission and equivalent bodies to ensure practices meet these standards.

Young people receive the worst level of basic care

We have seen improvements in basic care across all age groups, however the 18-29s persistently lag behind. Asthma care needs to be designed around the needs of the 18-29s and their lifestyles, as current models of care are not fully delivering for them. Two thirds of 18-29s with asthma are still not receiving basic care (502/751, 67%). Figure 4 shows that they rate among the lowest across all three elements of basic care. Only 44% have a written asthma action plan, 72% attended an annual review and 75% had their inhaler technique checked.

Figure 4: *Basic care level, by age*



As well as receiving the lowest level of basic care, young adults have the highest percentage of uncontrolled asthma (88%), rating the worst across all three elements of control level (figure 5). Figure 6 shows 34% of 18-29s reported using emergency care in the last 12 months, compared with the 25% average of all ages and 23% average of all adults. Since 2016, when the survey began to investigate this age group, they have consistently seen the worst basic care, asthma control and highest reporting of emergency care.

Figure 5: *Elements of asthma control, by age*

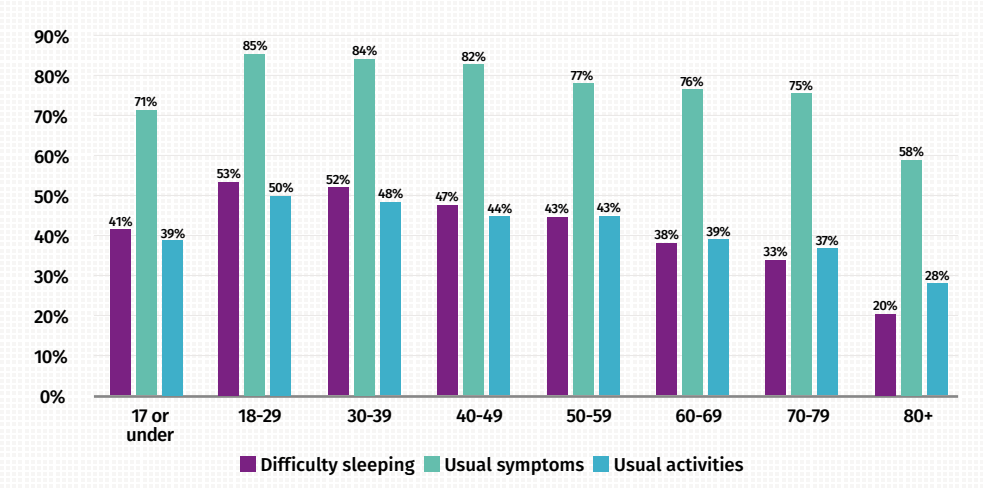
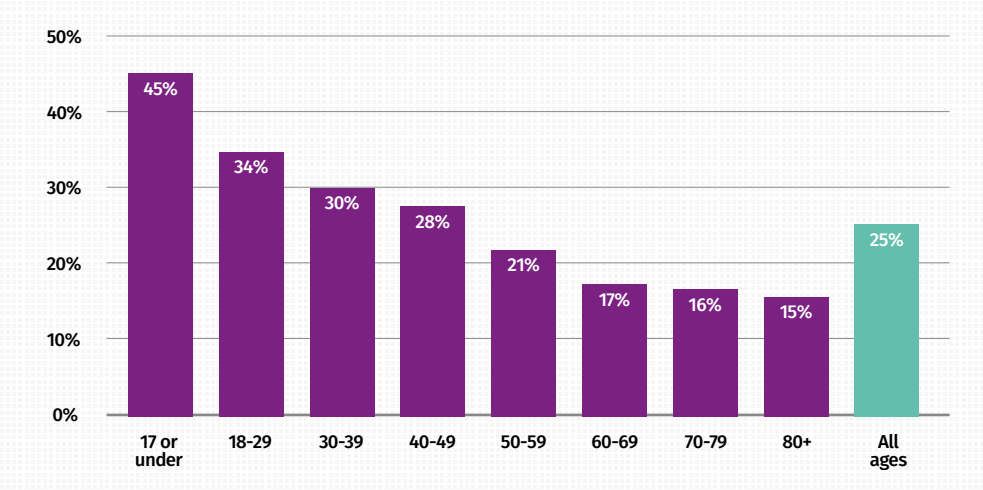


Figure 6: *Received emergency care in the last 12 months, by age*



Through our segmentation analysis, a bespoke audience segmentation created from Mosaic Public Sector consumer classification data and health data taken from health surveys and Hospital Episode Statistics, we found that a substantial proportion of 18-29s have poor health, the highest prevalence of asthma, increased likelihood of an asthma attack and poor adherence[21]. This is particularly the case for those with low income and other factors of deprivation.

This age group have been described as 'emerging adults' in psychology and many fall into the 'millennials' cohort[22] (those born between 1980 and the early 2000s). The theory behind emerging adults explains how the age at which adolescents become adults has become increasingly older, with young people staying in education longer, getting married and having children later, and establishing a long-term job later in their lives. This has given the 18-29s greater freedom with their choices, but also increased uncertainty and anxiety. Although research has shown 18-29s are now less likely than previous generations to take part in risky behaviours that negatively affect their health (such as smoking and drinking), other societal factors are impacting their health more than previous generations. Millennials have less access to secure and affordable housing[24], have greater financial uncertainty (they're at risk of being the first generation to earn less than their parents)[25] and less secure employment opportunities (they're more likely to be on zero hours contracts)[26]. These competing pressures may have negatively impacted their capacity to prioritise and self-manage their health. They also have different expectations of engagement – digital first, valuing convenience and collaboration. For these reasons, we decided to focus on this under-served age group in this year's survey results.

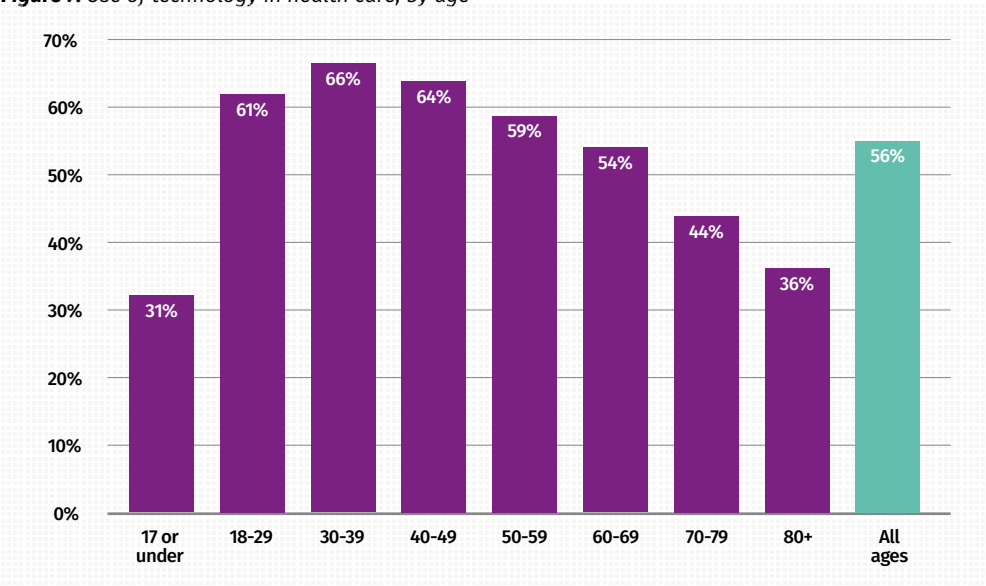
What do we think about it?

Our survey results have consistently shown the 18-29s to have the worst asthma control, and they're the most likely of all adults to use emergency care. It's shocking to see that 88% of 18-29s have uncontrolled asthma. We believe improving basic care is key to addressing these issues. However,

the barriers for this age group are complex and they're less engaged with current models of care than other age groups. Studies on emerging adults with diabetes have shown it can be difficult to transition from managing their condition with their family to managing it independently.[27] Services need to be redesigned to ensure this age group are able to effectively self-manage or else they will always be starting their working lives disadvantaged by their asthma.

Young adults, including young people with asthma, have a particularly high level of digital engagement*. However, this doesn't always correlate to health literacy. Our report, On the edge: how inequality affects people with asthma, has highlighted the 18-29s with low income and other factors of deprivation as having lower health literacy[28]. We also know people with limited health literacy are less likely to use preventative services (28% of 18-29s did not attend an annual review)[29]. It could be that this age group may engage better in their asthma self-management if we move away from traditional face-to-face care, to delivery through the digital channels they're already using. Last year's survey showed 61% (591/977) of 18-29s are already using technology in healthcare (figure 7) and 93% (207/222) of 18-29s are comfortable with sharing their data for service improvement.[30] Their digital-first lifestyles suggest a more digital approach could help embed self-management early on in their lives, better preparing them for managing their asthma throughout adulthood.

Figure 7: *Use of technology in health care, by age*



* Identified through Asthma UK's segmentation analysis.

What can you do about it?

If you fall into the 18-29 age group and are having difficulties with your asthma, or know someone who is:

- As previously mentioned, it's important to keep a written asthma action plan, have your inhaler technique checked regularly and have an annual asthma review. We have videos for many different inhalers[31] on our website and you can download a written asthma action plan here[32].
- If your asthma symptoms are causing you problems, such as interfering with daily activities or interrupting your sleep, the best way to address this is to arrange an asthma review with your doctor or asthma nurse.
- We have a 12-week support programme to help you better manage your asthma. If you're experiencing frequent symptoms or your asthma is uncontrolled (interfering with daily activities or interrupting your sleep), we recommend giving our our 12 week programme a go[33].
- Contact one of our Asthma UK expert nurses on 07378 606 728 on WhatsApp to ask questions about your asthma. More information about our WhatsApp service is available here. You can also call an asthma nurse specialist on 0300 222 5800 (Monday to Friday, 9am to 5pm).

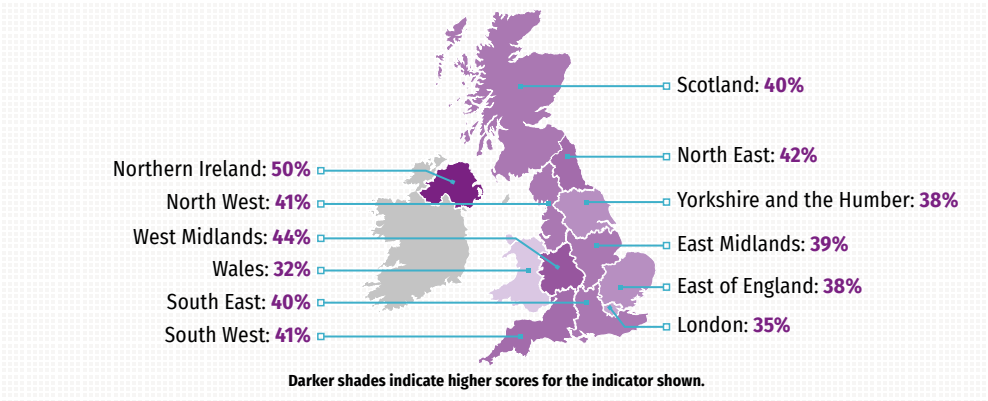
What do we want to happen?

- Asthma care needs to be designed around the needs of the 18-29s, the pressures they face, their digital-first communication styles and different preferences for engagement with professionals, as current models of care are not fully delivering for them.
- The variability of asthma and the increased likelihood of uncontrolled asthma in this age group could benefit from a more modern approach to annual reviews. More than one review a year may be necessary for those at high risk, whilst remote monitoring might be more suitable for those at lower risk. A more digital approach to reviews and written asthma action plans in this group could increase engagement in self-management[34].
- We want to see a comprehensive programme of real world trials of digital tools, such as connected 'smart' inhalers, to support self-management and data sharing. These digital solutions could facilitate passive data collection, identifying those most at risk of asthma attacks, as already shown in a trial with children[35], and providing data that could lead to new discoveries or new ways of managing or preventing asthma attacks. New technologies and connected data offer an opportunity to transform asthma care, improve efficiency and allow better use of resources within the NHS. Find out more in our reports Connected Asthma[36], Smart Asthma,[37] and Data Sharing and Technology[8].

There is variation in asthma care across the UK

As with the variation across age groups, the Annual Asthma Survey has consistently shown variation within the UK since it began. This year, Wales has the lowest level of people with asthma receiving basic care at 32% and Northern Ireland the best at 50% (figure 8). This appears to be driven by poor uptake of asthma action plans in Wales (38%), compared with better uptake in Northern Ireland (62%) (figure 11).

Figure 8: *Percentage of people with asthma receiving basic care, by region and nation*



Interestingly, Northern Ireland has the highest percentage of people reporting emergency care use (31%), which appears to contradict the basic care findings. However, due to the small sample size of this group, no strong conclusions can be made about this. Within England, there is also variation in basic care with only 36% of people in London receiving it. Annual review attendance appears to be driving this, with 75% of people in London attending an annual review compared to the national average of 80% (figure 9).

Figure 9: *Percentage of people with asthma attending an annual review, across the UK*

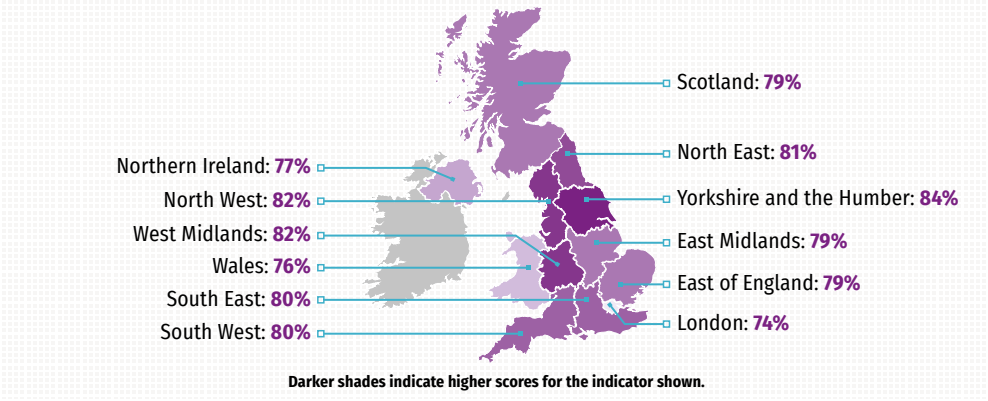


Figure 10: *Percentage of people with asthma receiving an inhaler technique check, across the UK*

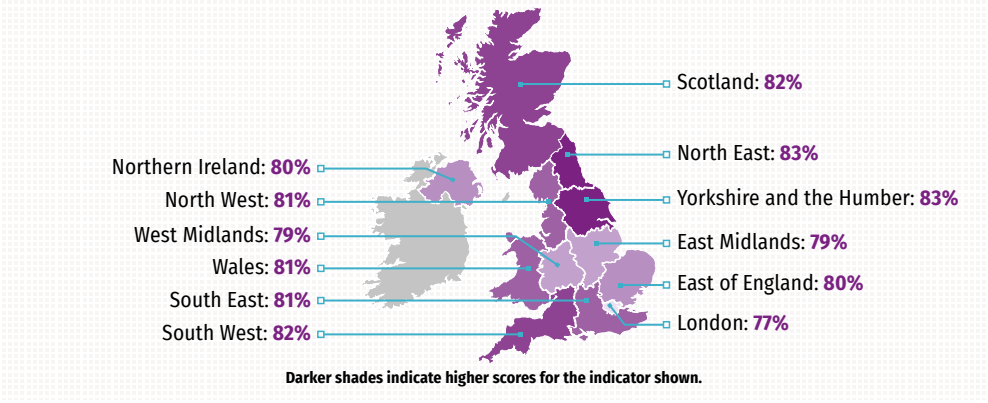
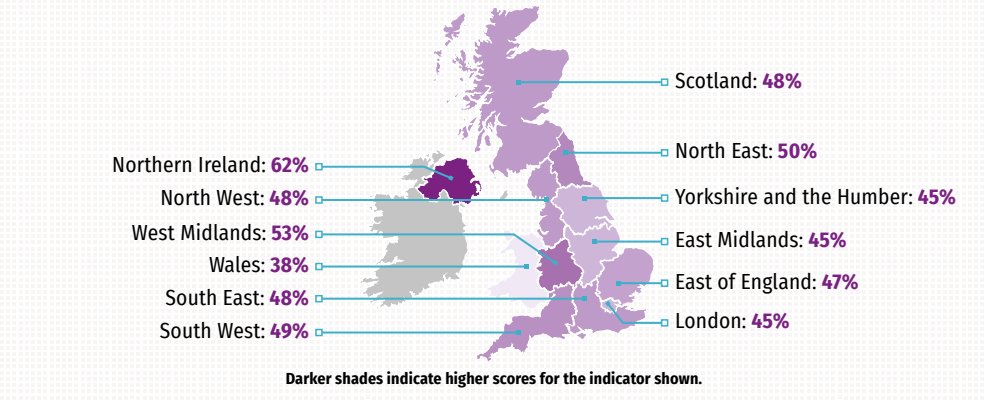


Figure 11: *Asthma action plan uptake, across the UK*



Basic care levels have doubled since 2013 for both Wales (16% to 32%) and England (19% to 40%). Northern Ireland and Scotland have seen smaller increases but began with a higher initial level (Northern Ireland, 42% to 50%, Scotland 27% to 40%). Similarly, a trend of improvement has been seen for regions across England, although London is persistently behind.

What do we think about it?

Everyone with asthma should receive basic asthma care, no matter where they live. Although we welcome basic care improvements across the UK, it is worrying to see that people in Wales are still receiving the worst level of care and that this 'postcode lottery' is so prominent. Our report on inequalities and asthma highlighted a disparity in asthma outcomes across England[39]. London is the only fully urban region included within the survey and therefore has a more unique health economy and a younger demographic than other regions. Other evidence, such as the King's Fund's report Improving Health and Healthcare in London, also shows London to rank the worst in terms of primary and community services (using the GP Patient Survey 2010-11), especially in terms of access to care and communication[40].

What can you do about it?

Wherever you live you should be receiving the basic level of care for your asthma. Remember these three important steps to keep your asthma well managed:

- If you don't have a written asthma action plan, you can download one from our website[41]. There are lots of different languages available and it can be kept on your phone, so it's always with you, or you can print it out and put it on your fridge.
- If you're worried about your inhaler technique or haven't had it checked in a while then ask your pharmacist or GP to check it. You can also visit our website, which has videos for many different inhalers[42].
- If you haven't received an annual review, arrange one with your practice.

What do we want to happen?

- NHS commissioners and planners must ensure equitable provision of basic care across all regions. Primary care in Wales and London in particular must improve standards to the national average.

Asthma care needs to be improved through innovation and collaboration

The survey has consistently shown variation within the UK and each country has its own unique policy environment for respiratory care. As the majority of people with asthma (and respondents to this survey) are in England, the results for England mostly track the UK average and are referenced to throughout the report.

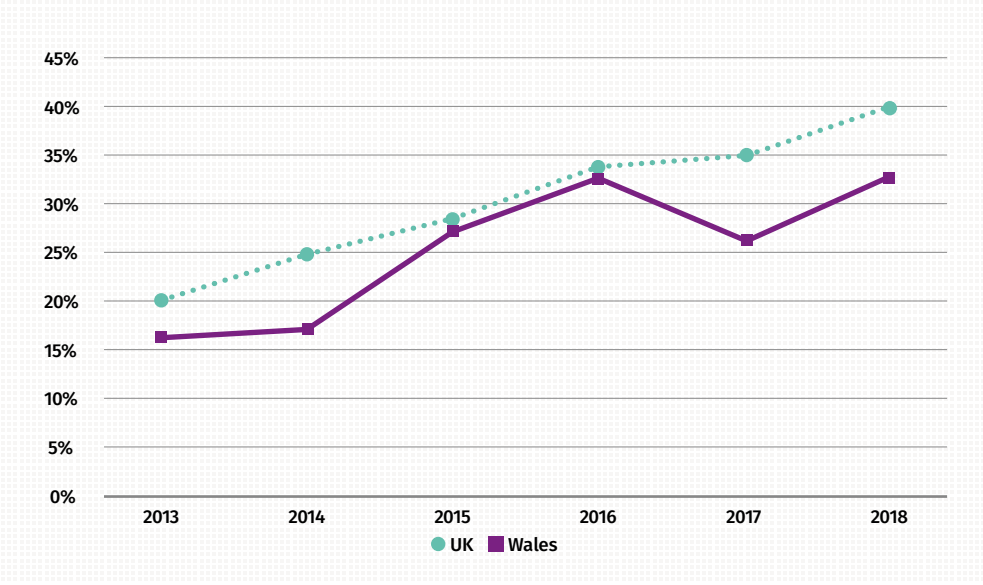
The NHS England Long Term Plan has highlighted respiratory conditions as a key priority for the next decade, which could be a significant opportunity to deliver our policy recommendations in this report and transform asthma care[43]. The Plan's commitment to trial the use of 'smart' inhalers is a particularly welcome step, which could radically improve asthma care.

Below are more detailed snapshots of the results and policy environments for Wales, Scotland and Northern Ireland. The relative success of Northern Ireland has shown us the advantage of respiratory improvement plans and frameworks. However, we have also seen slower progress for Northern Ireland, which could be partly due to the lack of executive government, but may also suggest that these plans only go so far in improving basic care. There is a chance now for respiratory plans to approach the problem more creatively and there is considerable opportunity to do this if policy makers collaborate with innovators.

Wales

Wales has consistently seen lower basic care levels than the UK average. The increase in basic care since 2013 is mostly due to the improvement in uptake of written asthma action plans. Yet most people (68%, which equates to ~210,000 people with asthma), are still not receiving basic care. In 2017, we saw a drop in the trend of improvement, driven by annual reviews (attendance dropped from 76% in 2016 to 71% in 2017). In terms of how well the condition is managed, 80% reported their asthma as uncontrolled this year. Surprisingly, Wales had the lowest percentage of those reporting having used emergency services in the last year (22%) and this is consistent with admissions rates, but the reason for this is not clear.

Figure 12: *Trend in percentage of people with asthma receiving basic care in Wales, 2013-2018 (NB figures for 2014 are for adults only)*

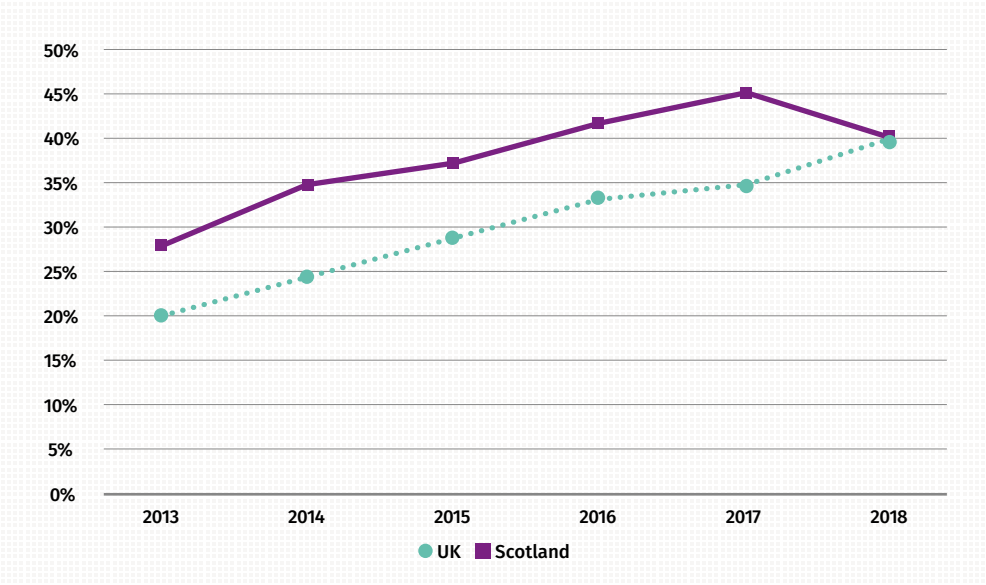


The situation in Wales is simply not good enough and it is not fair people with asthma are at increased risk of an asthma attack, just because of where they live. The continuation of the Respiratory Health Delivery Plan 2018-2020 provides an opportunity to improve outcomes, but the limited progress since 2015 highlights something must change[44]. Within the plan, both written asthma action plans and annual reviews are noted as measurable metrics for asthma care, but there should be more of an emphasis on the asthma attack follow-up within two working days. We see an opportunity for Wales with the launch of the first respiratory disease innovation centre in the UK. The centre could be used to transform basic care, with more modern and digital approaches to both annual reviews and action plans, redesigning the care pathway so it fits better with modern lifestyles, and improving other aspects of self-management through the use of 'smart' inhalers.

Scotland

Scotland has seen better basic care levels than the UK average, until this year where it has fallen for the first time. The survey has shown 60%, which equates to ~220,000 people with asthma in Scotland, are still not receiving basic care for their asthma. We've also seen that 79% of people in Scotland still have uncontrolled asthma – slightly below the UK average, but still far too high. Scotland also has the second highest number of people reporting to have used emergency services in the last year (26%).

Figure 13: *Trend in percentage of people with asthma receiving basic care in Scotland, 2013-2018 (NB figures for 2014 are for adults only)*

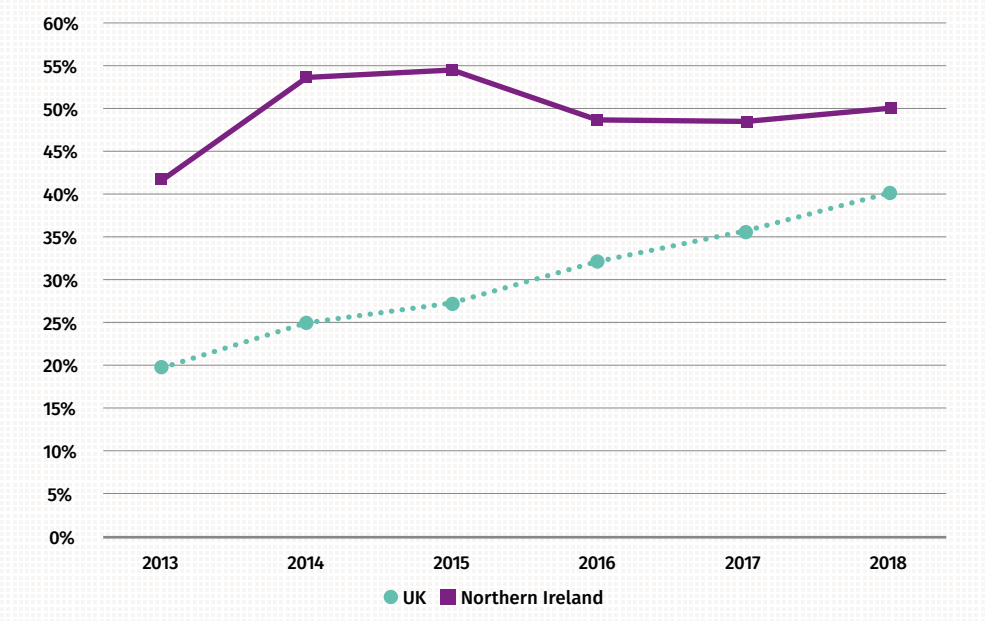


The imminent publication of a respiratory improvement plan for Scotland could be a promising step in making sure more people with asthma in Scotland are getting the care they deserve. We want to see all elements of basic care, the critical asthma attack follow-up within two working days, and text message reminders for reviews and follow-ups as part of the plan. We know that not having a written asthma action plan makes you four times more likely to end up in hospital, and both an annual review and getting your inhaler technique checked are set out in the national guidelines, but this doesn't mean basic care has to stay in its traditional form in order to work[45]. A more modern and digital approach to annual reviews and written asthma action plans may be the way forward. We recognise that Scotland has a community of innovators and along with the Chief Scientific Office we are joint-funding two innovation grants to explore novel applications of digital technology in asthma.

Northern Ireland

In terms of basic care, Northern Ireland has been consistently better than the UK average, but has seen little change over the years. After a fall in those receiving basic care in 2016, levels have been unable to reach the peak of 2015. The uptake of action plans is the main driving force for Northern Ireland's relative success at 62% this year (the UK average is 48%). In terms of asthma control, Northern Ireland has the lowest percentage of people with uncontrolled asthma (78%). However, 31% of people in Northern Ireland reported using emergency services last year, 6% higher than the UK average. They also rank worst for receiving a follow-up in two working days after emergency care, with only 26% receiving it compared to the UK average of 32%. Because the sample size (81/261) is quite small for emergency care within Northern Ireland, we cannot draw conclusions from these statistics.

Figure 14: *Trend in percentage of people with asthma receiving basic care in Northern Ireland, 2013-2014 (NB figures for 2014 are for adults only)*



Since 2009, a respiratory framework has existed in Northern Ireland. Our evidence suggests that this framework's effort to prioritise respiratory conditions has gone some way to improving the lives of people with asthma, even without an executive government[46]. We want to be able to understand Northern Ireland's relative success, so we can learn from it. The challenge for Northern Ireland now appears to be getting above that 50% basic care level and the rather plateaued trend seen here suggests more innovative ways of delivering basic care, as mentioned throughout this report, need to be considered in the future. Northern Ireland has made significant strides to create a single digital healthcare record for everyone and is also home to a thriving life sciences sector. Future iterations of the Respiratory Service Framework could work in collaboration with Northern Ireland's life sciences innovators to develop better ways of delivering basic care, redesigning the care pathway and improving asthma care overall.

People may be suffering from more asthma attacks than previously estimated

Previous estimates based on surveillance data of prescriptions of oral steroids showed that every 10 seconds someone has a potentially life-threatening asthma attack – one asthma attack every two years for the 'average' person with asthma*. This methodology is limited, since it does not capture those asthma attacks that do not need emergency care or a prescription of oral steroids. We felt there was a need to measure self-reported prevalence of asthma attacks and so for the first time in this survey, we asked for the number of asthma attacks experienced in the last 12 months.

The definition of an asthma attack was adapted from the current BTS guidelines, the NHS definition and the Primary Care Respiratory Society UK (PCRS) guidance[47]:

You're too breathless or it's difficult to speak, eat or sleep.

Your breathing is getting faster and it feels like you can't get your breath in properly.

Your symptoms are getting worse (cough, breathlessness, wheeze or tight chest).

Your reliever inhaler isn't helping or the effects lasting over four hours.

Your doctor has given you steroid pills to take because your asthma is so bad.

We have found that the number of asthma attacks people suffer from every year in the UK could be four times higher than previously estimated, with an average of two asthma attacks a year**. We have calculated a median of two asthma attacks per year, which could mean every three seconds someone has an asthma attack across the UK. This translates into over ~10 million asthma attacks each year in the UK. The average was constant across nations and varied very little across age groups. This median of two asthma attacks per year appears to be higher than has been estimated previously (0.57 attacks per year has been calculated from 2013 surveillance data). The definition we used was much broader than that used from health system measures (usually oral steroid use or emergency care). It's based on an adaption of expert clinical definitions of an asthma attack and captures those people with asthma who deal with an asthma attack at home and/or do not feel they require emergency care/oral steroid use. Whilst the sample size for this survey is robust at over 10,000, we do acknowledge people who have had an attack in the past year may also be more motivated to fill in our survey.

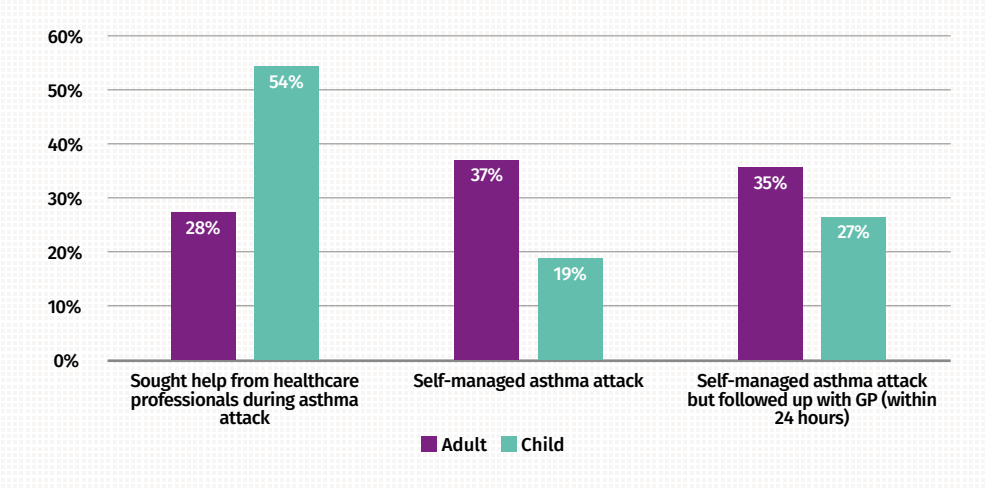
* This is research commissioned by Asthma UK. "Asthma attack" was defined as a prescription for oral steroids. Based on data from practices in Knowsley and South Gloucestershire CCGs in 2013, supplied by Health Intelligence ltd, an estimated 3.07 million are issued to people with asthma in a year, an average of one every 10.3 seconds.

** We excluded any answers over 52 (once per week), as this was deemed unrealistic by our experts.

Many people may be managing asthma attacks alone

Since not all asthma attacks require an emergency hospital admission, we were interested in how people with asthma were managing their asthma attacks. These findings indicate more people may be managing asthma attacks on their own than previously understood. Figure 15 presents the results for the different ways of managing an asthma attack. The greatest percentages were seen for managing the asthma attack yourself (37%, 2216/6075), and managing the asthma attack yourself but following up with your GP within 24 hours (35%, 2133/6075). Similar results were seen for children with parents answering on their behalf.

Figure 15: *Ways of managing asthma attack (in or out of health care services)*



As you would expect, those whose asthma was uncontrolled (81% of respondents) had a higher median number of asthma attacks in the last year. Those with uncontrolled asthma had a median of two asthma attacks per year, whereas those with controlled asthma had a median of zero.

What do we think about it?

From reviewing the literature, we believe this is the first large scale survey of self-reported asthma attacks in the UK. It may suggest that the number of asthma attacks people with asthma are experiencing could be far worse than we previously thought. What we see in hospitals and surgeries is not the full picture, and the extent to which people are managing asthma attacks out of health services must be understood. Since people with asthma self-select into the survey, this estimate may not be representative of the whole population, but it has indicated that we need more robust evidence and research into the scale of asthma attacks, including those that are managed at home and not reported to clinicians.

What can you do about it?

- If your asthma symptoms are getting worse, look at the asthma attack section of your written asthma action plan. It will have instructions on how to recognise an asthma attack and what to do in an emergency. Don't be afraid of causing a fuss, even at night. It's important that you seek help straight away. Visit our webpage for more information about what to do during an asthma attack[48].

- If you're experiencing frequent asthma attacks, such as two a year, arrange an asthma review with your GP.

- If you do manage an asthma attack yourself, always follow up with your GP, ideally within 24 hours afterwards. An asthma attack is not something you should deal with alone and could be an indicator that your medicine needs to be changed or you need more specialised care.

- If you've had an asthma attack in the last 12 months, then you're more likely to have another one in the next 12 months. Our asthma attack risk checker only takes a few minutes to complete and will show you if you're at risk. You'll also get a personal asthma report packed with simple tips and advice to help you deal with your asthma[49].

What do we want to happen?

- We need clear and consistent clinical guidelines and service standards for identifying and managing asthma attacks in primary and emergency care, as well as an awareness raising campaign so that people with asthma can recognise when they're having an asthma attack and when to contact their GP.

- This survey has identified a need for better research into the frequency of asthma attacks in the UK, including self-reported and self-managed asthma attacks, to understand the true impact of asthma.

"I managed the [asthma attack] myself, but still had chest pain and tightness the next day so rang 111 and then was asked to go to A and E."

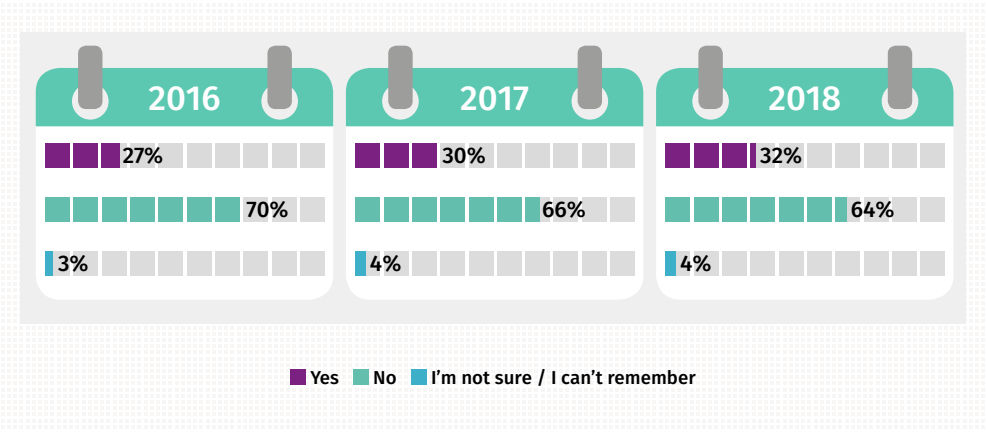
Survey respondent

Crucial follow-up after emergency care is still being missed

Every eight minutes, someone is admitted to hospital for an asthma attack in the UK. To find out more about people's experiences, we asked if they had received unscheduled emergency care in the last year. If so, we asked if they had attended a GP follow up appointment within two working days. We found one quarter of respondents had received emergency care in the last year and an alarming 64% said they didn't receive a follow-up within two working days. This potentially life-saving opportunity is recognised by clinical guidelines as being essential in stopping asthma attacks and preventing further hospital visits. It is simply not good enough that most people don't get it. More needs to be done to make sure this follow-up appointment happens.

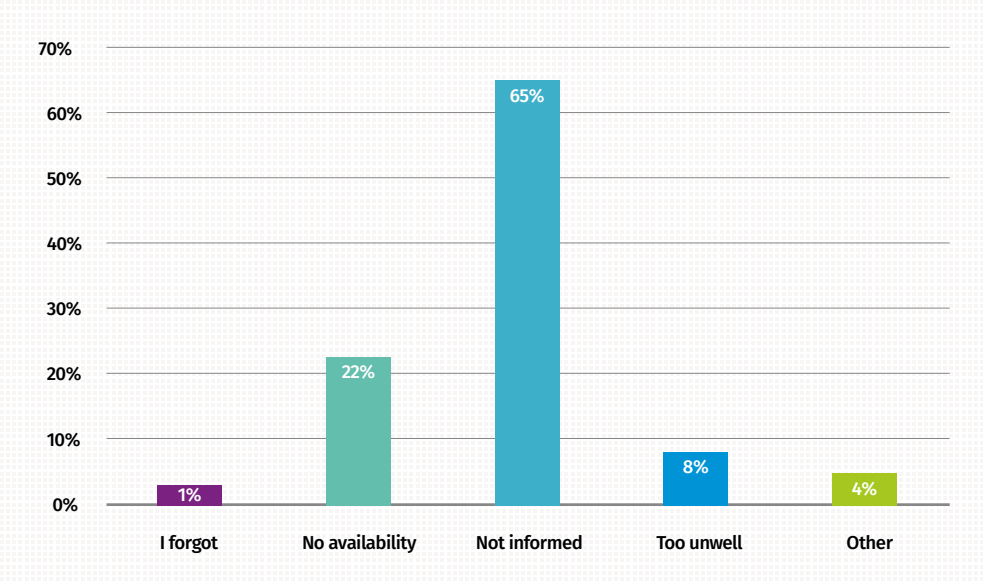
One quarter of respondents (25%, 2508/7492) said they had received emergency care at a hospital or out of hours service in the last year. Of those that received this emergency care, figure 16 shows 64% (1594/2508) said they did not have a follow-up appointment with their GP within two working days.

Figure 16: *Trend in two day follow-up appointments 2016 to 2018*



Of those that did not have a follow-up, 65% (1016/1570) said they were not told they should have one, and 22% (351/1570) said there was no availability within two working days (figure 17). We have been asking this question about emergency care since 2016. Figure 16 shows a slight improvement in those getting the follow-up within two working days from 30% to 32%.

Figure 17: *Reason for not receiving a follow-up within two days of receiving emergency care*



What do we think about it?

Once again, we find most people using emergency services are still not receiving a follow-up with their GP within two working days. This is a crucial part of integrated care for asthma because people who have had one admission for an asthma attack are at a much higher risk of having another one. Almost five years ago it was recommended by NRAD as a potentially life-saving opportunity[50]. Little progress has been made since then. Our research with people with asthma who are less engaged with their asthma care, shows that an asthma 'emergency' is the most effective opportunity to intervene and improve self-management[51]. Systems are too often not in place to share data between hospitals and GPs in real time – this means that by the time a discharge letter has been sent out, it's too late for useful follow-up.

What can you do about it?

- If you do attend A&E or receive out of hours care, make sure you arrange a follow-up with your GP, even if you are not told to do so. Ending up in emergency care is a warning sign you could be at risk of an even more dangerous asthma attack in the future. This follow-up can help keep you well and out of hospital. You must request an urgent appointment to get your follow-up within two working days. If there is still no availability within two days after asking for an urgent appointment, then ask for a phone call, so your GP can assess if you need to be seen face-to-face.

What do we want to happen?

- There needs to be a drive to ensure the asthma attack follow-up happens within two working days after emergency care is received. Most people are still not receiving this, even though it's a critical preventative measure in stopping future asthma attacks and trips to A&E. Ensuring awareness of the importance of this follow-up and making fast track appointments available at GP surgeries should be driven by commissioners, particularly in areas of high emergency care use for asthma.

- We would like to see investment in digital technology to improve data collection and data sharing, and to promote a behavioural shift towards preventative and co-ordinated care. High quality, personalised care cannot be achieved without the collection and appropriate sharing of data between health settings. Patient data records between primary and secondary care must be linked to allow asthma attacks to be better recorded and managed. This would enable healthcare professionals to identify people at increased risk of future attacks and who require further interventions to stay well.

Case study: Tamara Mills

Linkage of secondary and primary care databases could save lives.

In April 2015, 13-year-old Tamara Mills had a fatal asthma attack. When the coroner investigated how such a tragic event could have been allowed to happen, he found failings in the way her health records had been linked. In particular no one had flagged that, in the four years leading up to her death, she was seen by medical professionals 47 times in different parts of the NHS. Linking these records could have allowed her doctors to treat her differently and perhaps prevent her death.

What happened?

Over the last four years of her life, Tamara Mills' health was deteriorating. However, because each time she saw a medical professional it was treated as a unique incident, there was no overall appreciation of the trajectory which her condition was following.

After her death, the coroner identified a number of failings in Tamara's care. One of these was the lack of a co-ordinating record of the occasions on which she saw medical professionals. Each medical professional who saw Tamara should have been able to access a comprehensive summary of her previous interactions with the NHS and make an informed decision about the care needed. In particular, there was a lack of communication between the hospital and out-of-hours services, and her GP service.

How could it have been prevented?

If medical staff had access to a single record, they would probably have been able to see that Tamara's overall health was getting worse. This would have allowed them to identify the severity of the situation, review her medication and seek to control her symptoms. More comprehensive information and communication could have led to her being treated differently, and her death may have been prevented.

Conclusions

Most people with asthma in the UK are still not receiving basic care (60%). Since we began the survey in 2013, we haven't seen sufficient improvements for people with asthma, despite simple technologies now being available which could drive improvement. People may be suffering from even more potentially life-threatening asthma attacks than we previously thought, are still being admitted to hospital, and deaths are on the rise[4]. We've identified young adults as being under-served by current models of care. They need better provision of care through innovative digital solutions that fit in with their digital first lifestyles. It's unfair that they begin their working lives disadvantaged by their asthma because models of care haven't kept up with the tech and innovation that is taken for granted in other key sectors, such as banking, retail and housing.

Little has been achieved in decreasing the variation across the UK. Wales and London still rank the lowest in terms of basic care. In Northern Ireland, 50% of people are receiving basic care, so we know higher levels of care are achievable, even if still inadequate. However, Northern Ireland's slower progress shows we need a more innovative approach if we are to go beyond just one in two receiving basic care. We welcome the prioritisation of respiratory conditions through improvement plans and frameworks – however, to see the real improvement that people with asthma deserve, policy makers and innovators need to work together to develop better ways of delivering basic care and improving asthma care overall. There needs to be a national effort to improve basic care for everyone. We've seen some improvement, but the overall picture is just not good enough.

People are still not attending a follow-up appointment within two working days after receiving emergency care. It's hard to believe that 65% said they didn't even know it should be happening. More needs to be done between hospitals and GPs to ensure patients are aware this is needed and to make sure that it happens.

We have proposed potential policy solutions to tackle inequality in asthma care and improve asthma care overall. As well as encouraging the rollout of digital health solutions, such as 'smart' inhalers, we've highlighted text reminders as a simple tech solution that can be implemented by practices now. We continue to call for data sharing and data linkage between primary and secondary care, which we know are key in preventing asthma attacks and keeping people with asthma out of hospital.

The overall picture is once again so disappointing. We have shown that most people are not receiving basic care and many thousands are suffering asthma attacks alone. The complacency of policy makers, healthcare professionals and people with asthma is fuelling one of the worst death rates in Europe[52]. With a new respiratory focus in the NHS England Long Term Plan and other national strategies, now is the time to start taking asthma seriously.

This report was written by Lottie Renwick of Asthma UK.

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Every ten seconds someone in the UK has a potentially life-threatening asthma attack and three people die every day. Tragically two thirds of these deaths could be prevented, whilst others still suffer with asthma so severe current treatments don't work.

This has to change. That's why Asthma UK exists. 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.

We fight asthma in three ways:

- We fund world class asthma research.
- We campaign to improve the quality of care received by people with asthma.
- We help hundreds of thousands of people a year with our expert advice and support.

To find out more about Asthma UK's work:

Asthma UK Helpline:
0300 222 5800

Email us:
info@asthma.org.uk

Visit our website:
www.asthma.org.uk

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