

Living in limbo:

the scale of unmet
need in difficult and
severe asthma



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Foreword



People with difficult or severe asthma live in constant fear of literally losing their breath. Frequent asthma attacks, admissions to hospital and complicated drug regimens are a regular reality. They are often reliant on long-term, high-dose steroid tablets that cause toxic side effects including weight gain, mood changes and osteoporosis. Many are forced to give up work and miss out on everyday activities and family life.

Specialist services and breakthrough medicines offer new hope. But Asthma UK's new analysis shows that four in five adults in England who are at risk of having severe asthma – the most serious and life-threatening form of the condition – are still not being referred to specialists for the treatments that could transform their lives. Despite guidelines and recommendations, many GPs are not spotting the warning signs of severe asthma, including frequent severe asthma attacks.

New medicines that can reduce or stop the need for oral steroids and have far fewer side effects are now available on the NHS. But tens of thousands of adults who could be eligible are missing out on these new drugs.

This means that NHS resources are being wasted on treating avoidable side effects of oral steroids and preventable hospital admissions. It means that people are stuck at home with a treatable condition who would rather go to work. But most of all, it means that people with this serious, life-changing, potentially fatal condition are not getting the treatment they need.

For too long, people with severe asthma have suffered in silence. This report is a call to action for the NHS and healthcare professionals to take severe asthma seriously and end the life in limbo.

Dr Samantha Walker

Deputy Chief Executive and Director of Research and Policy, Asthma UK



Executive summary

While many adults with asthma are able to control their condition with the help of low-dose steroid inhalers, there are some whose asthma is difficult to control (difficult asthma) and who suffer frequent asthma attacks and trips to hospital. These include people with ‘severe’ asthma, a condition that is resistant to usual treatments, requires high-dose steroid tablets with serious side effects and leads to disability and higher risk of potentially fatal attacks.

The NHS should provide a care pathway for adults with difficult or severe asthma that enables people at risk to be identified, prompts referral to a local specialist and to a regional specialist centre if necessary. People should have access to expert clinicians to support their asthma management, diagnose severe asthma and prescribe new treatments if appropriate. But as Asthma UK has found, people with difficult or suspected severe asthma are left in limbo, relying on repeated rounds of toxic oral steroids after multiple asthma attacks without referral to a specialist. This report highlights the scale of these issues.

Currently, there are no statutory guidelines on the management of people with difficult and severe asthma which has contributed to the variable care received. The guidelines that do exist say GPs should refer people with asthma to specialist care if they are taking high-dose inhaled steroids. Our new analysis shows that for around 160,000 people in the UK this is not happening. Three-quarters of people who are taking three or more courses of oral steroids per year – in other words, suffering serious, life-threatening asthma attacks every four months – are not getting referred for a specialist medical opinion as they should be.

This report also shows that adults with severe asthma are not getting access to the treatments to which, under

the NHS constitution, they are entitled. New drugs known as monoclonal antibodies (mAbs) have been approved by NICE for use with this population, providing respite from frequent asthma attacks and toxic oral steroids. For the first time we are able to estimate that about 48,000 people are currently missing out on these new, life-changing treatments.

To enable all those who need these new treatments to be considered for them, an expansion of capacity in secondary and tertiary care will be needed. This will take leadership and a renewed effort to plan services around the needs of adults with difficult and severe asthma.

In this report, we recommend:

- the development of clear referral guidelines coupled with a national awareness-raising programme
- a review of capacity in secondary and tertiary care based on the unmet need highlighted in this report and the commissioning of new asthma services as required
- ensuring appropriate access to mAbs to address the unmet need outlined in this report.

Purpose of the report

This report is designed to help NHS policy makers, commissioners, managers and clinical leaders with responsibility for planning adult asthma services in primary care, local hospitals and regional specialist centres. It is also for GPs and primary care staff who are responsible for delivering asthma care.

“This report shows that an unacceptably low proportion of people (18%) are getting a referral for the care they need, and only 22% are receiving the life-changing biologic treatment they need.”

Dr Samantha Walker

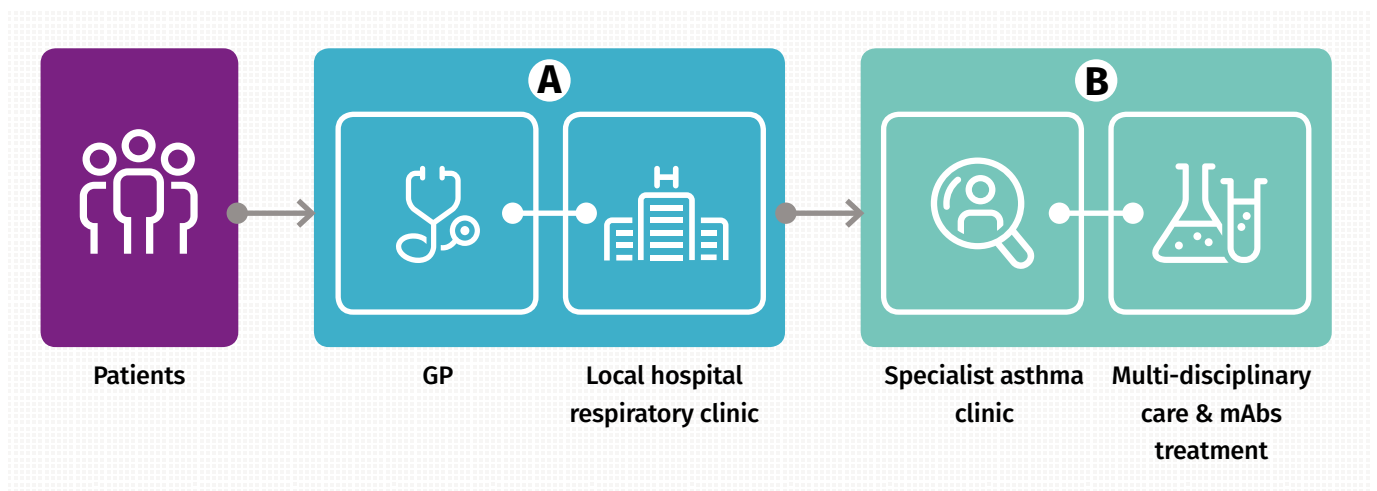
Introduction

Asthma affects 5.4 million¹ people in the United Kingdomⁱ. For a significant proportion of this group (about 1 million), managing their asthma requires more than an occasional visit to their GP or asthma nurse. Their asthma is difficult to control with standard inhaled steroids (preventer inhalers). Difficult-to-control asthma can have a devastating impact on the lives of those with the condition, with regular A&E visits and the disruption of their condition preventing them undertaking daily activities. This group are often reliant on oral corticosteroids (OCS), which are known to have debilitating side effects (such as weight gain, bone weakening and mood changes) and are unpopular with those prescribed them².

Many of these people would benefit from extra help from a team of specialists to control their 'difficult asthma', for example due to complex co-morbidities (other long-term conditions), psychological or social factors making adherence to complicated medications difficult. Others (about 200,000) have a type of asthma called 'severe asthma' which is resistant even with good adherence to standard treatments.

But after years of suffering, thanks to breakthrough research, there is new hope for people with severe asthma. New biologic drugs (also known as mAbs) have been approved that can target a type of asthma called 'severe eosinophilic asthma' and NHS services for adults in England are being organised into networks to ensure people who need it can get access to the care. Understanding the care needed, and what care is currently being provided, is vital to guide these service improvements. This report focuses on two parts of the care pathway – the referral from GP to respiratory clinic (A in Figure 1), and the access to mAbs via specialist asthma clinics, found in tertiary care (B in Figure 1ⁱⁱ).

Figure 1: The ideal care pathway for people with difficult or severe asthma



In our 2018 report *Slipping through the net: The reality facing patients with difficult and severe asthma*³, we outlined the data quality problem in difficult and severe asthma and recommended the development of clearer definitions and referral criteria to be followed consistently across the UK. Since the publication of this report, we have been encouraged to see the development of the NHS Improving Value⁴ programme on severe asthma in England. This programme, supported by Asthma UK alongside regional NHS leaders and clinical experts, is taking forward many of the recommendations from our report, such as improving data collection and data sharing, and aligning referral criteria.

ⁱ This includes 4.3 million adults. This report covers care for adults.

ⁱⁱ Data on referrals from specialist to tertiary care was not available. This stage in the care pathway is being addressed by other initiatives in the NHS in England.

About the data

This report uses several data sources:



Clinical Practice Research Datalink (CPRD). This is de-identified primary care data, that is linked to Hospital Episode Statistic data (in England) to provide a fuller picture of the care people with asthma receive. This data is used for prescribing activity and insight on the difficult/severe asthma population. The data extract used in this report used the health records of over 400,000 people.



Quality and Outcomes Framework (QOF). This data is based on a cohort of people registered as having asthma with their GP. Although this data may not provide a full picture of asthma prevalence, it does use data linked to NHS activity and is updated annually. This source is also used for difficult/severe asthma population size estimates.



Health surveys. This data is derived from responses to nationally representative surveys, and then applied to a population figure. We have used a single estimate in this report, as questions on asthma prevalence are asked sporadically in health surveys. This source is used for difficult/severe asthma population size estimates.



Eligibility data. Several data sources were used in the section looking at biologic treatment eligibility and prescribing activity, including data from IQVIA on hospital prescribing activity, and estimates from the IDEAL (Identification and Description of sEvere Asthma patients in a cross-sectional study) study⁵.

Full notes on this data are available on Appendix A.

What is difficult and severe asthma?

Asthma is heterogeneous, and those with difficult and severe asthma have an experience of living with asthma that is very different to that of the majority of the 5.4 million with the condition. It can be difficult to differentiate between severe and 'difficult' asthma, which is often the result of poor adherence, other co-morbidities and/or the wrong diagnosis (e.g. not having asthma at all). Both conditions are characterised by uncontrolled symptoms of wheezing, shortness of breath, and cough, which result in a high burden of symptoms and attacks, often leading to admission to hospital and even death⁶. Yet finding and agreeing a clear definition and getting widespread consensus and awareness amongst non-specialist clinicians, thus being able to find the scale of unmet need in difficult and severe asthma, has proved difficult.

Previous estimates of the size of the difficult and severe asthma population have derived from academic studies, with recent estimates based on a Dutch study which puts the difficult asthma population at 17.4% of adults with asthma and 3.6% having severe asthma⁷. Applied to the 4.3 million adults with asthma in the UK, this equates approximately 748,000 people with difficult asthma and approximately 155,000 with severe asthma. In England, services for adults with severe asthma are currently planned and commissioned based on a much lower estimate⁸ which puts the prevalence at 140 people per million – an estimated 7,700 people. This is a significant underestimation of the need for severe asthma services. There is a clear need for a new estimate, that reflects the difficult and severe asthma population in this country. This figure should be used to design asthma services to make sure everyone with difficult or severe asthma gets the treatment they deserve.

Clinical guidelines – a confusing picture

For several years, we have seen multiple guidelines used to treat people with asthma. Asthma diagnosis is difficult and imprecise, and there is much to do to bring it into the 21st century⁹. Accurate diagnosis of severe asthma is only possible via referral to specialist-led tertiary centres which have the appropriate expertise and equipment. We have previously identified the problem of misaligned referral criteria in clinical practice and identified it as a key challenge in improving the management of those with severe asthma¹⁰. Two clinical guidelines for the management of asthma are currently in use in England; the British Thoracic Society (BTS) / Scottish Intercollegiate Guidelines Network (SIGN)¹¹ and the National Institute for Health and Care Excellence (NICE)¹² offer alternative options for the management of asthma, although do not cover the management of difficult and severe asthma. The Global Initiative for Asthma (GINA) also offers further clinical guidance¹³. Further important recommendations for referral were discussed in the National Review of Asthma Deaths (NRAD)¹⁴. A summary of the different treatment-based referral thresholds is detailed below in Table 1, with the full list of referral criteria available in Appendix B.

Table 1: Criteria for referral to a specialist

BTS/SIGN	NICE/GINA	NRAD
<ul style="list-style-type: none"> • Prescription of high-dose inhaled corticosteroids (ICS) use and/or • Continuous or frequent use of oral corticosteroids (OCS) • Symptoms of acute severe or life-threatening asthma • Signs of occupational asthma 	<p>NICE does not mention referrals in its NG80 guideline (2017) but it does refer to the GINA definition of severe asthma as</p> <ul style="list-style-type: none"> • Use of high-dose ICS with long-acting beta2 agonist (LABA) or leukotriene modifier or theophylline • Six months or more on OCS 	<p>More than two courses of oral or injected corticosteroids in the previous 12 months</p>

Previous Asthma UK research with clinicians showed differing perceptions of the referral threshold. Responses showed uncertainty about who should be referred, ranging from two courses of OCS (11% of responses) to continuous (15%) being the criteria for referral¹⁵. Referral criteria were not included in the NICE NG80 asthma guideline.

Who are the people with difficult/severe asthma?

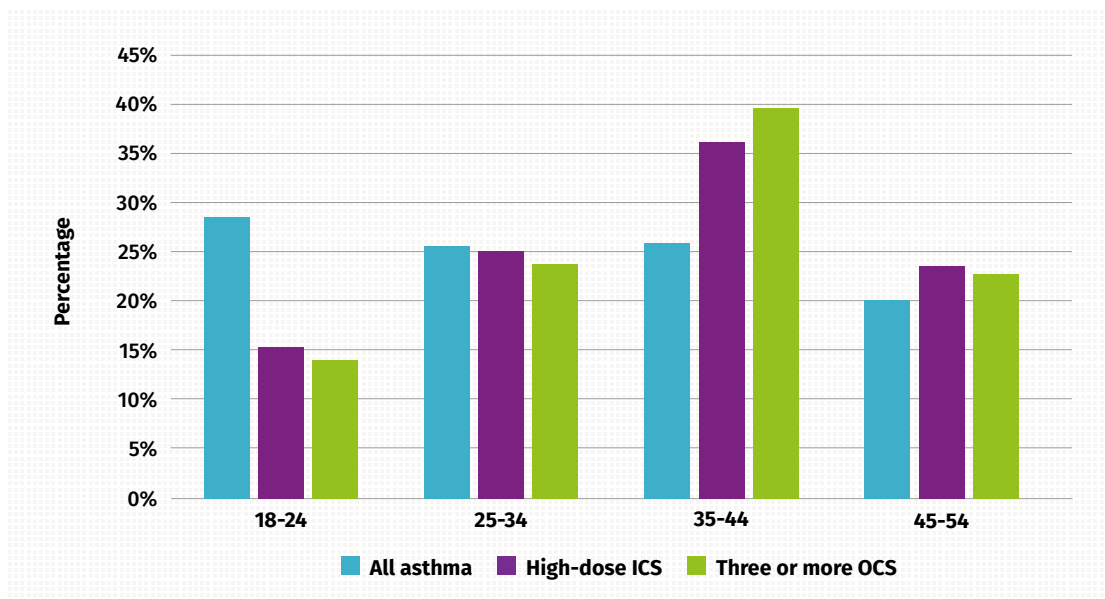
Key findings



- The difficult and severe asthma population has characteristics distinct from the general asthma population.
- There is a higher prevalence of difficult or severe asthma among people aged 35-44, and among women.
- Prevalence of difficult and severe asthma is higher in Wales and Scotland than the rest of the UK.

Asthma affects people of all ages, genders and life circumstances. Using the CPRD dataset, we can compare the demographics of people with difficult and severe asthma to the general asthma population. Better understanding of the difficult and severe asthma population will allow the better identification of those at risk, and the better planning of services.

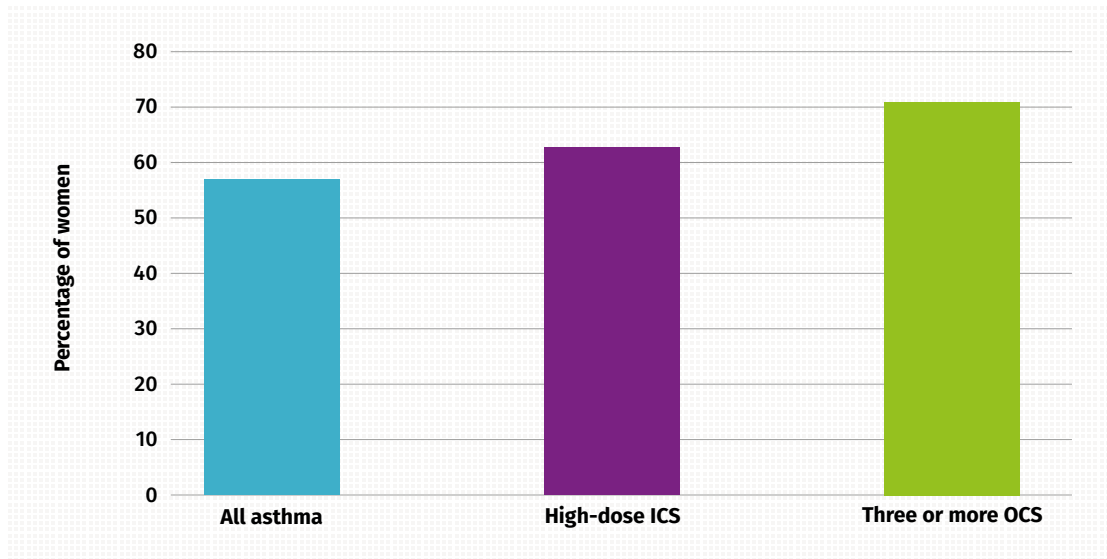
Figure 2: Age profile of all people with asthma vs those with difficult/severe asthma, 18-54



A higher percentage (39.4%) of people on 3 or more OCS are aged 35-44, in comparison to 25.8% of the general asthma population. This is a similar pattern to those on high-dose ICS, with 36.2% of the studied group aged 35-44. Interestingly, when this data is broken down by age band and gender, there is little difference in the distribution by genderⁱⁱⁱ. Adult onset asthma tends to be more severe than asthma developed in childhood¹⁶, so the data in Figure 2 represents this trend. Although the data used here stops at age 55, we recognise there is likely to be a significant further need in those older than this age group.

ⁱⁱⁱ This data is available in Appendix A.

Figure 3: Percentage of women in different asthma populations



Using an extract from this same dataset, Figure 3 indicates that women make up the majority of people with difficult and severe asthma in the UK. Women constitute 70.6% of those on three or more OCS courses, and 62.6% of those on high-dose ICS. These data show that the severe population is distinct from that of the general asthma population; this means that better identification of those at risk of severe asthma is possible which may help improve the proportion being referred and receiving the care they need.

Figure 4: Prevalence levels around the UK, 2016

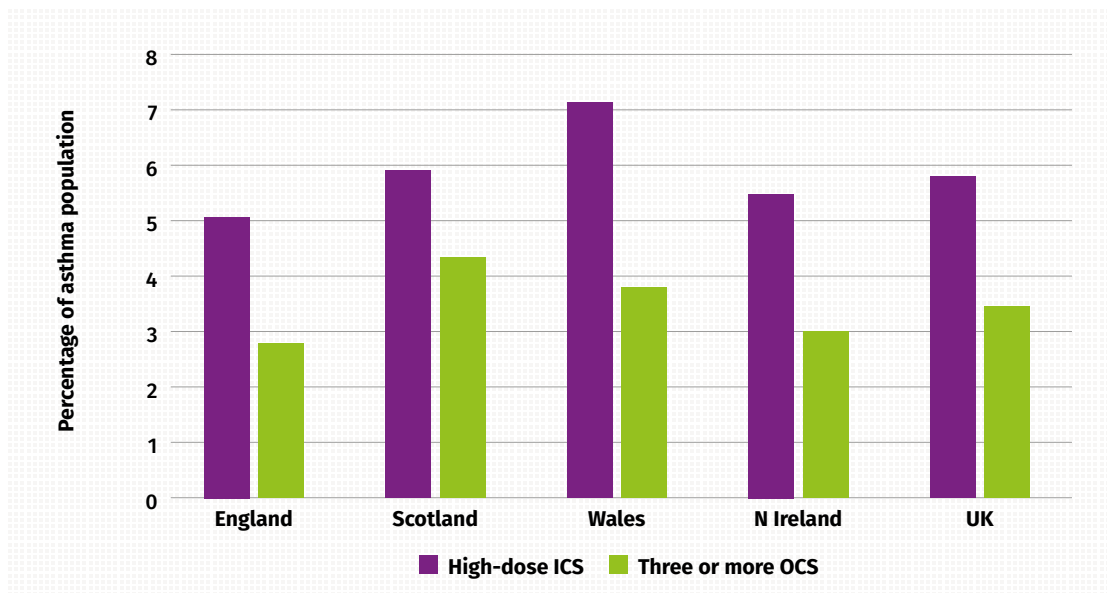


Figure 4 outlines the differences in difficult or severe asthma indicators across the nations in the UK in 2016. Wales has a higher proportion of people on high-dose ICS, (7.1%), compared to the UK figure of 5.7%. For three or more OCS prescriptions, Scotland has the highest figure in the UK, with 4.3%, compared to the UK figure of 3.4%. Wales has a higher asthma prevalence than other nations in the UK¹⁷, and this data indicates there is a higher proportion of people with difficult or severe asthma in Wales, and/or that there is variation in the management of difficult and severe asthma between nations, with some using more high-dose ICS and others using more OCS. These data further illustrate the complexities in defining the severe asthma population.

How many adults with suspected difficult or severe asthma need referral to a specialist?

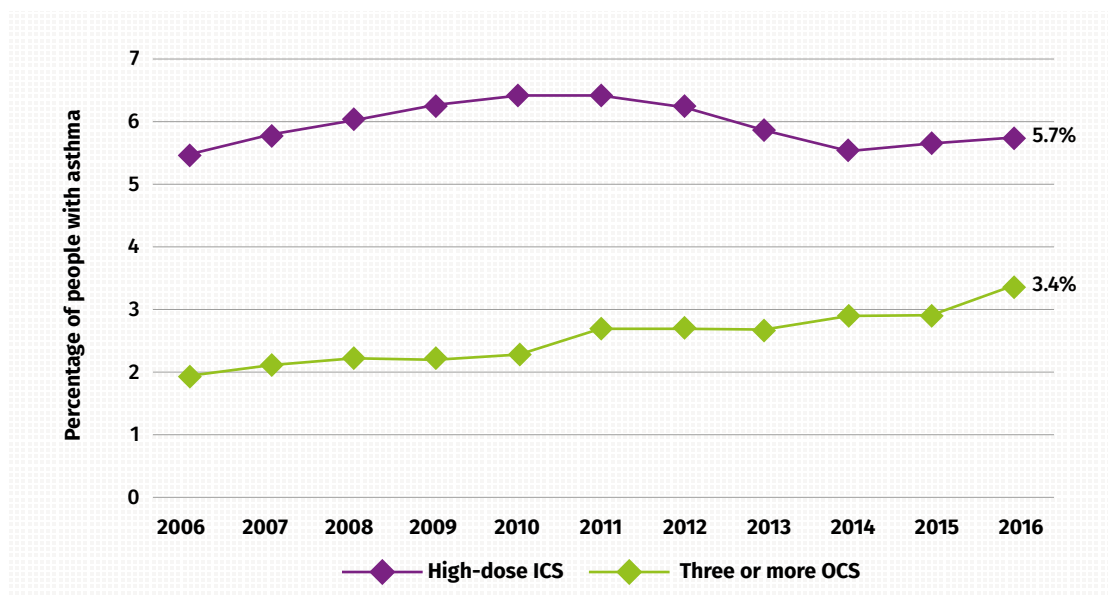
Key findings



- An increasing number of people are on multiple courses of OCS, with associated debilitating side effects.
- Over 200,000 people are on high-dose ICS, with over 130,000 on three or more OCS courses per year.

To estimate the need for difficult or severe asthma services, we have used CPRD data^{18 iv}. Data on people with difficult and severe asthma often defines them by the treatment they are prescribed. This source provides evidence of prescriptions for asthma that is proving difficult to treat, and this can indicate who should be receiving referral to a hospital asthma specialist. Inhaled corticosteroids (ICS) are preventer medication that aim to reduce inflammation, and dosage can be increased if poor asthma control persists. Oral corticosteroids (OCS) are prescribed following an acute asthma attack. We used the referral criteria from BTS (use of high-dose ICS) and NRAD (three or more OCS courses) outlined above to estimate the level of need for referrals to specialist care.

Figure 5: Annual prevalence of high-dose ICS or three or more OCS prescriptions in the UK



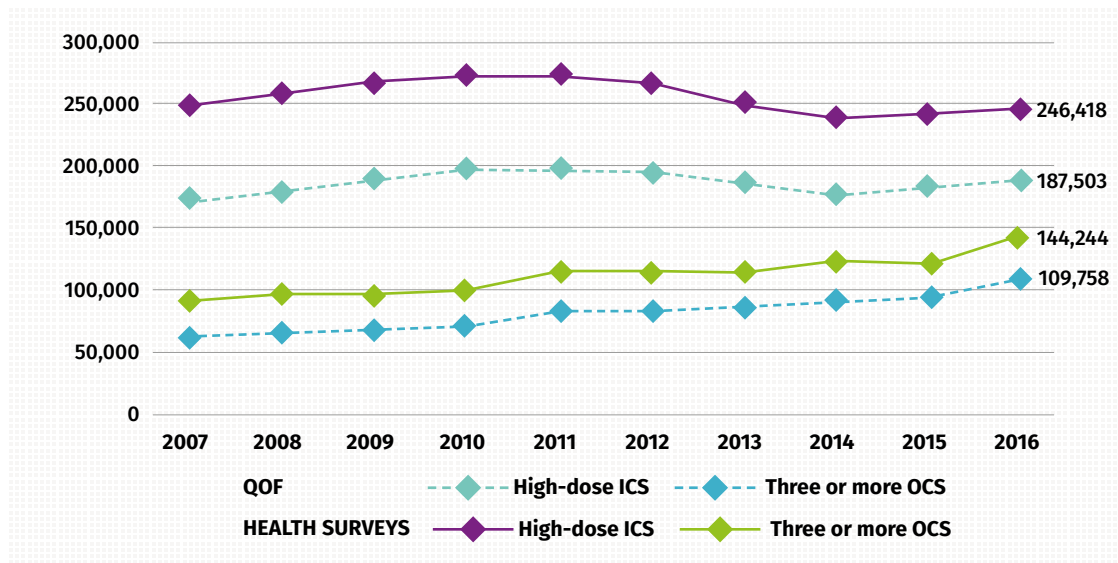
There has been an increase in those on three or more OCS courses in the decade the data covers, with 5.7% of people with asthma on high-dose ICS in 2016, and 3.4% on three or more OCS courses. This data is not discrete – there will be people who are on both treatments^v and the data covers new incidences, so long term use of OCS cannot be assessed.

We can apply the figures above to established asthma prevalence estimates to find out the number of people who met the criteria for referral to hospital in the UK. Based on QOF data, 109,748 people in 2016 were prescribed three or more courses of OCS. Alternatively, using health survey data, 144,245 people were prescribed three or more courses of OCS in 2016, up from 90,153 in 2007. Using QOF again, 187,504 were prescribed high-dose ICS in 2016, while on the health survey data, 246,418 were prescribed high-dose ICS.

iv Data used in this report from this source is available in Appendix A.

v A discussion of the differences between this data and other estimates of the difficult asthma population is available in Appendix A.

Figure 6: Estimates of need for referral to secondary care, using Health Surveys (solid lines) and QOF data (dotted lines)



This data brings new light to the scale of need for referrals to difficult or severe asthma services in the UK. Further analysis is needed to find out whether people are receiving the care they need, as recommended in clinical guidelines.

There is significant unmet need for referrals to specialist care

People with difficult or severe asthma should be managed differently to those with mild or moderate asthma. The most appropriate care for people with difficult or severe asthma is delivered in secondary or tertiary care, providing holistic assessment and support by a multi-disciplinary team, accurate diagnosis and assessment for new, life-changing biologic treatments.

Getting specialist care – only for the few

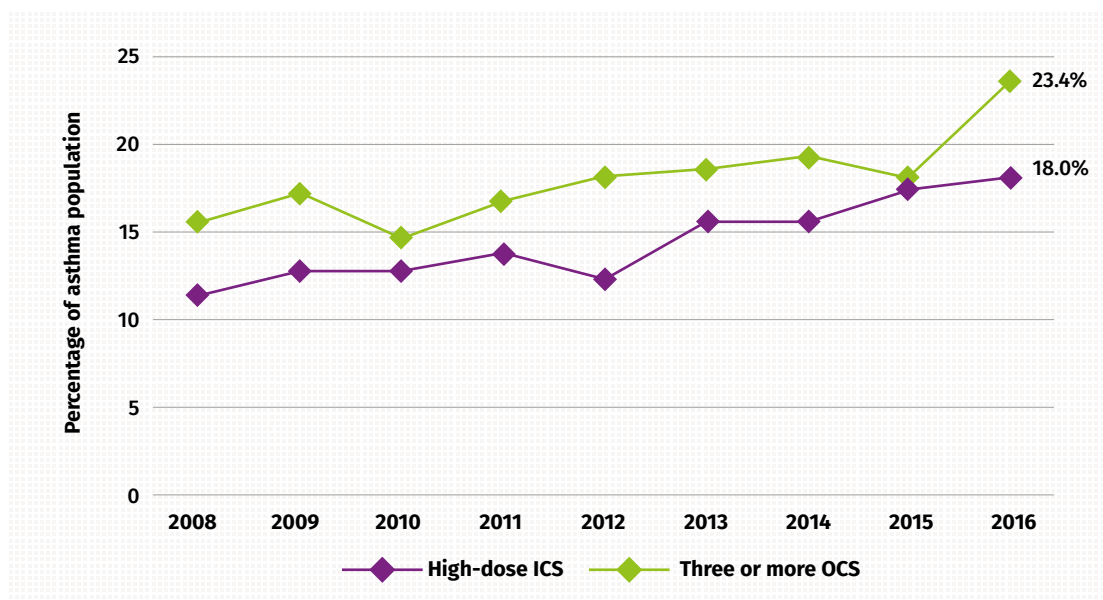
Key findings

- A total of 82% of people with difficult and severe asthma are not getting the care they need.
- Three quarters of those on three or more courses of OCS have not had an appointment with an asthma specialist. This means that they have had multiple asthma attacks but have still not been referred according to the guidelines.
- Rates of appointments in secondary care have climbed slowly, but a significant improvement in referral rates is needed to address the unmet need in people with difficult or severe asthma.
- These rates could be increased through better referral criteria, using data to identify people at risk and increasing capacity in secondary care.



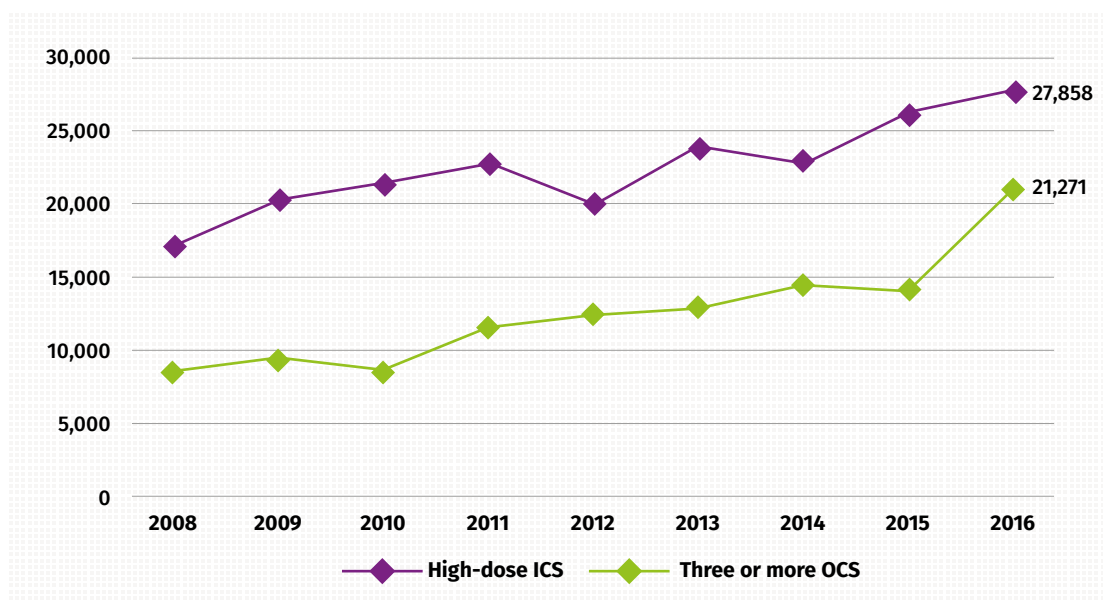
For someone with asthma to have been prescribed three courses of OCS, they will have had an asthma attack on average every four months. They may have expected their care or treatment to change to take account of this significant event, but this was not the case for the majority. Just 18% of people on newly prescribed high-dose ICS were referred^{vi} for the care they needed in 2016, with only 23.4% on three or more OCS being referred. This data presents a clear unmet need.

Figure 7: Annual incidence of referral to a specialist clinic in England



Applying the data from Figure 7 to the (QOF) numbers requiring referral, we find that 27,858 adults with asthma on newly prescribed high-dose ICS were referred in England in 2016, with 21,271 on three or more OCS. This still leaves over 120,000 people who have not been referred and the potential consequences of this include life-threatening asthma attacks, hospital admissions and death, all of which are potentially avoidable.

Figure 8: Number of adults with difficult asthma referred each year to secondary or tertiary care in England



^{vi}The data used in this section is for England only, as data for the rest of the UK was not linked. The overall proportion of people with asthma being referred to specialist care for all people with asthma on the database is 3.5%. Further data notes are available in Appendix B.

This data presents the scale of the unmet need among the group who suffer from the most debilitating form of asthma. A substantial increase in referrals to specialist treatment is needed to address this shocking situation. Referral would mean they would be able to access the care they need to help manage their asthma, including potentially life-changing biologic treatments. Better management of this key group of people with asthma would improve their lives and opportunities, as well as helping to stop asthma attacks, reduce hospital admissions and prevent asthma deaths.

Despite the presence of clinical guidelines and and after the publication of the NRAD five years ago, people with debilitating asthma are still not being referred for the care they need. We have also seen the number of people dying from asthma increase in this same period¹⁹, so there is clear room for improvement.

Asthma UK has previously called for clear and unambiguous referral criteria, and we see the news that NICE and BTS are going to work together to produce a Joint Guideline on Chronic Asthma as an opportunity to provide clarity in this area. We also recognise that lack of capacity in secondary care may contribute to this situation.

Recognising these constraints, three or more courses of OCS may be a more appropriate measure to ensure those at risk of an asthma attack, and who might benefit from new treatment, get the care they need. For the increase in referral that would be required, a boost to the workforce would be needed. This has also been called for by the Taskforce for Lung Health, which recommends a boost of 100 extra respiratory specialty training posts²⁰. Extra capacity will be needed in secondary and tertiary care to handle the higher numbers who need to be referred. There will also be associated costs with these further investigations and new treatments.

Better joining up of patient records would also help ensure people with difficult or severe asthma get the care they need. The use of data to identify those at risk would help increase referrals for those who need it most. People with asthma are keen for their data to be shared to better improve their care²¹, but we have not seen this potential realised.

We recommend that:



GPs and practice nurses ensure that they refer any patient who is on three or more courses of OCS (at a minimum). NICE should put in place new statutory guidelines reflecting this and ensure that healthcare professionals follow them.



A record of this prescribing activity, coupled with a record of emergency admissions and asthma attacks is maintained to better identify at-risk patients. This should be available on patient records and Primary Care Networks should set up data systems to flag up those automatically triggering a referral.



Increased focus on commissioning and delivering secondary and tertiary care asthma services to meet this unmet need. We recommend that national and regional commissioners produce updated national and local estimates of need and plan accordingly.



Consistent, referral-driven guidelines are needed to reduce unmet need and unacceptable variation.

Biologic treatment – a new source of unmet need

Key findings



- Only one fifth (20%) of people with severe asthma who are eligible for a mAb are receiving these potentially life-changing treatments.
- Data on eligibility and use of mAbs is limited and needs to be improved so that services can be planned and delivered effectively.
- NICE and the Scottish Medicines Consortium (SMC) must ensure consistent methodology is used for estimating the potential impact of new mAbs on both NHS resources and the unmet need of people with severe asthma.

Monoclonal antibodies (mAbs) are a type of biologic drug that has been developed for people with severe asthma. They target specific biological processes to reduce inflammation in the lungs, and currently either target ‘allergic’ asthma or ‘eosinophilic’ asthma. There are four mAbs approved by NICE for England, Wales and Northern Ireland (endorsed by Department of Health Northern Ireland) and three approved by the Scottish Medicine Consortium (SMC) for Scotland. NICE and the SMC have set strict eligibility criteria for patients receiving these drugs. This is partly to ensure that the patients with the right sub-type (phenotype) of asthma get the treatment they need, but also so that the mAbs are used in the most cost-effective way^{vi}.

We have shown that not enough people with suspected difficult or severe asthma are being referred. Without referral and formal diagnosis of severe asthma, they cannot access these potentially life-changing mAbs. We also estimate that more people are eligible for these drugs than are currently receiving them, but the numbers of people who might be eligible have not been consistently estimated across the different mAbs and neither have the numbers of people currently receiving a mAb.

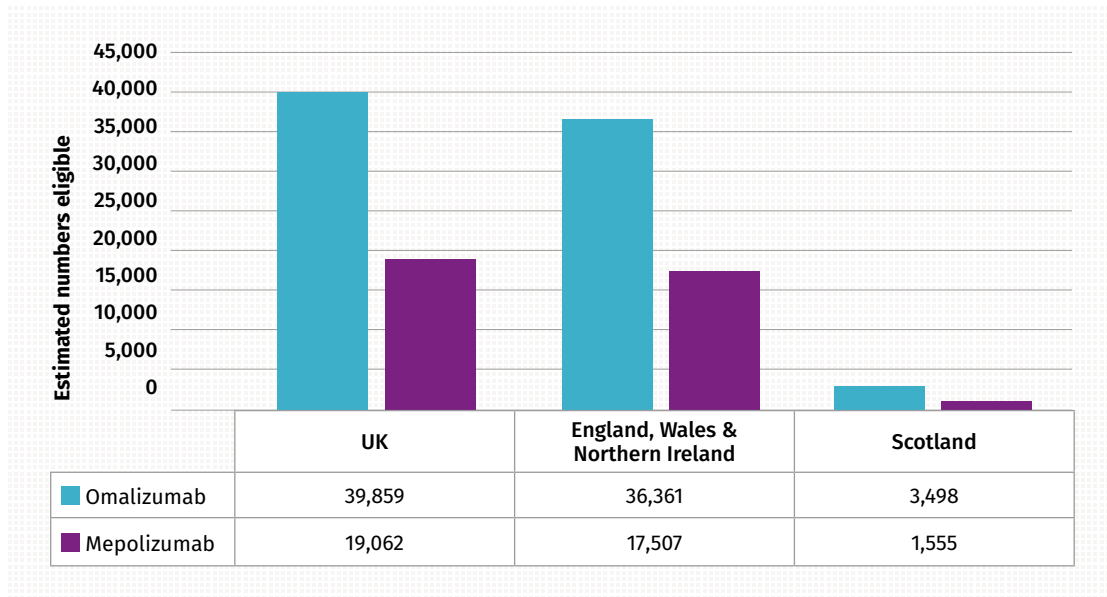
The data available to estimate the numbers eligible for each mAb is limited. We found only one study that estimated the percentage eligible for omalizumab and mepolizumab using NICE/SMC criteria, and there are yet to have been any that have estimated eligibility for reslizumab and benralizumab^{22 23 24 25}. We know there is also likely to be an overlap in eligibility, with some people qualifying for more than one mAb, but data is lacking in this area too. Using the data that is available, we have estimated the numbers eligible for omalizumab and mepolizumab (Figure 9), but not reslizumab or benralizumab. We have also estimated the numbers currently receiving omalizumab, mepolizumab and reslizumab using hospital prescribing data^{vii} (Figure 10), but not benralizumab, as it was only approved in early 2019 and numbers will be very small.

In order to complete this analysis, Asthma UK had to purchase commercial data, despite requesting the prescribing data from the NHS. To enable more transparent assessment of access to new treatments and accountability for public spending, we call for this data to be publicly available.

^{vi} Table 10 in Appendix A details these criteria.

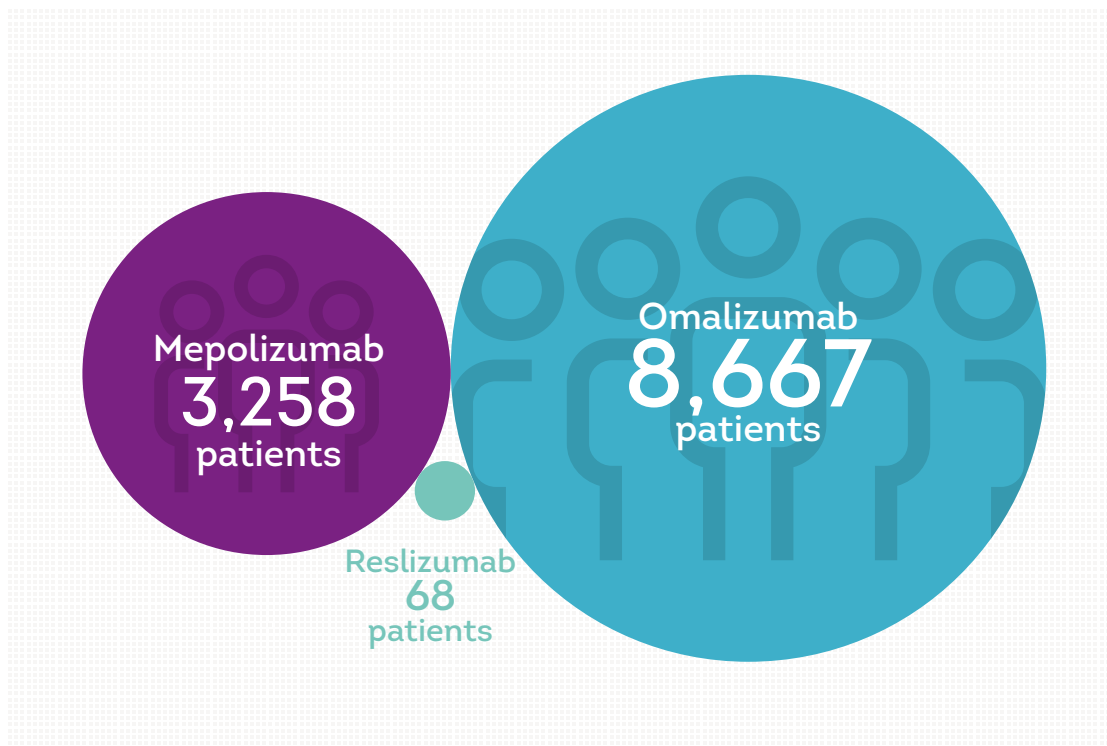
^{vii} We used the number of packs prescribed by hospitals in April 2019 to provide a snapshot of the numbers receiving each mAb. For mepolizumab the number of packs can equate to the number of people receiving treatment. Due to variable dosing schedules for reslizumab and omalizumab, we applied the same assumptions used by the World Health Organisation (WHO) Collaborating Centre for Drug Statistics Methodology (WHO CC) for the ATC/DDD Index 2019. This allowed us to estimate the number of people receiving each mAb by estimating the number of packs prescribed to each person in April 2019.

Figure 9: Estimated numbers eligible for omalizumab and mepolizumab in the UK



We assumed that the numbers eligible for omalizumab and mepolizumab combined are equal to the total number eligible for any mAb, this equates to 60,000 people^{viii}. The service specification of severe asthma in England only estimates that 7,700 people require specialist care. This evidence shows once again that there is a significant underestimation of unmet need.

Figure 10: The number of people receiving a mAb in the UK ²⁶



^{viii} There are limitations associated with using this assumption, but without better data on eligibility and eligibility overlap, more accurate estimations cannot be made.

We estimate that approximately 12,000 people are currently receiving omalizumab, mepolizumab or reslizumab. This means that only 20% of those eligible for treatment are currently receiving a potentially life-changing mAb.

It is recognised that NICE conducts an annual review of the resource impact reports, however there are currently big discrepancies between the NICE reports²⁷. When new mAbs become available, the approval process will prompt a resource impact report that estimates the numbers eligible for treatment and the potential cost to the NHS. We have found the assumptions used for the resource impact reports vary depending on the mAb being approved^{28 29 30}. This has meant that we are unable to compare eligibility numbers across the different mAbs. This variation is a further source of unacceptable unmet need, and more must be done to ensure those with severe asthma get the treatment they need.

We recommend that:



Clear referral guidelines and a consistently applied care pathway for difficult/severe asthma must be developed and implemented.



We need better data on the numbers eligible for each mAb, as well as publicly available hospital prescribing data to monitor the numbers receiving treatment.



We need NICE and the SMC to ensure consistent methodology is used for estimating the potential impact of a new mAb on both NHS resources and the unmet need.



We urge NICE to review the existing reports together to ensure they align. Without this alignment, the true scale of unmet need and impact on the NHS will continue to be misleading and unreliable.

“An estimated 12,000 people are currently receiving omalizumab, mepolizumab or reslizumab. This means that only 20% of those eligible for treatment are receiving a potentially life-changing mAb.”

Conclusions

In the two crucial stages of the care pathway for adults with difficult and severe asthma we have looked at, we have found substantial unmet need. Only 18% of people who, according to clinical guidelines, should be referred to a specialist, receive this care. And for those that do receive specialist care and are eligible for the biologic treatments, only 20% receive this life changing treatment. We have previously shown that 60% of people do not receive basic asthma care in the UK³¹, and this new report shows that care is also failing those who suffer from the most devastating form of asthma.

There has undoubtedly been encouraging progress in treatment for people with severe asthma since we first wrote about the unmet need in severe asthma in 2017³². We have heard countless stories from people whose lives have been changed by accessing new treatments, after being stuck on a cycle of OCS courses. Care for people with difficult and severe asthma has changed significantly in the ten years that the data in this report covers, with a large increase in the numbers being referred, the development and introduction of new biologic treatments and better organisation of specialist care. However, there was still a rising number of asthma deaths in this period³³, so it is clear there is a long way to go.

Part of the complexity of diagnosing difficult and severe asthma is that it is variable in the way it presents and its severity. The variability of the condition makes providing appropriate care to everyone who suffers from it an immense challenge. Asthma is not always taken seriously, and the unmet need apparent in this report should be a wake-up call to those with responsibility for commissioning and running asthma services in primary, secondary and tertiary care. We welcome the recent launch of the *NHS England Improving Value* review into severe asthma services³⁴. People with difficult and severe asthma have been neglected by policy makers and having a dedicated programme of work to investigate the care they receive, and to provide a roadmap to a better future, is welcomed. Coupled with the *Getting It Right First Time (GIRFT)*³⁵ respiratory workstream, the insight that will be gathered from the National COPD and Asthma Audit Programme (NACAP)³⁶ and the existing Severe Asthma Registry, there is the potential for improved data collection and analysis to help drive service improvements.

The NHS now needs to focus on designing and commissioning services with sufficient capacity to ensure that everyone who needs specialist care can receive it, and everyone who may be eligible for new biologic drugs has the opportunity to be assessed for them. We welcome the recent announcement that NICE and BTS will work together to develop guidelines for the asthma pathway. The challenge is for new referral criteria to deliver improvements in care, and address the unmet need highlighted in this report.

We have shown that the NHS is letting down people with suspected difficult and severe asthma, who are not getting the specialist care and access to new treatments to which they are entitled. There is huge source of hope for these forgotten patients, but it is up to everyone in the system to make sure that this is fulfilled³⁷.

People with difficult and severe asthma suffer from the most devastating impacts of the condition, and change is needed to ensure they get the care they need.

Acknowledgements

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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.

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