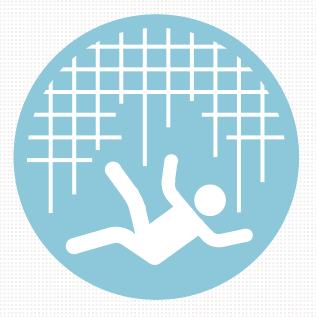


Slipping through the net:

The reality facing patients with difficult and severe asthma





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The views presented in this report are those of Asthma UK and do not necessarily represent the views of the individuals named above.

This report was written by Olivia Allen of Asthma UK.



Foreword & recommendations



'Severe' asthma is a type of asthma that does not respond to current readily available treatment. It can be difficult to differentiate between this and 'difficult' asthma¹ which is often the result of poor adherence,

other comorbidities 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 death. While asthma outcomes have improved over the last few years, many people with severe or difficult asthma are not getting the support and treatment they need. For example, severe asthma affects approximately 3.6% (~200,000) of the 5.4 million people in the UK with asthma, but their diagnosis, treatment and care are often not managed effectively. People with severe asthma have told us that it can take many years for them to be properly diagnosed and get the right treatment. Clinicians have also flagged the delay in patients being referred to specialists, a problem compounded by lack of awareness in primary care about the treatments on offer, and by inadequate data sharing. The introduction of specialised severe asthma services promised to offer more targeted care to people with difficult/severe asthma and thanks to decades of research there are now several new biologic drugs that are licensed and available for people with some types of severe asthma. For the first time, these new drugs offer

an alternative to oral steroids (which can cause toxic and debilitating side effects) for around 40% of the severe asthma population. But the route to these life-altering treatments isn't always quick or straightforward, leaving many people not accessing them when they need to. The problem doesn't just lie in one area but spans the entire care pathway. There is a lack of clarity about referral criteria, and as people move through different care settings the difficulties of data sharing and alignment further hinder their progress.

For people with difficult asthma, diagnostic tests are improving and are now available in specialist centres, and a whole raft of new technologies including smart, Bluetooth-connected inhalers are emerging that may help with managing adherence more effectively. This is important considering the high costs of the new biologic drugs.

Now that there are safe and effective treatment and management options for people with difficult and severe asthma, it is vital that they get the specialist care they need in order to access them. Significantly improving the care these patients receive, as well as the time it takes for them to receive it, has the potential to transform the lives of people with difficult/severe asthma, stop asthma attacks, and save lives.

Samantha Walker PhD

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

"Now that there are safe and effective treatment and management options for people with difficult and severe asthma, it is vital that they get the specialist care they need in order to access them."

Samantha Walker



Key recommendations:



Accurately determine the size of the UK difficult and severe asthma populations to allow effective service planning in primary, secondary and tertiary care.



Agree clear, unambiguous definitions of the different types of difficult and severe asthma to allow clinicians and people with asthma to understand what type(s) of asthma they have, and what the best management approach is likely to be.



Develop and agree clear and unambiguous referral criteria between primary, secondary and tertiary care.



Improve standards across tertiary centres through the commissioning toolkit, peer review, and sufficient resources.



Develop, publish and promote new evidence-based strategies for the management of difficult and severe asthma.



Link and share patient care records across care settings and ensure that data is collected and used to improve service commissioning and delivery.



Through the development of the UK Severe Asthma Registry, gain a deeper understanding of the characteristics of the UK difficult/severe asthma population, to avoid unjustified variation, to aid service planning, delivery and the development of new treatments for the types of difficult/ severe asthma that still do not have effective pharmacological interventions.

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Explore digital opportunities to support people with difficult/severe asthma and lessen pressure on services.



Introduction

Asthma is one of the most prevalent long-term conditions in the UK, with around 5.4 million people currently receiving treatment. An estimated ~1 million people have 'difficult' asthma¹ including ~200,000 people with severe asthma^{1,2}. For those people who have severe asthma symptoms despite taking maximum drug therapy, there are a range of new biologic treatments. However, these are expensive, and only work in certain sub-types of severe asthma, and so patients need to be carefully selected.

Uncontrolled severe asthma can have a devastating impact on people whose lives are disrupted by regular A&E visits, hospital admissions and the debilitating side effects of the mainstay of severe asthma treatment, oral corticosteroids. People with uncontrolled severe asthma cost four times as much to treat as the average patient³. 'Severe' asthma symptoms caused by poor or non-adherence to treatment are common, and it requires time, effort and multi-disciplinary support to change behaviour.

One of the main problems is that we don't have a good understanding of how many people have difficult or severe asthma, or how many are receiving specialist care. From the limited data available and from feedback from people with uncontrolled asthma, Asthma UK suspects that many are not getting access to the right services or treatments. We estimate that there are as many as ~200,000¹ people with difficult or severe asthma who would benefit from better assessment, diagnosis, management and/or treatment. But only 894 people (as of 01/05/18) are recorded as having severe asthma (data taken from the UK severe asthma registry⁴). This does not reflect the NICE estimate of 140 per 1 million people eligible for new severe asthma treatments⁵. Others estimate the UK severe asthma population to be <1% (~54,000) of the general asthma population³. As a starting point, we urgently need clear definitions of difficult and severe asthma and a more accurate estimation of the numbers of people with both types of asthma so that services can be planned and delivered effectively.

About this report

To explore how the difficult/severe asthma care pathway works in practice, we interviewed 17 difficult/ severe asthma clinicians and nurses from across the UK to understand their experiences of severe asthma services. We also surveyed 72 primary and secondary healthcare professionals to further understand how asthma care is delivered.

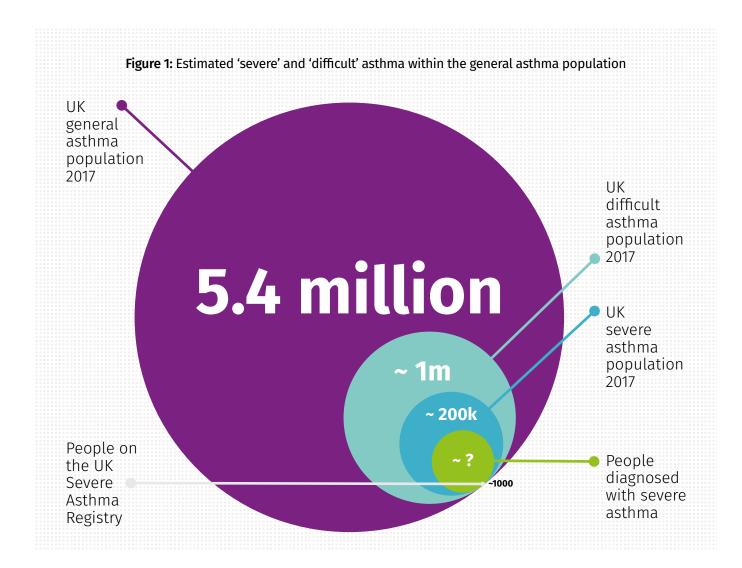
This report builds on our previous work regarding treatments for severe asthma and the need to better identify the different types of difficult and severe asthma⁶. We hope this report will stimulate discussions about asthma services and prompt action to ensure that everyone with difficult or severe asthma gets access to the right management and/or the right treatment.





The size of the UK difficult/ severe asthma population

There are varying estimates of the size of the difficult/ severe asthma populations. Currently, estimates of the severe asthma population range from just under 1%⁵ to as much as 3.6% of the general asthma population. Difficult asthma is estimated to affect around 17%¹.



Without accurately defining and quantifying these populations, it is impossible to plan services effectively and work out who is eligible for the new biologic treatments.

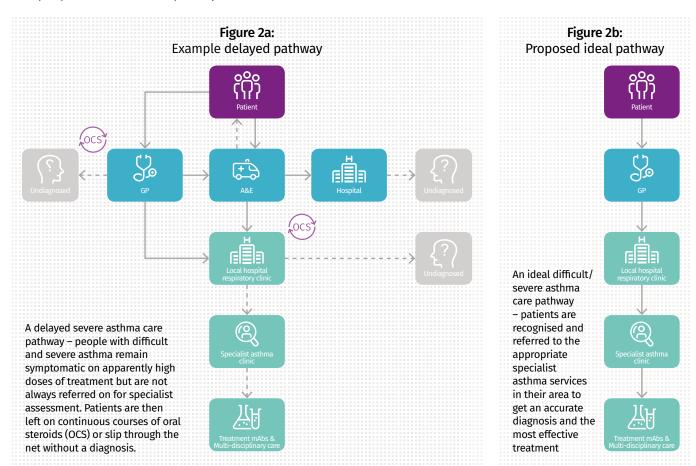
Recommendation 1

Specialised commissioners and tertiary centres should work with asthma researchers to determine accurately the size of the UK difficult and severe asthma populations to allow effective service planning in primary, secondary and tertiary care.



The difficult/severe asthma care pathway

The clinicians we interviewed are sure that people with difficult/severe asthma would be in better health if there were fewer delays to referral. Delays mean that people's lives are disrupted by uncontrolled asthma symptoms and the side effects of potentially inappropriate and ineffective treatment, as well as increased healthcare costs.



The clinicians we spoke to told of wide variation in difficult/severe asthma care across the country. Variation included the distance patients must travel to see a specialist, the type of specialists available, and whether the clinicians have access to patients' care records.

The fact that there are no guidelines that are universally and consistently followed for recognising and treating difficult/severe asthma⁷ may well be underpinning some of the variation across services and clinicians. For example, the new monoclonal antibodies (mAbs) have been hailed as a treatment to control asthma symptoms and reduce severe asthma patients' need for oral steroids⁸, yet some clinicians are concerned that many patients are still using oral steroids regularly and experiencing toxic side effects.

Monoclonal antibodies (mAbs)

New biologics that target the inflammation at the root of a type of severe asthma. For more information see our 2017 *Severe asthma* report⁶

"The problem is long-term damage done by steroids by the time patients get to us. Also, once they are stable on steroids, they kind of slip through the net. Their hospital admissions reduce, so they're not flagged up as often." **Severe asthma clinician**



THE DIFFICULTIES OF DIAGNOSIS AND REFERRAL

"People with severe asthma and their families are better off with specialist care. It's made such a difference for me."

Person with severe asthma

"There needs to be more awareness of [the impact of] asthma on the patient at the severe end, and more resources into severe asthma. Support between primary and secondary care needs to be strengthened [...] where we are all working in the same direction with clear guidelines and patient support. Having quick access to secondary care is required so we don't have patients waiting a long time to be booked in." **Severe asthma clinician**

"There is a serious lack of understanding out there about which patient might benefit from additional treatment and how prednisolone has significant consequences. It is not something that should be used frequently." Severe asthma clinician

Diagnosis of difficult/severe asthma is complicated because asthma-like symptoms can be caused by several other conditions and diagnostic tests that can accurately and objectively differentiate between them have yet to be developed. Specialist diagnostic skills and experience are required to confirm severe asthma and identify likely mechanisms and effective treatments.

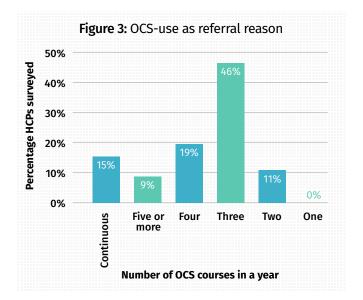
As mentioned previously, the term 'severe' refers to those who have severe symptoms despite taking optimal treatment and effectively managing any co-morbidities. However, it is still often used to refer to people who have severe symptoms because they do not take sufficient preventer (anti-inflammatory) treatment and people who struggle with co-morbidities that compound the severity of their symptoms and make them more difficult to manage.

When it comes to identifying and managing (or referring on) other co-morbidities that might be driving asthma-like symptoms, specialist difficult/severe asthma services have the tools and experience that are not usually available in non-specialist centres or primary care. However, referrals to specialist care vary significantly, with many people with possible severe asthma missing out. There are currently no clear and consistent national referral criteria for difficult or severe asthma. Nonspecialist clinicians may not recognise the need for referral or know that better treatments are now available. The lack of referral criteria and poor management of low adherence may result in referrals to specialists for simple non-adherence which is an expensive solution to a sometimes straightforward problem.

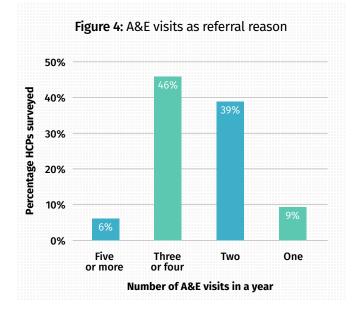
Our survey of primary and secondary healthcare professionals demonstrated that reasons for referral vary, with HCPs using varying thresholds of numbers and/or the severity of events to decide whether they would refer a patient.

The majority of healthcare professionals surveyed indicated that they would refer a patient with suspected severe asthma if they had received three courses of oral steroids over the year (Figure 3). However, many suggested that anywhere from two courses to continuous steroid use may warrant a referral. The clear differences in referral thresholds is worrying – oral steroids can have toxic and debilitating side effects and should be avoided as far as possible. Faster referral to an asthma specialist could play a big role in transforming health outcomes.

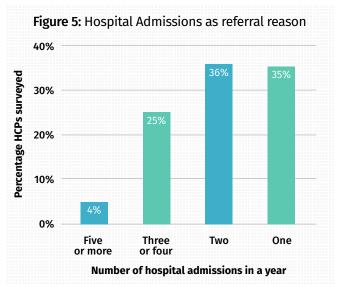




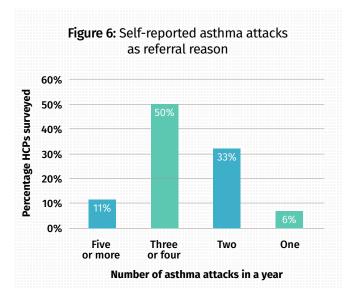
There was also variation in the number of A&E visits (Figure 4) that would trigger a referral, with 39% of respondents indicating that two A&E visits should trigger a referral while 46% suggested three or four A&E visits should do so.



The survey of primary and secondary healthcare professionals found a clear variance in the number asthma-related hospital admissions (Figure 5) that would warrant a referral for further treatment. Although 71% of respondents considered one or two admissions in a year concerning enough to warrant referral, 29% of respondents had a threshold of three or more admissions before referring a patient to a respiratory or asthma specialist.

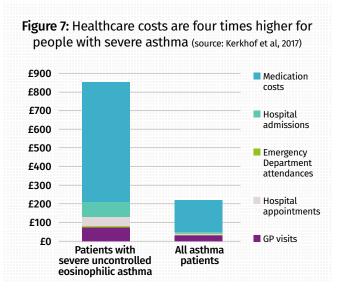


Similarly, there was some variation in the number of asthma attacks (self-reported) over a 12-month period that would warrant a referral. Figure 6 shows that a third of respondents would refer after two attacks, while over half would only refer a patient after three, four or five asthma attacks. This variation means that patients in some areas may have worse outcomes and more exacerbations and hospital admissions than others, resulting in costs for the NHS that could be avoided with better management through specialist referral.



Patients with uncontrolled asthma cost the NHS four times more than other patients (Figure 7)⁵. The combination of delayed referral and treating the side effects of using oral steroids probably increases the cost of managing severe asthma, as patients will be making more regular use of A&E, hospitals and GP time⁹.





Recommendation 2

Clinicians and researchers should agree clear, unambiguous definitions of the different types of difficult and severe asthma, to allow clinicians to explain, and people with asthma to understand, what the best management approach is likely to be. The 2014 National Review of Asthma Deaths (NRAD) report¹⁰ recommended that patients with asthma be referred to a specialist asthma service if they require more than two courses of systemic corticosteroids (oral or injected) within 12 months, or require management using BTS stepwise treatment 4 or 5 to achieve control. However, our research demonstrates that these recommendations are not being followed, with 89% of primary and secondary care clinicians indicating that they would only refer after three or more courses of corticosteroids. A clear threshold for referral must be agreed and implemented across primary, secondary and tertiary care so that all people with severe asthma have equitable access to the specialist diagnosis and treatment they need.

Recommendation 3

Commissioners and clinicians should develop, adopt and monitor clear and unambiguous referral criteria between primary, secondary and specialised care, ensuring patients get equitable access to specialised diagnosis and treatment.

SPECIALISED SERVICES, STANDARDS AND RESOURCES

Even when people with difficult/severe asthma are referred to specialised care, there is variation in the quality of care and access to new treatments between different specialist asthma clinics.

The service specification⁵ in England is in place to drive consistent high standards of care. Some of the requirements of the current service specification include:

- Difficult/severe asthma patients are systematically evaluated by a dedicated multidisciplinary team (MDT) service utilising a team experienced in the assessment and management of difficult/severe asthma
- Patient outcomes recorded on the UK Severe Asthma Registry
- A minimum of two service-dedicated respiratory physicians

- Access to an MDT and ability to refer to occupational lung diseases consultants and clinical psychologists
- Weekly MDTs involving consultant respiratory physicians, clinical nurse specialists, radiologists, physiotherapists, voice therapists, dieticians, respiratory pharmacists and allergists.

The aim of the specification is to ensure consistent standards across England that are based on national clinical expertise. However, many clinicians told us that some services cannot meet these basic criteria. For example, one severe asthma clinician told us: "We have a long waiting list for psychology as it's an intensive therapy, and we don't have enough clinical psychology time."

This means that people with difficult/severe asthma experience variation in quality of care even within



specialised services. Specialised commissioners within NHS England need to work with tertiary centres to ensure that evidence-based quality standards in the specification are met consistently so there is equity in provision across England. The NHS improvementsupported *Getting It Right First Time* (GIRFT) initiative provides an opportunity for peer-to-peer review of clinical standards to improve consistency and value for money across services in England.

Clinicians also told us that it can be difficult for difficult/ severe asthma centres to fulfil all the requirements within current funding levels. If people with difficult/ severe asthma are going to receive a high standard of specialist care there needs to be sufficient investment in services to ensure they are sustainable. It is also important that service specifications are flexible and focused on improving quality and value, so that

ACCESS TO COST-EFFECTIVE TREATMENTS

Although there is a severe asthma service specification in England, there are currently no specific treatment guidelines for difficult/severe asthma for patients who are ineligible for the new biologic treatments.

The mainstay of treatment until recently was oral steroids which can cause toxic long-term side effects such as osteoporosis and diabetes as well as short term mood swings, sleep disturbance and increased appetite. Without specialist referral, people often end up being prescribed multiple courses of oral steroids without realising that other treatment options may be available. In the last ten years, several new, injectable biologic treatments have been approved by NICE and should be available to people with a specific type of asthma called eosinophilic asthma, via referral to a severe asthma clinic. These drugs offer an effective alternative or addition to oral and/or inhaled steroids and can be transformational for some individuals.

However, non-steroid-based treatments for severe asthma are still relatively new and many healthcare professionals may not know if their patients could benefit from the new treatment options. This could partly explain low referral rates and as a result why there may be many people eligible for monoclonal antibodies (mAbs, also called biologics) who are not receiving them. resources for severe asthma can be targeted on un-met need and cost-effective improvements.

The service specification needs to drive and maintain standards of care, but adequate resources need to be provided to ensure that each of the centres can fully meet the specification.

Recommendation 4

Reduce variation and improve standards across tertiary centres through the commissioning toolkit peer review, and ensuring sufficient resources (or equivalent in Wales, Scotland and NI).

Similarly, there may be patients currently on a biologic that is not effectively controlling their asthma symptoms and as a result is not the right treatment. Steps are already being taken to ensure that the treatment of patients started on mAbs before the severe asthma services were commissioned are reviewed and that appropriate action is taken. This will ensure that patients have the correct diagnosis and care, and will reduce inappropriate prescribing of highcost drugs. New difficult and severe asthma guidelines supported by a targeted awareness-raising campaign would help primary care doctors and nurses become more aware of the treatments available. This should drive more appropriate referrals and allow the better allocation of resources for difficult and severe asthma. Measuring and managing adherence as far as possible prior to referral is vital.

Recommendation 5

NHS England and equivalent bodies should continue to work with clinicians, researchers and people with severe asthma to develop, publish and promote evidence-based strategies for the management of difficult and severe asthma.



Harnessing data to improve severe asthma care

"The main problem that remains is linking up with primary care better, and having better access to primary care records. If I see a patient, I can go into the computer and see exactly how many inhalers they picked up over the last year and understand if ... they've got severe disease." **Severe asthma clinician**

ACCESS TO PATIENT DATA ACROSS CARE SETTINGS

Joined up clinical data is vital to plan and improve clinical services and enable research. The clinicians we spoke to were clear that not having access to a patient's medical record before they enter specialised care can make accurately assessing the severity of their asthma very difficult.

Records should be shared across care settings, to identify asthma patients, track their care through the system and ensure that their response to treatment can be measured more accurately.

Recommendation 6

Link and share patient care records across care settings to ensure that care is joined up.

IMPROVING OUR UNDERSTANDING OF SEVERE ASTHMA

Beyond individual patient records, the availability of real-time data including useful clinical and biological information about the UK severe asthma population would allow clinicians to see how and whether their patients respond to a new treatment. A live database could help track progress on new treatments and generate alerts for patients not responding well.

Although the way we store and use personal data is heavily regulated, a recent Asthma UK survey¹¹ into data sharing found that 82.7% of respondents were happy to share their data for targeted treatments and 87.9% were happy to share their data for the purposes of service improvement. Collecting data about severe asthma patients would serve exactly these purposes. In many ways, the UK Severe Asthma Registry⁴ is beginning to fill this gap, although currently only includes a small selection of potentially eligible patients (894 in May 2018). People with difficult asthma are not recorded anywhere. The clinicians we spoke to were broadly positive about the need for a registry but felt that further consideration needs to be given on how it might help with better care planning and service development.

Key issues raised concerning the registry were lack of funding or time to update the registry. There is also a feeling that the registry in its current form does not help with service planning, and so centres without a specific research interest may choose not to use it. Five of the 18 clinicians we spoke to cited funding and/or time constrictions as barriers to entering patient data into the registry in addition to their own local databases. We need to explore the development of an electronic patient management system that can be plugged into hospital software to improve patient care, provide feedback for clinicians and feed into a national registry. The use of incentives such as a Commissioning for Quality



and Innovation (CQUIN) goal could be introduced to encourage clinicians to add to the registry. This would provide detailed data which could be used to drive quality improvement locally, as well as allowing real-time clinical audits.

Collecting the health outcomes of difficult/severe asthma patients in one place could also help with research and enable pharmaceutical companies to design better medicines, especially for those who don't respond to existing therapies. It would provide an opportunity to perform live trials with patients on novel treatments, undertake risk stratification, and identify potential biological targets for new treatments. It would also align with the UK Rare Diseases Strategy¹² and the UK Life Sciences Industrial Strategy¹³ by utilising data and registries to improve treatment, care and research.

Recommendation 7

Commissioners, providers, clinicians and researchers should build on the UK Severe Asthma Registry, aiming to achieve a comprehensive, real-time database of all difficult/severe asthma patients.

This would facilitate deeper understanding of the characteristics of the UK difficult/severe asthma population, to avoid unjustified variation, aid service planning and delivery, as well as helping the development of new treatments for the types of difficult/severe asthma that still do not have effective pharmacological interventions.

IMPLEMENTING NEW TECHNOLOGIES

We need to take advantage of alternative, less time-intensive means of supporting the management of difficult asthma by implementing new digital tools and platforms.

Data and digital tools have already begun to be utilised in other disease areas, e.g. diabetes management, to support behaviour change, encourage patients to take their medicines and potentially improve health outcomes¹⁴. Similar tools should also be researched, tested and rolled out in asthma management. For example, 'smart' inhalers that can accurately measure and report adherence could be a useful first step in assessing adherence to medicines in primary care prior to referral and before prescribing expensive mAbs¹⁵.

Recommendation 8

Explore digital opportunities to support people with severe asthma and lessen pressure on services.



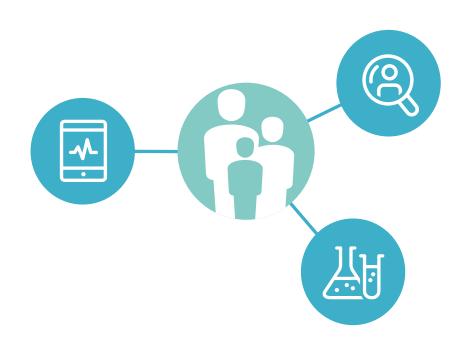
Conclusion and next steps

Many of the issues we identified through these interviews with severe asthma clinicians echo those from the 2014 National Review of Asthma Deaths (NRAD) report¹⁰, and it is worrying that, four years later, many of the problems identified in the report have not been addressed.

We identified several themes, including difficulties in aligning and sharing data across the healthcare system; difficulty differentiating between difficult and severe asthma; lack of clinical consensus on when to refer patients with suspected difficult/severe asthma; and problems fulfilling the NHS England service specification. However, the key barrier to better care is the lack of consensus on the actual number of people in the UK who have difficult and severe asthma.

This report has set out the case for change. All parts of the NHS need to work together to meet these challenges, and to fulfil the opportunity to transform care and improve lives for everyone with difficult or severe asthma. Severe asthma services have come a long way in recent years, for example, in establishing specialised commissioning; availability of new treatments; and creation of the national registry. There is significant appetite for further improvement among both clinicians and NHS decision makers. NHS England, clinicians and researchers are working together with Asthma UK and people with severe asthma to drive improvements. Over the next year we are expecting new commissioning tools and improvement programmes to be launched to address some of the issues outlined in this report.

People with difficult and severe asthma deserve access to the full range of diagnostic tests, new technologies and new treatments so that severe attacks and hospital visits can be prevented and quality of life improved. This will need dedicated effort on the part of policy makers, clinicians, people with difficult/severe asthma, and the NHS, but we hope that by clearly defining the size and scope of the problem we can work together to improve difficult/severe asthma care and transform health outcomes.





Appendix A - Primary care survey questions (referred to in text only)

Severe asthma pathways: primary and secondary care professional survey

- 1. Where do you work in your main role?
- a. Primary care
- b. Secondary care
- c. Community care
- d. Tertiary care
- e. Other

2. Which of the following do you factor in to your decision to refer a patient for their asthma? (filter Q's8-14 to show only those selected)

- a. Oral steroid tablet prescriptions
- b. A&E visits
- c. Hospital admissions
- d. Asthma attacks (self-reported)
- e. Reliever inhaler prescriptions
- f. Preventer inhaler dose
- g. BTS step
- h. Other

3. What would trigger you to refer a patient for their asthma in relation to oral steroid tablet prescriptions? (select as many as appropriate as may want continuous and other)

- a. One course of oral steroid tablets
- b. Two courses of oral steroid tablets in a year
- c. Three courses of oral steroid tablets in a year
- d. Four courses of oral steroid tablets in a year
- e. Five or more courses of oral steroid tablets in a year
- f. Continuous use of oral steroid tablets

4. What would trigger you to refer a patient for their asthma in relation to A&E visits?

- a. One A&E visit in a year
- b. Two A&E visits in a year
- c. Three or four A&E visits in a year
- d. Five or more A&E visits in a year

5. What would trigger you to refer a patient for their asthma in relation to hospital admissions?

- a. One hospital admission in a year
- b. Two hospital admissions in a year
- c. Three or four hospital admissions in a year
- d. Five or more hospital admissions in a year

6. What would trigger you to refer a patient for their asthma in relation to asthma attacks (self-reported)?

- a. One asthma attack
- b. Two asthma attacks in a year
- c. Three or four asthma attacks in a year
- d. Five or more asthma attacks in a year



Appendix B

Survey results (questions referred to in the text only)

Table 1: Roles of respondents

Main healthcare role	Number of respondents	Percentage
Primary	40	56%
Secondary	23	32%
Community	5	7%
Tertiary	4	6%
Total	72	100%

Table 2: Reasons to refer a patient with asthma for specialist treatment

Which factor into your decision to refer a patient?	Number of respondents	Percentage
Hospital admissions	56	89%
Oral steroid tablet prescriptions	56	89%
A&E visits	54	86%
Reliever inhaler prescriptions	38	60%
Asthma attacks (self-reported)	37	59%
Preventer inhaler dose	28	44%
Other	22	35%
Total	63	100%

Table 3: Distinguishing between severe asthma and difficult-to-control-asthma

Do you distinguish between severe asthma and difficult-to-control-asthma?	Number of respondents	Percentage
Yes	44	66%
No	23	34%
Total	67	100%



Table 4: Number of oral steroid courses in a year, that would warrant a referral

Number of OCS courses in a year	Number of HCPs	% of HCPs surveyed
Continuous	8	15%
Five or more	5	9%
Four	10	19%
Three	25	46%
Тwo	6	11%
One	0	0%

Table 5: Number of A&E visits course in a year, that would warrant a referral

Number of A&E visits in a year	Number of HCPs	% of HCPs surveyed
Five or more	3	6%
Three or four	25	46%
Тwo	21	39%
One	5	9%

Table 6: Number of hospital admissions in a year, that would warrant a referral

Number of hospital admissions in a year	Number of HCPs	% of HCPs surveyed
Five or more	2	4%
Three or Four	14	25%
Тwo	20	36%
One	19	35%

Table 7: Number of asthma attacks (self-reported) in a year, that would warrant a referral

Main healthcare role	Number of respondents	Percentage
Primary	40	56%
Secondary	23	32%
Community	5	7%
Tertiary	4	6%
Total	72	100%



References

- 1 Pieter-Paul W. Hekking et al., 'The Prevalence of Severe Refractory Asthma', *The Journal of Allergy and Clinical Immunology* 135, no. 4 (2015), 896-902, <u>https://doi.org/10.1016/j.jaci.2014.08.042</u>
- 2 Pranab Haldar et al., 'Cluster Analysis and Clinical Asthma Phenotypes', American Journal of Respiratory and Critical Care Medicine 178, no. 3 (2008), 218-24, https://doi.org/10.1164/rccm.200711-1754OC
- 3 Marjan Kerkhof et al., 'Healthcare Resource Use and Costs of Severe, Uncontrolled Eosinophilic Asthma in the UK General Population', *Thorax* (2017), thoraxjnl-2017-210531, <u>https://doi.org/10.1136/thoraxjnl-2017-210531</u>
- 4 Heaney LG, Brightling CE, Menzies-Gow A, et al., 'Refractory asthma in the UK: cross-sectional findings from a UK multicentre registry', *Thorax* (2010); 65(9): 787-9. <u>https://thorax.bmj.com/content/65/9/787</u>
- 5 https://www.england.nhs.uk/wp-content/uploads/2017/04/specialised-respiratory-services-adult-severe-asthma.pdf
- 6 Asthma UK, Severe asthma: the unmet need and the global challenge (2017)
- 7 Vivi Q. Nguyen and Charlotte S. Ulrik, 'Measures to Reduce Maintenance Therapy with Oral Corticosteroid in Adults with Severe Asthma', Allergy and Asthma Proceedings 37, no. 6 (November 2016): 125–39.
- 8 Szefler, Stanley J., 'Asthma across the lifespan: Time for a paradigm shift', Journal of Allergy and Clinical Immunology (2018).
- 9 Hoskins, Gaylor, et al., 'Risk factors and costs associated with an asthma attack', Thorax 55.1 (2000): 19-24.
- 10 M. Levy et al., '*Why Asthma Still Kills*: The National Review of Asthma Deaths (NRAD)' (2014), <u>https://www.rcplondon.ac.uk/projects/national-review-asthma-deaths</u>
- 11 Asthma UK, Data sharing and technology: Exploring the attitudes of people with asthma (2018).
- 12 Department of Health and Social Care, The UK Strategy for Rare Diseases (2017)
- 13 Life Sciences Industrial Strategy A report to the government from the life sciences sector (2017)
- 14 Avivit Cahn, Amit Akirov and Itamar Raz, 'Digital Health Technology and Diabetes Management', *Journal of Diabetes* 10, no. 1 (1 January 2018): 10–17, <u>https://doi.org/10.1111/1753-0407.12606</u>
- 15 Asthma UK, Smart asthma: Real-world implementation of connected devices in the UK to reduce asthma attacks (2017).

All hyperlinks in the references above, and elsewhere in the report as a whole, are accessible as of July 2018.



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



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