Optimising the severe asthma pathway –
A case for change

According to NHS England, severe asthma has an estimated prevalence of 140 in every 1 million people in England,\(^1\) while Asthma UK suggests that this disease could affect as many as 200–250,000 people in the UK.\(^2\) In a study involving 610 adults, it was indicated that patients with severe asthma have more symptoms and exacerbations than those with a mild or moderate form of asthma, with a worse quality of life and higher levels of anxiety and depression.\(^3\)

The European Respiratory Society (ERS)/American Thoracic Society (ATS) guidelines were developed by international experts to outline a multi-step approach to severe asthma diagnosis, which focus on the exclusion of “difficult-to-treat” and milder forms of asthma.\(^4\) NHS England affirms that patients with severe asthma need to be considered as a separate group from the majority of people with mild to moderate disease\(^1\) and mandates that patients with severe asthma receive systematic assessment and specialist care.\(^7\) In a prospective study of 346 patients in the UK, diagnostic assessments at specialist severe asthma centres have demonstrated benefits in terms of quality of life, disease control and a reduction in unplanned healthcare use.\(^5\) However, some patients describe waiting years to obtain a conclusive severe asthma diagnosis.\(^6\)

Four years after the National Review of Asthma Deaths identified that severe asthma patients made up 39% of severity-assessed asthma deaths,\(^7\) Asthma UK states that “we can and must do better” to improve the treatment of people with severe asthma.\(^2\)

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**Call to Action**

In 2017, two roundtable meetings organised and funded by AstraZeneca, involving an NHS Foundation Trust Chair and former Member of Parliament, healthcare professionals and a patient group representative, were convened to examine opportunities for reform across the severe asthma pathway. This paper outlines local and national level recommendations that, if delivered, may have the potential to transform the lives of people with severe asthma:

- Establish a set of identifiable referral criteria from primary and secondary care for severe asthma investigations.
- Identify a named asthma lead within every hospital to act as a lead in driving improvements across care settings.

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**What is severe asthma?**

The best practice ERS/ATS guidelines define severe asthma as a disease requiring treatment to prevent it from becoming uncontrolled, or which remains uncontrolled despite this treatment.\(^4\) Severe asthma is distinct from “difficult-to-control” asthma which is experienced by 12% of people with asthma and can also cause frequent life-threatening asthma attacks, according to Asthma UK.\(^8\) While individuals with difficult-to-control asthma may have difficulty breathing most of the time,\(^9\) unlike those with severe asthma they will be able to regain control of their asthma, according to the European Lung Foundation.\(^8\)

It is recognised that patients living with severe asthma experience a long-term, debilitating burden, distinct from milder forms of asthma:\(^10\)

- According to Asthma UK, severe asthma can “destroy daily lives, severely limiting activities and causing long periods of time away from school and work”.\(^2\)
- Severe asthma requires access to specialist services, with NHS England identifying that there is a growing body of evidence to support the presence of several different subtypes (phenotypes) of severe asthma, some with different mechanisms driving their symptoms.\(^1\)
- NHS England has stated that the aims of the severe asthma service will be to improve patient outcomes, including a decrease in exacerbation frequency, emergency visits, hospitalisation, rescue courses of oral steroids and mortality – whilst improving lung function and quality of life.\(^1\)
- One of the treatment options recommended by the British Thoracic Society for people with very severe asthma (not controlled with high-dose inhaled steroids) is the continuous or frequent use of oral steroids.\(^11\)

The latter course of treatment has been associated with side effects in some patients including weight gain, diabetes, osteoporosis, glaucoma, psychiatric disturbances (such as anxiety and depression\(^3\)), cardiovascular disease and immunosuppression amongst other conditions.\(^12\) Asthma UK reports that long term use of oral steroids cause “toxic and debilitating” side effects, and these treatments are “loathed” by some patients.\(^2\)
What is the current pathway for patients suspected of having severe asthma?

The NHS England Service Specification for Severe Asthma requires that those suspected of having severe asthma are referred from primary or secondary care to a Severe Asthma Centre, to confirm diagnosis by a full multidisciplinary assessment. If diagnosed, NHS England and experts recommend that severe asthma patients continue under specialist care for regular review, with access to specialised tests, multidisciplinary support and treatments. This care is commissioned directly by NHS England and overseen by the Clinical Reference Group for Specialised Respiratory Services.

Due to the specialist nature of Severe Asthma Centres and calls from broader experts to both improve patient care, and deliver more accountable, efficient models, the latest NHS England Service Specification for these services allows for a networked approach to delivery. Centres are able to engage with a small number of other sites within their regions to reduce travel, waiting times, and "inappropriate referrals" – whilst ensuring access to treatment close to a patient’s home (where possible). Furthermore, centres are expected to play a wider role in the education of primary and secondary care physicians as well as other members of the multidisciplinary team, liaising closely with patient support organisations to ensure that they are providing the services that the patients want.

Barriers to optimal care across the severe asthma pathway?

In this context, AstraZeneca convened two roundtable meetings to examine areas where care can be improved to the benefit of severe asthma patients within and outside of specialist centres. The meetings, involving a patient group representative, an NHS Foundation Trust Chair and former Member of Parliament, and healthcare professionals involved in severe asthma care, examined the entirety of the patient pathway, in addition to the associated system burden. The following bullet points are based on notes from those discussions:

- Participants discussed the normalisation of suboptimal care experiences, low-awareness of severe asthma as a specialised condition and limited joint working between clinicians at the various entry points as examples of barriers to delivering optimal care.
- They noted that while science and treatment options have advanced, the overriding perception of severe asthma has not changed at the same pace across the health system.
- Despite recommendations for patients to be referred to a Severe Asthma Centre if they meet the criteria set out by NHS England, the participants noted that they are not always referred as quickly as they should be.
- In secondary care, they suggested this was caused by a lack of defined criteria on whether and when an individual should be referred and low-awareness around the role of Severe Asthma Centres – where patients can benefit from a full range of asthma tests, and be assessed for specialist treatments tailored to their specific type of asthma. This means that sometimes respiratory teams may delay referral for specialist opinion, diagnosis and treatment.
- Commissioning approaches and the delivery of services were noted to vary across the country, while it was suggested this was right to meet the needs of a population within a local geography, it was noted that there was a risk severe asthma services could be delivered without full clarity or deprioritised.

1 in 5 severe asthma patients reported that their disease prevents them from working or studying.

71% of severe asthma patients surveyed* said that their disease affected them on a weekly basis – with 1 in 4 claiming their symptoms affected them daily.

*Source: A European survey of 869 people with severe asthma, conducted on behalf of a medical devices manufacturer.
What impact may suboptimal care have on patients and the NHS?

NHS England states that the objective of Severe Asthma Centres is to improve patient outcomes,\(^1\) and it has been demonstrated that access to dedicated severe asthma services delivers benefits in quality of life, asthma control and reduction in healthcare burden.\(^2\) However, these services rely on referrals from primary, secondary and urgent care.\(^1\)

Clinical guidelines state that management of severe asthma symptoms in primary and secondary care should focus on the use of continuous or frequent use of oral steroids if they are not controlled with high-dose inhaled corticosteroids.\(^1\) As previously stated, the prolonged use of oral steroids can lead to serious side effects.\(^2\) One study found that patients with severe asthma on maintenance oral steroids are 43% more expensive to the NHS than those not on oral steroids, due to the additional costs of managing side effects.\(^1\) Patients’ concern over the side-effects associated with their prescribed oral corticosteroids, can lead to compromised adherence.\(^2\) It has been demonstrated that the cost associated with treating severe asthma patients is higher than those with poorly controlled difficult asthma, referred to the same clinics.\(^1\) NHS England highlights that an individual package of care for severe asthma is calculated to be 50 times more expensive than care for the mildest form of controlled asthma.\(^1\) NHS England anticipates that access to a Severe Asthma Centre would improve the consistency in quality of care, and lead to reductions in hospitalisations and death.\(^1\)

Opportunities for improving the severe asthma care pathway

There is support in the UK to improve access to, and the quality of, severe asthma care – this is spread across academia, clinicians and leaders such as Asthma UK, the British Thoracic Society and Respiratory Futures.

Based on the discussions from the two roundtable meetings, the following recommendations have been proposed for implementation to improve the experience and outcomes of people with severe asthma in 2018 and beyond.

**National ask:**

Establish a set of identifiable referral criteria for severe asthma investigations

**Action to be explored**

**Step one** – Assemble a collaboration across interested parties to recommend areas for standardisation in severe asthma referral

**Step two** – Establish a set of identifiable criteria for referral for consideration

**Step three** – Endorse and conserve referral criteria within national guidance and the Service Specification, and encourage improved sharing of good working practice.

**Impact**

- These criteria would be simple to implement and audit against, and would be the foundation for all subsequent training, technological developments and patient information
- Improve the efficiency and ultimately the quality of patient care in those who are currently uncontrolled or prescribed chronic OCS, without specialist support or diagnosis
- Once underway, the collaborative could then be tasked with supporting audits and improvement across the whole patient pathway based on these criteria
Action to be explored

All network leads, or the leads of Severe Asthma centres, should work with local Trusts to ensure the presence of a named asthma lead within every hospital, as outlined by the National Review of Asthma Deaths.7

Impact

• Despite the National Review of Asthma Deaths7 recommending that every NHS hospital should have a dedicated clinical lead for asthma services, 56% do not.18 Each named asthma lead should proactively seek discrepancies in patterns of referral to severe asthma specialist services on a regular basis.

Appendix

In 2017, AstraZeneca conducted two expert group meetings to seek recommendations to optimise severe asthma care in England. AstraZeneca would like to thank the following individuals who attended and provided input into the recommendations listed above, but were not involved in the drafting of this discussion paper itself.

• Dr John D Blakey, Respiratory Medicine, Royal Liverpool Hospital, Liverpool, UK.

• Dr James Calvert, Consultant Respiratory Physician, North Bristol NHS Trust.

• Dr Ian Clifton, Consultant in Respiratory Medicine, Lead for the Leeds Difficult Asthma Service, The Leeds Teaching Hospitals NHS Trust.

• Daisy Ellis, Head of Policy and External Affairs, Asthma UK.

• Dr S Faruqi, Lead for the Severe Asthma Service, Consultant in Respiratory and General Medicine, Honorary Senior Clinical Lecturer, University of Hull and Hull and York Medical School, Department of Respiratory Medicine.

• Natalie Harper, Respiratory Advanced Nurse Practitioner, representing The Association of Respiratory Nurse Specialists (ARNs).

• Dr Binita Kane, North West Severe Asthma Network, Regional Strategic Lead for Specialised Asthma Services.

• Dr Adel Mansur, Consultant Physician, Lead of Birmingham Regional Severe Asthma Service.

• Dr Andrew Menzies-Gow, Clinical Lead for Severe Asthma, Royal Brompton Hospital.

• Professor Ian Sabroe, University of Sheffield and Honorary Consultant, Sheffield Teaching Hospitals NHS Foundation Trust.

• Dr Dermot Ryan, Allergy and Respiratory Research Group, Ulster Institute for Population Health Sciences and Informatics, University of Edinburgh.

• Dr Rahul Shrimanker, Specialist Respiratory Registrar, Oxford University Hospitals NHS Foundation Trust.

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