



## Specialised Services Commission: Asthma UK consultation response

Date submitted: 25/01/2016

### About Asthma UK

Asthma UK is the UK's leading asthma charity. We support people with asthma when they need us the most and fund world-leading research to find better treatments and ultimately a cure. Our goal is to prevent asthma attacks, especially those that result in death and emergency hospitalisation.

### Summary

- Severe asthma affects nearly 5% of people with asthma - around 250,000 people in the UK.
- While we believe that the commissioning model for specialised services adopted by NHS England has had a positive effect on overall service provision for severe asthma, there is still a need to ensure that this is being applied on the ground at a local level
- There is a strong pipeline of new treatments which will emerge over the coming years that will help address current unmet needs of people with severe asthma, with expected high costs. NHS England and the pharmaceutical industry need to ensure a sustainable model is in place to ensure these innovative treatments are available to all people with severe asthma that would benefit from them, regardless of where they live
- It is important to ensure that there is comprehensive, robust national data collection on specialised asthma services to assess condition-specific use in each nation

### Introduction

There is nothing as frightening as not being able to breathe, yet that is the reality for someone in the UK every 10 seconds as they have a potentially life-threatening asthma attack. Three people still die as a result of an asthma attack every day in the UK.

Asthma UK welcomes the call for evidence launched by the Specialised Services Commission to examine the challenges and opportunities currently facing specialised services within the NHS. Asthma is one of the most prevalent long-term conditions in the UK, with 5.4 million people currently receiving treatment. Severe asthma affects nearly 5% of people with asthma - around 250,000 people. The National Review of Asthma Deaths highlighted that almost 40% of those who died had severe asthma.<sup>1</sup>

Severe asthma is a specific type of asthma, rather than simply an extreme form of the condition. It often does not respond to standard treatments and requires more intensive and expensive therapies to control symptoms to prevent attacks, hospitalisations and deaths. People with the most severe asthma represent a particular challenge: they not only have greater morbidity, but they also fall outside the robust evidence base that informs most asthma care, requiring specialist attention, treatment and pathways.<sup>2</sup>

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<sup>1</sup> Royal College of Physicians. Why asthma still kills: The National Review of Asthma Deaths; 2014.

<sup>2</sup> Wenzel S. Characteristics, definition and phenotypes of severe asthma. In: Chung KF, Bel E, Wenzel S, editors. ERS Monograph: Difficult-to-Treat Severe Asthma. 51: European Respiratory Society; 2011.

People with severe asthma require expert, multi-disciplinary assessment to comprehensively characterise their condition, evaluate psychological burden and tailor treatments, some of which may be high cost treatments (such as monoclonal antibodies or bronchial thermoplasty). As treatments become more personalised, these are also likely to be targeted at specific subsets of the severe asthma population. The Salford Lung Study for example is using real-world data to assess the effectiveness of new, pre-licence clinical treatments for asthma and chronic obstructive pulmonary disease.<sup>3</sup>

Ongoing severe symptoms and a complex medicine regime are often accompanied by frequent hospital admissions for many people with severe asthma. Numerous hospital admissions to respiratory wards, intensive care units and high dependency units lead to further social isolation and economic disadvantage for people with severe asthma as well as high costs to the NHS.

### **Service provision and implementation**

Following the reforms to specialised commissioning, severe asthma was commissioned as a specialised service for the first time in 2013. A representative from Asthma UK sits on the Clinical Reference Group for Specialised Respiratory Services.

Direct commissioning of specialised services by NHS England was a welcome development. This has meant that people with severe asthma should have access to the same high standard of treatment and care wherever they live in England. It has presented an opportunity to raise standards through the widespread adoption of standard protocols and procedures and through the sharing of data and expertise.

Severe asthma should continue to be commissioned as a specialised service to ensure effective cost management of highly complex and costly treatments for a small population group and to ensure consistency of services and outcomes for patients. There is national clinical consensus that a centralised service is the most effective and efficient way of delivering severe asthma care and that this can be complemented with a networked model to facilitate the effective delivery of this service in practice.<sup>4</sup>

However, we are aware of some current issues implementing these services, which indicate that there remains a need to ensure that this national direction is being applied on the ground at a local level. Ensuring national standards are implemented will take on increased importance where local and regional leadership on health and social care develops, for example in Greater Manchester.

### **Ensuring innovation in specialised services**

Specialised centres are fundamental to the successful delivery of severe asthma care, using innovative care models to ensure appropriate diagnosis, and use of existing and new high-cost medications. There is a substantial unmet need for people with severe asthma in the treatment options available to them. People with severe asthma have very limited treatment options that involve high doses of drugs with very poor side effect profiles.

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<sup>3</sup> New JP, Bakerly ND, Leather D, Woodcock A. [Obtaining real-world evidence: the Salford Lung Study](https://doi.org/10.1136/thoraxjnl-2014-205259). Thorax doi:10.1136/thoraxjnl-2014-205259

<sup>4</sup> Asthma UK. A Network-Based Approach for Specialised Severe Asthma Services: A proposal to support specialised commissioning for adult severe asthma services

There are a number of treatments currently in development that would offer new options for some people with severe asthma. For example, the National Institute for Health and Care Excellence is currently considering Mepolizumab for the treatment of severe eosinophilic asthma. The nature of specialised services is that many are targeted at populations that have an unmet need in treatment options, and that as new innovative treatment options become available that they are incorporated within these services. As they are new, innovative treatments relevant to small population sub-groups, it is often likely to carry a large cost. However, without specialist assessment the targeting of high cost novel therapies for severe asthma would not be possible, leading to the potential of inappropriate use, unnecessary risk to patients and spiralling costs to the NHS. With the NHS under increasing funding pressures, it is essential that there is a sustainable model in place to ensure innovative treatments are available to those people with unmet needs accessing specialised services.

Whilst the NHS faces pressure to reduce the specialised services budget, it is essential that conditions such as severe asthma remain within the specialised services portfolio, determined, funded and implemented at a national level. In turn, this will ensure the most efficient and consistent service delivery across England and, it is hoped, the most reasonable purchase cost for new treatments - which would otherwise take longer to reach people with severe asthma.

### **Data collection**

At present, data on specialised services is currently collected in different ways by each region, and what local data is collected for severe asthma is not publicly available. The lack of data collection nationally means that it is difficult to accurately assess and compare the numbers of people accessing services for severe asthma, in addition to planning to ensure that these are suitable for people with severe asthma in the future across the UK. There are no severe asthma services at all in Wales, but specialised asthma services in Scotland and Northern Ireland are well-established although they also lack data on patient need to help ensure sustained investment or growth.

The issue of data collection was highlighted within Workstream 2.2 of the National Information Board in 2015.<sup>5</sup> Key gaps highlighted include national standards on specialised services for commissioning and other secondary uses, in addition to a need to better understand this data landscape in order to join this up.

Without accurate national information on the population of people with severe asthma, in addition to the numbers accessing specialised services, it is very difficult for decision makers to plan services effectively to meet the needs of this group in appropriate ways across the clinical pathway, or to identify whether the right people are accessing the services they need.

It is important to ensure that there is comprehensive robust data collection on specialised asthma services to assess condition-specific use in the UK.

### **Contact details**

For further information, please contact our Senior Policy Officer Joseph Clift at [jclift@asthma.org.uk](mailto:jclift@asthma.org.uk) or on 020 7786 4930.

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<sup>5</sup> National Information Board. [Work Stream 2.2 Roadmap: Giving the right people access to the health and care data they need](#); 2015.