

A Network-Based Approach for Specialised Severe Asthma Services

*A proposal to support specialised commissioning
for adult severe asthma services*

Sent to NHS England on 14 July 2014

List of Contributors:

Midlands

Dr Ruth Green, University Hospitals of Leicester NHS Trust

Dr Tim Harrison, Nottingham University Hospitals NHS Trust

Dr Adel Mansur, Heart of England NHS Foundation Trust

Dr Dominick Shaw, Nottingham University Hospitals NHS Trust

London

Dr Runa Ali, Barts Health NHS Trust
Mr Hasanin Khachi, Barts Health NHS Trust

Dr Simon Lloyd Owen, Barts Health NHS Trust

Dr Andy Menzies-Gow, Royal Brompton and Harefield NHS Foundation Trust

Professor Douglas Robinson, University College London Hospitals

North

Dr John Blakey, Aintree University Hospital, NHS Foundation Trust

Dr Ian Clifton, Leeds Teaching Hospitals NHS Trust

Dr Stephen J Fowler, Lancashire Teaching Hospitals and University Hospital of South Manchester NHS Foundation Trusts

Dr Bernard Higgins, Newcastle upon Tyne NHS Foundation Trust

Dr Jaymin Morjaria, Hull and East Yorkshire Hospitals NHS Trust

Dr Rob Niven, University Hospital of South Manchester NHS Foundation Trust

Dr Dorothy Ryan, University Hospital of South Manchester NHS Foundation Trust

Professor Ian Sabroe, University of Sheffield

Dr Dinesh Saralaya, Bradford Teaching Hospitals NHS Foundation Trust

South

Dr Suresh Babu, Portsmouth Hospitals NHS Trust

Professor Anoop J Chauhan, Portsmouth Hospitals NHS Trust

Dr Paddy Dennison, University Hospital Southampton NHS Foundation Trust

Dr Hans Michael Haitchi, University Hospital Southampton NHS Foundation Trust

Dr Ramesh J Kurukulaaratchy, University Hospital Southampton NHS Foundation Trust

Dr Matthew Masoli, Plymouth Hospitals NHS Trust

Professor Ian Pavord, University of Oxford

Wales

Dr Daniel Menzies, NHS Wales

Scotland

Professor Neil Thomson, University of Glasgow and Gartnavel General Hospital

Northern Ireland

Professor Liam Heaney, Queens
University, Belfast

Asthma UK

Sophie Cramb, Policy Officer

Emily Humphreys, Head of Policy
and Public Affairs

Deborah Waddell, Lead Clinical
Advisor

Dr Samantha Walker, Executive
Director, Research and Policy
and Deputy Chief Executive

Val Hudson, person with
severe asthma

Contents

Executive Summary	6
1. Introduction	7
2. Severe asthma overview	10
a) Asthma kills three people a day	10
b) Medical drivers for change.....	10
c) Provision of severe asthma services	11
3. The Severe Asthma Service Specification	13
a) Features of the service specified.....	13
b) Questions to consider when implementing the service specification....	16
4. Implementation of the service specification using a networked approach	18
a) Overview	18
b) How could a networked approach work in practice?.....	19
c) Network governance and accountability	23
d) A network of networks	23
e) What benefits can commissioners expect to realise through a networked approach?	24
5. Summary	26
References.....	28
Appendices	31
Appendix A: Three hypothetical examples of possible patient pathways using networks	31
Appendix B: Examples of existing severe asthma network models	32
Appendix C: Abstract: The impact of a specialist multi-disciplinary approach to difficult asthma on healthcare outcomes in a district hospital. Presented at the European Respiratory Society Congress, 9 September 2013 (P2023).	36

“The primary purpose of the NHS is to improve the outcomes of healthcare for all: to deliver care that is safer, more effective, and that provides a better experience for patients.”

Equity and Excellence: Liberating the NHS

“There are two reasons why I would be willing to travel further for my severe asthma care - to get an accurate initial diagnosis and as a way to monitor how I’m coping with frequent oral steroids. I wouldn’t be willing to travel further for standard maintenance of my severe asthma, or if I needed urgent assistance for an exacerbation.

I personally welcome the highly specialised centres and would be willing to travel to them. However, consideration does need to be made for people who may find their access to such sites restricted due to financial challenges, or a number of other personal issues.”

Val Hudson, a person with severe asthma

Executive Summary

Severe asthma affects less than 5% of people with asthma. It is a potentially devastating condition which does not respond to regular asthma therapies, and increases the likelihood of life-threatening asthma attacks; people with severe asthma therefore require complex treatments and expensive medications in order to manage their symptoms and prevent unplanned attendances. Specialised centres, commissioned by NHS England, are fundamental to the successful delivery of severe asthma care, using innovative care models to achieve improved patient outcomes and deliver cost savings.

Specialised commissioning allows adult severe asthma services to meet the needs of these patients using highly trained, specialist staff dedicated to identifying, treating and managing the condition at specialist centres, enabling accurate referral and diagnosis whilst delivering robust financial control of these expensive services. However, there are some practical challenges to address when initially commissioning these specialist centres.

In order to support those sites which have already been commissioned, and to aid those who are yet to be commissioned, this document proposes that specialist centres should have the opportunity to lead a supporting network to address these implementation challenges. The approach should be incorporated into the service specification document for consideration by providers and commissioners when planning services. Networked models of care could then be designed locally to meet the capacity and travel issues of the local population where they exist, and to capitalise on existing expertise across the region. With the support of NHS England, and the adoption of networked approaches where appropriate, all barriers to a national severe asthma service can be removed by April 2015, to deliver effective patient care and robust management of services.

1. Introduction

Specialised commissioning for severe asthma services ensures that adults with severe asthma receive the same high standard of care across the country, improving patient outcomes, experience, and quality of life in line with the national guidelines. NHS England has placed these services on a sustainable footing using a specialised service model which has the potential to ensure appropriate diagnosis, and use of existing and new high-cost medications such as Omalizumab (Xolair). We therefore strongly endorse specialised commissioning for adult severe asthma services.

Since the release of the NHS Standard Contract for Severe Asthma in 2013, however, some questions have been raised as to how the model outlined in the service specification will cater for all patients in practice. For example, queries have been raised around the likelihood of significant travel increase to commissioned sites, especially for patients with practical or financial challenges. There is also uncertainty around capacity in some areas if all individuals meeting the referral criteria are referred to fewer specialist sites.

It is important that momentum is not lost in implementing specialised commissioning for severe asthma as there is an opportunity to not only improve patient care, but also to deliver more accountable, efficient models of care. This document therefore identifies the factors to consider when establishing the specialised severe asthma centres to address these questions and proposes the concept of a locally designed network approach to support the regional specialist centres.

This report presents the argument that different, relevant, network model approaches can be adopted at a local level, dependent on local needs and local patient requirements, based on cost, capacity and demand analysis. Such analysis will need to be aligned with the confirmation of the regional specialist centre locations. A centrally commissioned service has the potential to standardise care, deliver consistent outcomes, and provide clear accountability to this small population group whilst enabling robust, more effective management of expensive treatments and services. Networks can support the specialist centres to overcome many of the practical challenges involved in delivering a highly centralised service,

ensuring effective and efficient patient pathways from primary and secondary referral to the specialist centres.

We hope that this document will facilitate the successful implementation of the service specification where this is yet to occur, and provide support to commissioners who are considering, or have already commissioned, networked models. The document has been created with input and agreement from a large number of leading severe asthma clinicians and experts from across the country, in addition to Asthma UK.

Please note that this proposal does not refer to paediatric severe asthma as this is covered by the Paediatric Respiratory Medicine E3 service specification.

The Rapid Review into specialised commissioning

The group acknowledges the ongoing Rapid Review into specialised commissioning and welcomes their recommendations on how to put commissioning arrangements on a stronger footing in the longer term. However, we want to ensure that the review does not delay progress for severe asthma service improvement and hope to demonstrate that:

- 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.
- A networked approach removes all barriers to delivering a national severe asthma service, so there should now be no delay in commissioning the final centres and working together to achieve the identified strategic objectives of a more sustainable, effective service.

Although this proposal is being presented to NHS England commissioners for their endorsement in advance of the October Clinical Reference Group meeting, we

would welcome the opportunity to work with any of the seven workstreams of the Task Force before the review ends in October to facilitate effective financial control of severe asthma in the long-term whilst improving patient outcomes.

2. Severe asthma overview

a) Asthma kills three people a day

Asthma is the most common chronic disease in the United Kingdom, affecting 5.4 million adults and children. Individuals with asthma frequently have symptoms of poorly controlled disease(1) and it remains a recurrent reason for urgently seeking medical attention(2); it can also be fatal, and three people die from asthma each day(3).

Asthma-related admissions to hospital also remain common, and the rate of admission has not changed greatly over the past 20 years(4). Asthma is therefore a source of significant physical and psychological morbidity(5) and major healthcare expenditure, with preventative inhaler therapy being the largest drug cost faced by the NHS(6).

Within this large group, there is a small group of patients who pose an even greater risk and expense than other asthma patients; those who suffer from severe asthma. This is a specific type of asthma, rather than simply an extreme form of the condition, which does not respond to standard treatment and requires more intensive and expensive therapies to control symptoms to prevent attacks, hospitalisations and deaths. As widely discussed in the literature(7), patients with the most severe asthma represent a particular problem: they not only suffer greater morbidity, consuming a disproportionate amount of healthcare resources, but they also fall outside the robust evidence base that informs most asthma care, requiring specialist attention, treatment and pathways.

b) Medical drivers for change

There is growing recognition and understanding that asthma differs in severity, symptoms, response to triggers, variability and risk (of severe attacks) between individual groups (known as phenotypes)(8). Moreover, there is growing evidence that tailoring research based on objective markers of disease type can be more effective than basing them on symptoms alone, and there is a pipeline of drugs in development that only work for specific types of asthma. The ability to identify specific phenotypes is beginning to be possible although the science is in its early

days and existing biomarkers require interpretation by highly skilled clinicians to translate these into benefits to patients.

The wealth of research occurring into asthma phenotypes(9), the fact that research can lead to treatments based on measurable characteristics rather than solely on symptoms(10) and the fact that both the newer, high-cost treatments and older, potentially toxic treatments appear suited to specific subgroups (or phenotypes) of patients(11, 12), means that there is an increasing need to undertake specialist tests (such as induced sputum cytology) to identify and treat patients. These investigations should be available at all centres seeing patients with severe asthma.

There are also several conditions which present in a very similar way to severe asthma, which makes diagnosis even more challenging. The phenotyping process therefore also involves investigating and treating conditions related to asthma such as vocal cord dysfunction, dysfunctional breathing, psychological comorbidity, gastro-oesophageal reflux or chronic rhinosinusitis(13), in order to identify how or whether these conditions relate to asthma. Again, these processes require investigations and skilled personnel in a multi-disciplinary team that should be universally available, with specific standards to work towards.

c) Provision of severe asthma services

Before 2013, care for the small percentage of adults with severe asthma was identified as a specialised area for commissioning, however commissioning arrangements did not reflect this in practice; these complex services were commissioned by either 10 separate regional Specialised Commissioning Groups (SCGs) or by Primary Care Trusts (PCTs) at a local level, with some of the service delivered in standard asthma clinics. This resulted in a lack of consistent, effective, commissioning arrangements across different areas; the size and composition of severe asthma teams, and their access to newer treatments, drugs or research studies was determined by local financial factors and the enthusiasm of local healthcare professionals. This lack of cohesion also contributed to a lack of clarity around exact national prevalence figures.

The distributed nature of severe asthma care has therefore presented problems: there has been a significant variation in both record keeping and clinical practice.

There have been steps toward improving this(14, 15), and we welcome the forthcoming quality dashboard for commissioned severe asthma services, and its link to a Commissioning for Quality and Innovation (CQUIN) goal. However, no formal standardisation and benchmarking process has been in place for severe asthma care nationally, leading to inconsistent service provision, variation in patient outcomes and accessibility problems for some patients.

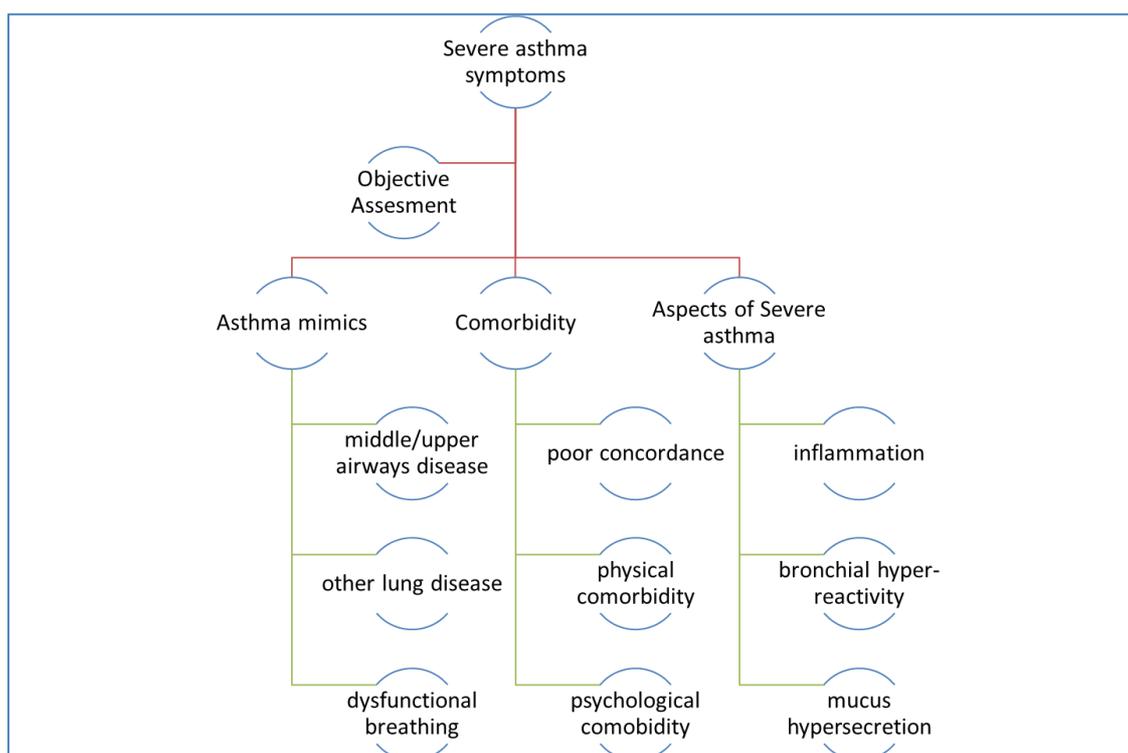


Figure 1: Example of the complex severe asthma pathway which needs to be addressed in specialist severe asthma clinics.

Finally, the heterogeneity of severe asthma and its treatment, and the unpredictability of the underlying conditions limited much-needed research on this patient population. Despite some progress (e.g.(16)), there exists a large unmet need for research in severe asthma, and for “real-world” data on effectiveness of treatments that appear effective in trials such as bronchial thermoplasty (17).

When severe asthma was incorporated into the new approach to specialised commissioning in 2013, it brought an opportunity to raise standards of severe asthma care nationally using a sustainable and cost-effective service model which controls the use of highly expensive therapies to the benefit of both patients and commissioners. The NHS England service specification A14/S/b relating to severe

asthma in adults outlined the minimum service requirements for a centrally commissioned service.

3. The Severe Asthma Service Specification

a) Features of the service specified

The service specification document uses the Innovative Medicines Initiative (IMI) consensus statement(18) for its definition of the adult population with severe asthma. “Problematic severe asthma” includes asthma and asthma-like syndromes that lead to uncontrolled symptoms despite high-intensity asthma therapy. In practical terms these individuals are defined as having ‘difficult asthma’ according to the British Thoracic Society definition, and at least one of the following:

- An event of acute severe asthma which is life threatening, requiring invasive ventilation within the last 10 years.
- Continuous or frequent treatment with oral corticosteroids (defined as 4 or more courses in the previous year).
- Fixed airflow obstruction, with a post bronchodilator forced expiratory volume in 1 second (FEV1) less than 70% of predicted normal.
- Referred as an adolescent transition patient from a paediatric severe asthma service.

The aims of the Severe Asthma Service are given as:

- To confirm the diagnosis and severity of individuals referred with suspected severe difficult to control asthma.
- To identify and remove aeroallergen and occupational triggers.
- To diagnose alternative conditions mimicking severe difficult to control asthma and refer to the appropriate specialist team.
- To diagnose and appropriately treat co-morbidities contributing to severity of asthma (e.g. allergic bronchopulmonary aspergillosis or Churg Strauss syndrome).
- To improve adherence to prescribed therapies using patient education and health psychology when required.
- To diagnose and treat, or refer to the appropriate service, co morbidities associated with severe difficult to control asthma, such as gastroesophageal reflux disease (GORD) and obstructive sleep apnoea.

- To treat and where possible prevent the complications of long term oral corticosteroids.
- To decrease exacerbation frequency and improve patient quality of life through effective self-management and appropriate patient support, including telephone clinics, rapid access review and other appropriate support when required.
- To optimise disease management by using existing therapies in a patient specific fashion by quantifying each patient's asthma phenotype.
- To use measures of airway inflammation to guide therapy where appropriate.
- To use omalizumab and other novel therapies for the correct patient groups and objectively assess response to new treatments/interventions.
- To enhance research and education in this area of unmet clinical need.

In order to meet these aims the specification requires a full range of diagnostic investigations to be undertaken, with a multi-disciplinary assessment including physiotherapist, asthma nurse specialist, clinical psychologist, dietician, pharmacist and allergist over two day case visits. Centres will also act as a gatekeeper for the use of expensive or novel therapies. They will have a wider role in education of primary and secondary care physicians and provide a resource to improve the care of patients that have moderate to severe asthma but do not meet the referral criteria, and train specialist registrars and other multi-disciplinary trainees in severe asthma.

The specification sets out the expectation that 70% of cases will remain under the specialist service (see Figure 2), with patients being reviewed every 6 months if clinically stable. This figure will need to be continuously reviewed as better data becomes available. Finally, there is a requirement for the central collation of data on asthma-related outcomes to drive service improvement.

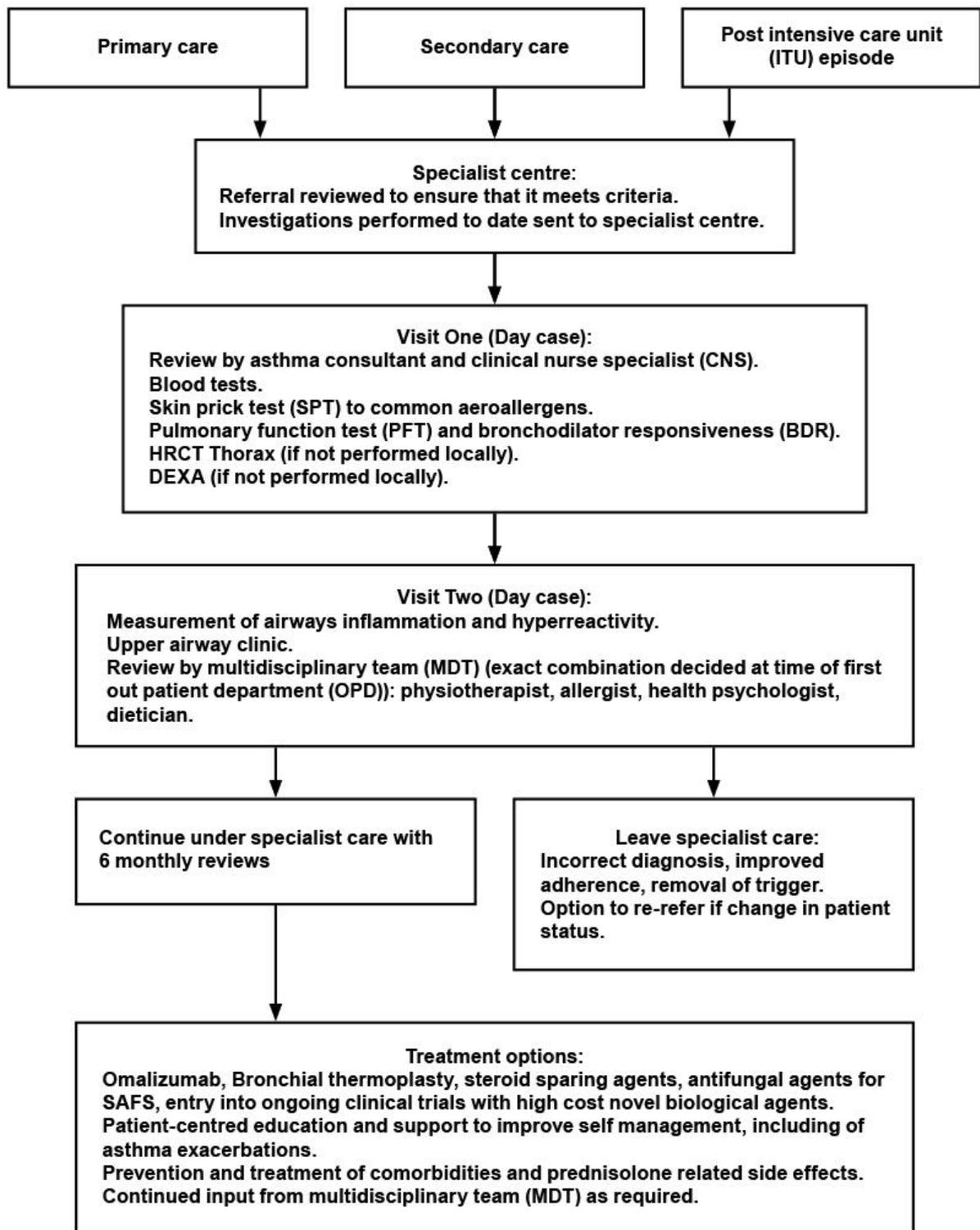


Figure 2: Initial patient assessment as described in the service specification document A14/S/b. Please note that the imminent update to the service specification includes pharmacy as integral to a successful MDT.

b) Questions to consider when implementing the service specification

The service specification outlines how severe asthma centres must be designed to deliver improved outcomes for patients and robust financial management. Clinicians involved in the commissioning of severe asthma centres have outlined the following factors as requiring attention during the planning process, when implementing the new specifications.

1. Can the proposed centres deliver accessible services?

The ability of a site to meet the needs of a whole regional population, taking into consideration geography, travel times and local needs of patients, must be considered when commissioning a severe asthma centre.

Inevitably, the concentration of services in specialist centres will result in some patients being expected to travel greater distances for investigations, consultations, and treatment than they currently experience. The centralisation of services may affect patient groups differently, according to their location and personal circumstances. The benefit of travelling is likely to be substantial if service improvements are made and many patients would likely be happy to do so. However, it could be a barrier to some patients taking up referrals or attending follow up appointments if they are unable to cope with the increase in journey time or travel costs.

2. How will non-specialist sites retain an awareness and understanding of severe asthma?

Centralising services into fewer, highly-specialised sites implies that doctors and nurses in some areas may have significantly less exposure to patients with severe asthma, and may be without the direct, immediate support of senior clinical figures with experience in managing severe asthma. Their skills will need to be maintained in order to accurately and rapidly identify severe asthma patients within primary and secondary care, especially in remote or isolated geographic areas, in order to initiate appropriate referrals to the severe asthma service.

This issue is arguably best addressed at the regional Speciality Training Committee (STC) level or through further discussion with the Royal College of Physicians (RCP)

Specialist Advisory Committee (SAC): it is envisaged moving forward that specialist centres will offer post Certificate of Completion of Training (CCT) training fellowships in severe asthma.

That said, multidisciplinary team (MDT) support could also have a huge impact on maintaining skills and specialised support to ensure appropriate referrals, and should be considered by commissioners of specialist severe asthma centres as a way to retain an awareness and understanding of severe asthma locally.

3. Will the specialist sites have the capacity to meet referral demand?

Questions have also been raised regarding the actual number of individuals who fulfil the referral criteria in a region, and the impact increased numbers may have on existing tertiary centres' capacity if they are taking patients from a larger geographical area.

There are challenges associated with identifying the definitive figures of severe asthma prevalence due to poor recording and inconsistent service delivery in the past. The service specification was only able to provide indications of population size, estimating the numbers as being less than 5% of all adults with asthma, although a recent study completed in Holland showed only 3.7% of all adults with asthma fulfilled the IMI criteria of 'severe refractory asthma'(19). Asthma UK is scoping some projects to better understand the numbers and treatment needs of people with severe asthma across the UK and this work can be used to help inform this planning phase moving forward.

Overall, it is very difficult to identify exact numbers of patients with severe asthma until a comprehensive, consistent and controlled national service is in place; flexibility will therefore need to be built into the commissioning process to cater for fluctuations in demand in different areas. For example, the provision of MDT resources (technology, visual and tele-communications, data entry), and increased capacity in other areas such as diagnostics may also need to be taken into account.

4. How can the new system best capitalise on existing experience and facilities across the region?

The previous decentralised nature of asthma care means that, in some regions, individuals and teams have developed sub-specialty interests and facilities over time. Examples of speciality areas include: allergy, basic research, concordance, diagnostics, dysfunctional breathing, exercise, obesity, Churg Strauss syndrome, psychology, and vocal cord dysfunction.

These activities are based on good local working relationships with healthcare professionals in other disciplines, with local health service managers, and with academia, and it would clearly be of benefit to sustain these relationships and leverage these resources and expertise if possible to support the severe asthma centres.

4. Implementation of the service specification using a networked approach

a) Overview

To address the questions raised by clinicians who have already been engaged in the commissioning process, we propose that severe asthma services can be provided following a regional “hub and network” model where necessary; for example, when there is insufficient capacity at the hub site to match demand, or when individual circumstances prevent the patient from travelling longer distances. This approach endeavours to ensure that specialist centres are implemented effectively to benefit patients, whilst ensuring a sustainable, cost-effective service. It recognises the importance of the patient experience, the local needs of the population, and the expertise and resources outside commissioned centres, in shaping how specialist centres will be supported in each area.

This networked proposal is based on the premise that regional specialist centres will be granted their status because of their excellence, not simply for their geographical location.

b) How could a networked approach work in practice?

The specialist, “hub”, site would be the specialised centre which is commissioned to provide severe asthma services in line with the service specification. As previously note, it would be staffed by clinicians who have responsibility for severe asthma only, provide specialised investigations, and act as gatekeepers for high cost treatments. The wider network could be used to supplement the specialised centre, rather than act as an alternative, and support the central service in delivering the best care for patients.

In general, it is expected that the wider network would be made up of two types of sites: “satellite” and “peripheral”. Satellite sites would be entrusted with a level of responsibility to provide certain services, governed by a contracted agreement. The level of responsibility devolved would vary across networks and individual satellite sites, depending on local needs and the expertise and capacity available at these sites.

Peripheral sites would not have any provider responsibility but would refer patients to the service in accordance with established protocols. The responsibilities of satellite sites, and the structure of the network overall, would be designed based on the location of the hub site, the needs of the local population, the number of referrals into the service, the capacity of the hub site, and the skills and capacity available at potential satellite sites.

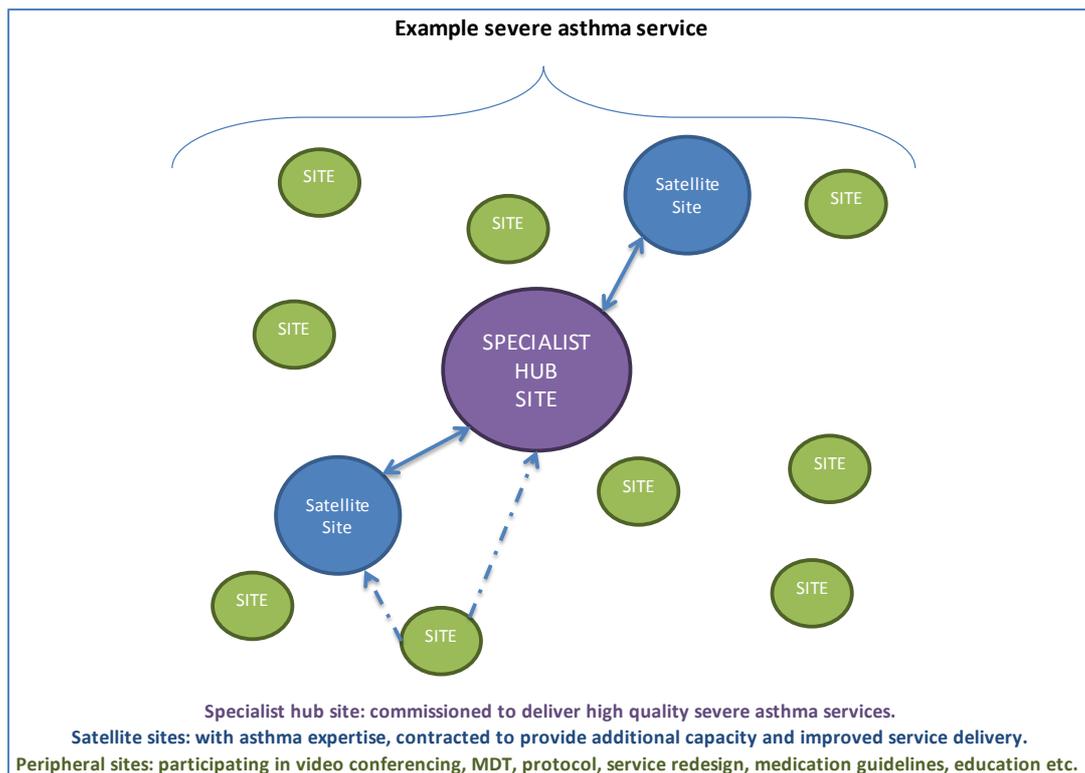


Figure 3: One example of a possible network arrangement.

Regardless of how the network is established regionally to meet the needs of the local population, it is suggested that the specialist hub site could lead a network in a number of potential ways, in addition to its duties as outlined in the service specification.

- a) Specialist hubs could have the opportunity to contract specific aspects of its service to a small number of sites in the region, should this be necessary to meet local needs. These satellite sites therein would provide their service to the same protocol-driven high standard as the commissioned centre, and would be reinforced by contract-defined standards, volumes of work, and reimbursements. The centre would need to agree in advance how to deal with sites that deviate from contracted arrangements.
- b) The commissioned hub site should strongly embrace their role as lead for a regular MDT videoconference with healthcare professionals in their network to discuss potential referrals. This approach will reinforce the standardisation of referrals and usual practice, thus reducing unnecessary referrals and maximising the value of the central expertise, and determine treatment options for high-cost therapies.

- c) The hub site should also take responsibility for the delivery of appropriate regional training on referral pathways across the network to ensure the service is efficient and effective.
- d) The hub site should take responsibility for the delivery, oversight, and advancement of severe asthma research within the region including the delivery and monitoring of bronchial thermoplasty, and the organisation and conduct of clinical trials.

This list is indicative only, and should not be considered exhaustive.

It is suggested that the supporting, non-specialist, network sites could contribute to the commissioned service in a number of potential ways.

- a) As mentioned, a small number of satellite sites could be contracted to undertake certain aspects of the patient pathway on behalf of the specialist hub site. This could include detailed assessment of patients who can then be discussed at MDT meetings hosted by the hub. Alternatively, a satellite site may not be equipped to undertake a full assessment, but may have a first class service in a particular area and could be contracted to deliver this work: examples include long term delivery of previously commenced biologic therapy, or delivery of speech therapy for previously diagnosed vocal cord dysfunction. The contract would require the satellite site to perform to the same high standard as the commissioned centre, and could obviate the need for the patient to travel to the hub site where inconvenient. It would also provide extra capacity should this be needed, or if resources are stretched at the hub site.
- b) Peripheral sites would not provide any severe asthma care, but simply refer into the service through the appropriate pathways as permitted and outlined by the network hub. They will support the rest of the network through appropriate referral and by being engaged with the network in terms of feedback, input, and receiving education.
- c) Both satellite and peripheral sites would contribute to the optimal delivery of severe asthma services across the region by implementing the correct referral pathway. Included in this will be the increasing standardisation and transparency of activity (such as performing CT scans to a pre-set standard to avoid the need to repeat them) and establishing the correct patient pathways. The input of relevant stakeholders will be required into the

organisation of areas including multi-centre research, patient involvement and education, protocols and guidelines, IT systems and performance dashboards, outreach/cross-speciality working, and oversight of the network in terms of accountability and transparency. Arguably this should also occur at specialist centres which do not require a networked model to deliver the service; however, a network can facilitate and intrinsically support success in this area.

This list is indicative only, and should not be considered exhaustive.

Analysis would need to be completed at each specialist centre to understand their local population, demand, and capacity, to identify whether a networked model is required to meet the needs of the patient. Such an approach would also provide an opportunity to establish effective, integrated, pathways from emergency care through to tertiary care, and the opportunity to work more cohesively and effectively with paediatric severe asthma services.

Some hypothetical patient pathways using possible network models are outlined in Appendix A.

Evidence of Effectiveness

A networked model for severe asthma is not new, and similar network models have already been developed by severe asthma teams across the country in areas such as Yorkshire and the North West to meet the service specification requirements and improve patient outcomes. A number of these networks have been commissioned already in this format, or are in the process of being commissioned, such as West Midlands, East Midlands and Wessex. Each network has been designed based on local needs and some have already had direct impact on severe asthma outcomes through the development of pioneering clinical trials, and reducing unplanned attendances to A&E and GP services through innovative clinics. A number of these examples can be found in Appendix B.

Many of these networks have evolved over a number of years to make severe asthma services more centralised and standardised, and the new specialised commissioning specifications are facilitating these networks to work in a more

cohesive and formal manner. The Specialised Healthcare Alliance has also endorsed the formation of networks for each specialised service to facilitate seamless care and integrated pathways from the patient perspective.

We would like this approach to be formally recognised as a potential model for commissioning severe asthma services, and to introduce mechanisms which enable effective governance when such models are commissioned.

c) Network governance and accountability

In order to commission a robust and accountable service, and support those regions wishing to develop a networked model, steps need to be taken to define a network, and agree minimum criteria for satellite and peripheral sites that are contracted to undertake any work on behalf of the specialist centre.

We recommend that such factors are considered and agreed by the Respiratory Clinical Reference Group (CRG) and that the Service Specification is revised to incorporate this information. The CRG would need to consider criteria such as appropriate aspects of work to contract out, minimum numbers of referrals and minimum training in order for a site to qualify as a contracted satellite site. The criteria should be taken to the October 2014 CRG for approval, after which the amendments to the specification will need to go out for public consultation. These actions would need to be completed with the aim of having a fully commissioned national severe asthma service by April 2015.

It should also be specified that any contracted sites need to meet the same requirements and standards as the specialist centres, as defined by the original service specifications. It is also recommended that consideration is given to patient involvement in the governance of services, and their ability to meet the service specification, at both a national and local level.

d) A network of networks

In recent months the move to specialised commissioning has generated many positive meetings with discussion of best practice and the sharing of successful ideas with and across regions. Furthermore, these discussions have encouraged all major centres to found or join networks that support their centre to facilitate full

population coverage, and have been developed differently according to regional needs.

Clinicians with an interest in asthma are keen to advance these services now and in the future by continued dialogue between networks. We therefore propose a “network of networks”; providing local, excellent services for people with severe asthma whose participants will be able to share information and productive discussions around:

- i. Adopting working practices that have been successful in one region
- ii. Collaborative development and refinement of documentation such as patient information leaflets and protocols
- iii. Benchmarking performance between regions
- iv. Facilitating multi-site research.

A cohesive regional and national network structure will greatly facilitate interactions with national commissioners, and also begin to standardise the agreements with local commissioners. Overall, a network approach should reassure patients that they are receiving the same level of care wherever they reside, and that this level of care represents the highest standard as judged by the collective of experts across the country.

e) What benefits can commissioners expect to realise through a networked approach?

As a new model of care, the new national service will - for the first time - enable commissioners to benchmark performance and costs, in addition to providing evidence of the best models of care. This will enable us to generate strong evidence on how best to organise services.

In the meantime, as severe asthma experts, the group anticipates that the network approach proposed in this paper has the potential to achieve some, or all, of the following benefits for commissioners, summarised below.

Potential for improved patient care:

- Enhance support and care models for patients who are unable to travel to accommodate increased travel to the specialist hubs. Evidence has suggested that asthma mortality rates and poor asthma control increases with increased travel time to hospital(20,21).
- Reduce waiting times for appointments, diagnosis and treatment through flexible and increased capacity.
- Prevent inappropriate referrals - patients will not progress through the severe asthma pathway unless absolutely appropriate, so that the patients are seen at the right time, by the right people, in the right place, from the outset.
- Improve overall access to specialist dedicated services for relevant patients and with improved clinical outcome, to reduce the need to attend A&E of see their GP. Evidence suggests that when seen by a specialist, people with asthma are less likely to relapse and present back in A&E(22).

Potential for efficiency savings:

- Restrict access to expensive, specialised care with a positive impact on healthcare utilisation outcomes such as unplanned admissions and repeat GP visits: for example, one existing outreach model identified this network approach had saved over £65,000 for the clinic cohort over 12 months (see Appendix C). The study identified a reduction in unplanned A&E, hospital and GP attendances.
- A networked model has the potential to prevent the overprescribing of high cost severe asthma drugs through robust oversight and clear prescribing protocols. Asthma costs the NHS £1billion each year(23), and 80% of this expenditure is spent on the 20% of people with most severe asthma symptoms(24). A recent paper identified medication as the major driver of severe asthma costs(25), so there is significant scope for efficiency savings by reducing overprescribing.
- Deliver additional capacity for high volume, non-specialised activity, such as screening, to reduce waiting times and improve efficiency of the pathway; this will allow the specialist unit to utilise its expensive and restricted time and resources in the most efficient way.
- Improve risk profiling and self-management support from the start of the patient journey, even while referral is still being considered.

- Improve integrated care pathways and education across regions.
- Identify and treat poorly controlled and potentially severe asthma earlier in the patient pathway to reduce future costs.
- Increase opportunities for participation in research trials which would potentially offset costs in a commissioned pathway.
- Aside from potential investment in MDT technologies, establishing networks should in general be a low-cost initiative as they draw on existing networks and relationships.

5. Summary

The small number of people with severe asthma - estimated at just 3.7% of all people with asthma - do not respond to standard asthma treatment, and they are therefore at higher risk of a life-threatening asthma attack. They require systematic and detailed investigation, specialist multi-disciplinary team input, and highly expensive therapies to control their symptoms effectively, reducing the chance of unplanned hospital or GP attendances.

The authors of this document subsequently strongly endorse the formalisation of specialised commissioning for severe asthma: this formalisation has provided the opportunity to establish pathways so that the right patients are identified and treated in the right environment, whilst ensuring tight financial control of these expensive services.

We also suggest that a networked model, based on local needs, can be adopted to address practical implementation challenges when commissioning these severe asthma services; the potential to adopt a network approach for large regions could improve both the patient experience and the efficiency of service delivery. We advise that additional criteria are included within the service specification to define how this networked approach will be implemented and governed in practice, to aid effective commissioning of specialised severe asthma services.

To realise an effective, efficient national severe asthma service by April 2015, we recommend that the following actions need to occur:

1. NHS England accepts this proposal for a networked approach for severe asthma and endorses the recommendations - by no later than 11 September 2014
2. The CRG discuss network criteria which will be incorporated into the service specifications - 3 October 2014
3. The new service specification goes out for consultation - October-November 2014
4. The new service specification is endorsed and published - November 2014
5. All severe asthma services are commissioned and the service specification is used as a guide by all sites, whether networked or otherwise - April 2015

In summary, the specialised service specification has allowed severe asthma centres the opportunity to improve the consistency of patient outcomes, preventing unplanned attendances and costly over-prescribing. To remove all barriers to its delivery, a network-based approach could be considered when commissioning severe asthma services as the most effective, and cost-effective, way to address implementation challenges and support specialised centres at a local level.

References

1. Prieto L, Badiola C, Villa JR, Plaza V, Molina J, Cimas E. Asthma control: do patients' and physicians' opinions fit in with patients' asthma control status? *J Asthma*. 2007 Jul-Aug;44(6):461-7. PubMed PMID: 17654133. Epub 2007/07/27.
2. Fletcher M, Hiles D. Continuing discrepancy between patient perception of asthma control and real-world symptoms: a quantitative online survey of 1,083 adults with asthma from the UK. *Prim Care Respir J*. 2013 Dec;22(4):431-8. PubMed PMID: 24217859. Epub 2013/11/13.
3. Asthma UK website, <http://www.asthma.org.uk/asthma-facts-and-statistics>
4. Anderson HR, Gupta R, Strachan DP, Limb ES. 50 years of asthma: UK trends from 1955 to 2004. *Thorax*. 2007 Jan;62(1):85-90. PubMed PMID: 17189533. Pubmed Central PMCID: 2111282. Epub 2006/12/26. eng.
5. Thomas M, Bruton A, Moffat M, Cleland J. Asthma and psychological dysfunction. *Prim Care Respir J*. 2011 Sep;20(3):250-6. PubMed PMID: 21674122. Epub 2011/06/16. eng.
6. Moon JC, Flett AS, Godman BB, Grosso AM, Wierzbicki AS. Getting better value from the NHS drug budget. *BMJ*. 2010;341:c6449. PubMed PMID: 21169320. Epub 2010/12/21.
7. 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.
8. Brown HM. Treatment of chronic asthma with prednisolone. Significance of eosinophils in the sputum. *Lancet* 1958;ii:1245-7.
9. Lotvall J, Akdis CA, Bacharier LB, Bjermer L, Casale TB, Custovic A, et al. Asthma endotypes: a new approach to classification of disease entities within the asthma syndrome. *J Allergy Clin Immunol*. 2011 Feb;127(2):355-60. PubMed PMID: 21281866. Epub 2011/02/02. eng.
10. Green RH, Brightling CE, McKenna S, Hargadon B, Parker D, Bradding P, et al. Asthma exacerbations and sputum eosinophil counts: a randomised controlled trial. *Lancet*. 2002 Nov 30;360(9347):1715-21. PubMed PMID: 12480423. Epub 2002/12/14. eng.
11. Pavord ID, Korn S, Howarth P, Bleecker ER, Buhl R, Keene ON, et al. Mepolizumab for severe eosinophilic asthma (DREAM): a multicentre, double-blind, placebo-controlled trial. *Lancet*. 2012 Aug 18;380(9842):651-9. PubMed PMID: 22901886. Epub 2012/08/21. eng.

12. Heaney LG, Brightling CE, Menzies-Gow A, Stevenson M, Niven RM, British Thoracic Society Difficult Asthma N. Refractory asthma in the UK: cross-sectional findings from a UK multicentre registry. *Thorax*. 2010 Sep;65(9):787-94. PubMed PMID: 20805172. Pubmed Central PMCID: 2975949. Epub 2010/09/02.
13. Chung KF, Wenzel SE, Brozek JL, Bush A, Castro M, Sterk PJ, et al. International ERS/ATS guidelines on definition, evaluation and treatment of severe asthma. *Eur Respir J*. 2014 Feb;43(2):343-73. PubMed PMID: 24337046.
14. Blakey JD, Woolnough K, Fellows J, Walker S, Thomas M, Pavord ID. Assessing the risk of attack in the management of asthma: a review and proposal for revision of the current control-centred paradigm. *Prim Care Respir J*. 2013 Sep;22(3):344-52. PubMed PMID: 23817678.
15. Pavord I. Complex airway disease: an approach to assessment and management. *The Lancet Respiratory Medicine*. 2012;1(1):84-90.
16. Wan YI, Shrine NR, Soler Artigas M, Wain LV, Blakey JD, Moffatt MF, et al. Genome-wide association study to identify genetic determinants of severe asthma. *Thorax*. 2012 May 5. PubMed PMID: 22561531. Epub 2012/05/09. Eng.
17. Castro M, Rubin AS, Laviolette M, Fiterman J, De Andrade Lima M, Shah PL, et al. Effectiveness and safety of bronchial thermoplasty in the treatment of severe asthma: a multicenter, randomized, double-blind, sham-controlled clinical trial. *Am J Respir Crit Care Med*. 2010 Jan 15;181(2):116-24. PubMed PMID: 19815809. Pubmed Central PMCID: 3269231. Epub 2009/10/10. eng.
18. Bel EH, Sousa A, Fleming L, Bush A, Chung KF, Versnel J, et al. Diagnosis and definition of severe refractory asthma: an international consensus statement from the Innovative Medicine Initiative (IMI). *Thorax*. 2011 Oct;66(10):910-7. PubMed PMID: 21106547. Epub 2010/11/26. Eng.
19. Hekking PP, Wener R, Bouvy M, Bel E, Amelink M. The Prevalence Of Adult Severe Refractory Asthma In The Netherlands, A1288, A31 Severe Asthma Pathogenesis and Treatment Strategies, *American Journal of Respiratory and Critical Care Medicine, Meeting Abstracts*, 2014: 189
20. Jones, AP, Bentham, G, Horwell, C. Health service accessibility and deaths from asthma. *International Journal of Epidemiology*. 1999;29(1):101-105.
21. Jones, AP, Bentham, G, Harrison, BDW, Jarvis, D, Badminton, RM, Wareham, NJ. Accessibility and health service utilization for asthma in Norfolk, England. *Journal of Public Health*. 1998;20(3):312-317.

22. Zeiger, SR, Heller, S, Mellon, MH, Wald, J, Falkoff, R, Schatz, M. Facilitated referral to asthma specialist reduces relapses in asthma emergency room visits. *Journal of Allergy and Clinical Immunology*. 1991; 87(6):1160-1168.
23. Methodology: R. Gupta*, A. Sheikh, D. P. Strachan* and H. R. Anderson* 'Burden of allergic disease in the UK: secondary analyses of national databases' *Clin Exp Allergy* 2004; 34:520-526
24. Chung KF et al, Severe therapy resistant asthma. *Eur Respir Mon* 2003, 23:313
25. O'Neill, S, Sweeney, J, Patterson, CC, Menzies-Gow, A, Niven, R, Mansur, AH, Bucknall, C, Chaudhuri, R, Thomson, NC, Brightling, CE, O'Neill, C, Heaney, LG on behalf of the British Thoracic Society Difficult Asthma Network. The cost of treating severe refractory asthma in the UK: an economic analysis from the British Thoracic Society Difficult Asthma Registry. 10 June 2014. *Thorax* doi:10.1136/thoraxjnl-2013-204114.

Appendices

Appendix A: Three hypothetical examples of possible patient pathways using networks

Satellite site contracted to provide a specific service to enable care closer to home:

Patient A was diagnosed with severe asthma a number of years ago and has recently received Xolair from her local hospital centre 5 miles away every 2-4 weeks. She does not work or drive due to her symptoms and her friend has always driven her to these appointments. She lives in an isolated, rural area.

A new specialist centre has now been commissioned 100 miles away, although the local hospital remains part of the severe asthma network as a satellite site (due to its expertise). Patient A's friend is unable take her all the way to the specialist centre and there is no direct public transport.

Patient A's consultant therefore arranges for her to continue her regular appointments, with her Xolair administered, locally. This local team discusses her case as part of the MDT teleconference with the specialist centre. When required, the consultant calls her in for a follow up at the specialist site, but this is only twice a year and she is able to make travel arrangements in advance.

Satellite site contracted to provide specific investigations to address capacity challenges at specialist site:

Patient B is being treated by the severe asthma service. He is awaiting further allergy investigations, but the specialist centre has been experiencing capacity challenges for this clinic and the waiting times are extensive.

The specialist centre therefore arranges for the patient to attend the allergy clinic at a local satellite site (which has been previously contracted to provide support in this field due to their specific expertise and additional capacity). The results are discussed via MDT at the specialist centre where he attends for the rest of his care.

Satellite site contracted to provide full diagnostic screening, utilising existing local expertise to prevent unnecessary referral to specialist centre:

Patient C presented at her local A&E with a number of symptoms, some of which may be caused by severe asthma; she is referred to the severe asthma service in line with the network referral protocol. Her local hospital has been contracted by the specialist centre to complete a full range of initial investigations as they have some leading severe asthma clinicians based there, with full diagnostic screening facilities. After Patient C has had her investigations completed, the case is discussed by the MDT with the specialist centre. It is agreed that Patient C does not have severe asthma symptoms, and she is instead referred on to have her other symptoms reassessed at her local hospital.

Appendix B: Examples of existing severe asthma network models

These examples are just a select number of existing networks which have been offered as illustrations by clinicians involved. It should be noted that all regions - which may or may not use a networked model, or be referenced below - continue to strive for excellence in delivering patient care, working collaboratively to learn and develop.

Example 1: North West Severe Asthma Network

The North West Severe Asthma Network (NWSAN) is a multidisciplinary group that aims to promote high quality care for patients with severe asthma via a network approach. NWSAN comprises representatives from 10 hospitals: these members commit to regular participation in network meetings and initiatives, and to core standards of severe asthma service provision defined in a constitution. It provides a forum for the discussion of difficult cases, the exchange of successful practice, and the collective provision of services and development of research. It also facilitates continuing professional development, for example by hosting external speakers, and acts as a single entity interact with external agencies.

The network demonstrates the potential for non-commissioned sites to contribute to severe asthma care as noted above. For example:

- Standards of assessment have improved across the network, facilitating case discussion and clinical decision-making, e.g. five sites are able to undertake induced sputum processing within an NHS framework
- Individual hospitals have developed services that receive referrals from across the region, such as vocal cord dysfunction at The Royal Preston Hospital.
- Members of the network have developed evidence-based protocols, such as for the use of azithromycin in asthma.

Example 2: Yorkshire Severe Asthma Network

The Yorkshire Severe Asthma Network was founded in March 2012. Its activities to date include a quarterly MDT rotating through regional hospitals to discuss difficult cases, provide education, and seek opportunities to improve asthma care in the region. It is active in ensuring good referral patterns for patients with asthma from

secondary care to the regional severe asthma clinics, and promotes liaison with primary care to improve standards of asthma management. It has undertaken a regional survey of facilities, needs and compliance with national commissioning guidelines. The Yorkshire Network has created effective working patterns between secondary care asthma service providers and secondary/tertiary care difficult asthma clinics, and is developing shared assessment protocols. Induced sputum is available in region (Sheffield, Pinderfields), and plans to develop thermoplasty are in progress.

If commissioned as a specialised centre, the network plans to increase MDTs to monthly, using rotating meetings, videoconferencing and partnership arrangement amongst asthma specialists in the region including clinicians and clinical nurse specialists to maximise participation from around a large region. Other key relationships include excellent occupational lung disease services at Sheffield, with immunology and allergy support available at several centres, particularly Sheffield and Leeds.

The network's approach is to discuss challenging cases at the regional MDT and triage referrals from district hospitals to central asthma providers in tertiary care. By harmonising care and approaches where possible, it can facilitate referral of patients into specific hubs (for example, Leeds/Pinderfields/Bradford and Sheffield) which work in partnership with specialists providing asthma care in the district general hospitals. The network's aim is to harmonise approaches across our centres, and allow patient travel to be minimised whilst retaining high standards of assessment and care.

The clinical trials units in Yorkshire have also been leaders in severe asthma research, and have taken part in both phase 2 and phase 3 severe asthma trials. In Bradford, patients are currently taking part in 2 phase II and 1 phase III severe asthma trials. They have outperformed other centres in the UK with regards to recruitment to both time and target. In several of these trials they have been chief investigators in the UK.

Example3: East Midlands Severe Asthma Network

Glenfield Hospital and Nottingham University Hospitals NHS Trust (City Campus) have agreed to work together to provide tertiary asthma care for the East Midlands

region. Geographically this covers Nottinghamshire, Leicestershire, Lincolnshire, Derbyshire and Northamptonshire.

Preliminary discussions have taken place with Yorkshire and West Midlands severe asthma leads about creating a midlands super-hub, to share best practice across regions and networks. They believe they have much to learn from each other, and suggest that bi-annual meetings at regional level would be productive.

Example 4: The Birmingham Network Model

This region incorporates the West Midlands and other neighbouring areas. They already have broad agreement on a hub/spoke model with Heartlands Hospital being the specialist centre. They expect to approve 6-8 spokes within the network which conduct dedicated difficult asthma clinics with specified standards. The network has established MDTs and agreed algorithms for patients' assessments and certain therapies. They aim to use dendrite system for data capture for quality measures (which is already in use at Heartlands).

Example 5: Wessex Asthma Network

The network includes lead Centres in Southampton and Portsmouth, with referral pathways from Bournemouth, Dorset, Winchester, Chichester, Basingstoke, Salisbury and the Isle of Wight, as well as many extra-regional pathways including Devon and Cornwall, Berkshire and Somerset. The network has developed a common pathway for characterisation of patients with severe asthma with the "Wessex Severe Asthma Cohort", an MRC-NIHR funded cohort of over 400 severe asthma patients that has defined severe asthma characteristics allowing phenotype-led treatment and co-morbidity assessment, leading to stratified entry into relevant trials of novel therapies (<http://bit.ly/19GsEwe>). The network continues to provide unparalleled opportunities for severe asthma patients to participate in novel research trials (e.g. <http://lasertrial.co.uk>). It is incorporating the Dendrite solution to develop a Wessex-wide patient registry.

The Wessex Network has also developed successful regional initiatives such as outreach specialist clinics, inpatient in-reach pathways to the regional centre, and is establishing community-based Xolair clinics. It has developed successful patient communications with a dedicated website (www.wessex-asthma.com) with

associated social networking (@WessexAsthma), and partnered with local commissioners and the Academic Health Science Network to identify poorly controlled potentially severe asthma patients with new commissionable models of care (MISSION-Severe Asthma). The network has, in addition to the service specification, expertise in allergy (World Allergy Organization Centre of Excellence), paediatric transitional clinics, Churg Strauss Syndrome, cardio-pulmonary exercise assessment, clinical psychology, full polysomnography and airway acidification assessments. It also provides multi-disciplinary led “difficult breathing” clinics encompassing associated co-morbidities such as dysfunctional breathing and vocal cord dysfunction. A specific outreach clinic based on the Isle of Wight was presented at the European Respiratory Society Congress in 2013 and an abstract can be found in Appendix C.

Appendix C: Abstract: The impact of a specialist multi-disciplinary approach to difficult asthma on healthcare outcomes in a district hospital. Presented at the European Respiratory Society Congress, 9 September 2013 (P2023).

Veeresh Patil, Christine Townshend, Ramesh Kurukulaaratchy, Bernard Dyke, Tasneem Rahman, Vijay Joshi.

Background: Guidelines advise that patients with Difficult Asthma are managed by an experienced Specialist Multidisciplinary Team (MDT). That often requires referral to a Tertiary Centre. Can such care address Difficult Asthma in a District Hospital (DGH) setting?

Aim: To assess impact on healthcare utilization (HCU) of creating DGH outpatient access to a Difficult Asthma MDT.

Methods: A Difficult Asthma MDT was created in a pre-existing DGH Allergy Clinic. This included Consultant, Nurse Specialist, Dietitian and Respiratory Physiotherapist. Retrospective study of referred patients (n= 19) compared HCU for the 12-months prior to referral against the 12-month period that followed being under the MDT for 6-months. Measures assessed included Accident Emergency (A&E) use, General Physician (GP) visits, Inpatient (IP) days and Intensive Care (ITU) admissions.

Results: All patients were on BTS Step 4/5 treatment at referral (mean age 51.9 years, 73.3% female and 68.4% atopic). High asthma associated Secondary HCU costs were present at baseline. After being under the MDT for 18 months, (mean follow-up every 4.1 months) there was a 50.4% reduction in mean annual GP asthma visits (from 5.63 to 2.79), 68.8% reduction in mean annual asthma A&E visits (from 1.6 to 0.5), 80.4% reduction in mean annual asthma IP days (from 5.6 to 1.1) and a 100% reduction in mean annual asthma ITU days (from 1.6 to 0). Estimated savings for reduced Secondary Care asthma usage were $\leq 67,265.74$ for the 12-month observation period.

Conclusion: An MDT approach can be successfully applied to Difficult Asthma patients in a DGH setting leading to significantly reduced HCU and associated costs.