

**Difficult asthma clinic requirements**

* I will have access to **high quality, evidence based care** from primary, secondary and tertiary healthcare professionals within a timely manner, 24 hours a day, seven days a week.

There are a number of children who have persistent symptoms and / or frequent exacerbations despite optimal management in secondary care.

Problematic severe asthma (PSA) is defined as that which is poorly controlled (chronic symptoms, episodic exacerbations, continued requirement for short-acting ß agonists) despite a daily dose of at least 800 μg budesonide or equivalent for 6 months or longer.

Work in children with problematic severe asthma has demonstrated the benefits of addressing the basics of asthma management (adherence, allergen exposure, psychosocial issues and smoking)30

Children with PSA should be referred to a specialist difficult asthma team in tertiary care. The criteria for which children MUST be referred to a tertiary service are set out below; however, other children in whom the primary or secondary care has concerns (for example psychosocial concerns, adrenal suppression, breathing pattern disorder) should also be considered for referral. Such teams should consist of a number of professionals including respiratory pediatricians, clinical nurse specialists, psychologists, physiotherapists (and access to a social worker) with the necessary skill and expertise to address three key areas:

24: There are **systems in place in acute and community care for**

**identifying patients at high risk, poorly controlled or severe**

**asthma and monitoring/tracing and managing** those CYP who have

had in the last year:

„. More than one admission.

„. Admission to HDU, ICU, PICU.

„. Two or more attendances to the emergency department or out of

hours care in the last year.

„. Two or more unscheduled visits to the GP (requiring short courses of

oral steroids).

„. Ten or more salbutamol inhalers.

„. 80 per cent or less uptake of repeat preventer prescriptions.

25: There is access to paediatric physiotherapist with an interest in

dysfunctional breathing (ideally ability to direct refer from primary care).

Diagnosis; assessment of severity; management

**Diagnosis**

Diagnosis may involve a number of the following tests

* Clinical evaluation
* Spirometry (including bronchodilator response)
* Airway hyper-responsiveness tests
* FeNO -fractional exhaled nitric oxide
* Sputum
* Bronchoscopy
* High resolution chest CT

**Classification of asthma severity**

It is thought that up to 10% of adults with asthma remain poorly controlled despite prescription of high intensity treatment including inhaled and oral corticosteroids, evidence for children and young people is less clear. These children are labeled as problematic severe asthma.( Bush et al, 2010)[[1]](#footnote-1) However, following a multi-disciplinary assessment addressing the basics of asthma management (diagnosis, co-morbidities, adherence, exposure to allergen and environmental tobacco smoke) over half do not need any further investigations or escalation of treatment[[2]](#footnote-2) and are no longer considered to have severe disease. These children have improved outcomes in terms of exacerbations and reduction in treatment burden compared to those with true severe asthma (Sharples, 2012)[[3]](#footnote-3)

***Specialist Commissioning***

NHS England commissions severe and difficult-to-control asthma services from five Highly Specialist Respiratory Centres for adults in section 3 of the [manual of prescribed services](http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf). ‘Difficult’ asthma is defined as patients who have symptoms despite Step 4 of the therapeutically defined threshold being applied.

NHS England in its [manual of prescribed services](http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf) define it as:

* An event of acute severe asthma which is life threatening, requiring invasive ventilation within the last 10 years
* Requirement for maintenance oral steroids for at least six months at a dose equal to or above 7.5 mg prednisolone per day or a daily dose equivalent of this calculated over 12 months
* Two hospitalisations within the last 12 months in patients taking and adherent to high dose inhaled steroids (greater than or equal to 1000mcg of beclomethasone or equivalent)
* Fixed airflow obstruction, with a post bronchodilator FEV1 less than 70% of predicted normal
* Referred as an adolescent transition patient from a paediatric severe asthma service.

<http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf>

They also commission highly specialised allergy services from 18 centres across the country. (see page 132 manual of prescribed services <http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf> All other allergy services are commissioned by CCGs

Service specification for paediatric allergy services:-

<http://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-medi-allergy.pdf>

The paediatric medicine CRG developed a CQUIN this year pertaining to the assessment of children with difficult to control asthma within 12 weeks

<https://www.england.nhs.uk/wp-content/uploads/2016/03/pss-cquin-guide.pdf> See page 17

**Example Paediatric problematic severe asthma (tertiary) service outline**

**Paediatric problematic severe asthma (PSA)**

**Background**

The majority of children with asthma will have their symptoms controlled with occasional bronchodilator use or low-dose inhaled corticosteroids (ICSs). These children can be managed in primary and or secondary care. For the minority of children with problematic severe asthma (PSA) who remain uncontrolled despite being prescribed high doses of conventional therapy, systematic specialist evaluation and treatment by a multi-disciplinary team is needed. This approach has been demonstrated to lead to de-escalation of treatment and improved asthma control in over half of these children and rational, targeted therapy in the remainder leading to a reduction in morbidity, hospital admissions, ad hoc use of health services, treatment costs, and long term health benefits1;2 The majority of children with PSA have potentially modifiable causes for poor control. Those with true severe therapy resistant asthma may need further escalation of treatment including novel monoclonals, the need for which should only be assessed and initiated by an experienced regional specialist team.

**Problematic severe asthma**

This is the umbrella term to describe all children who present with ongoing persistent symptoms or frequent severe symptoms despite high intensity treatment (Step 4/5 BTS/SIGN guidelines). Those children who improve once the basics of asthma management are addressed are termed “difficult asthma” and those with ongoing poor control despite attention to the basics of asthma management are termed “severe therapy resistant asthma”.

**Difficult asthma**

Despite the simple definition of difficult asthma the multiplicity of causes make this far from simple to manage. Children with difficult asthma are a heterogeneous group, in terms of contributing factors and in underlying pathology. The diagnosis of asthma itself may be incorrect; there may be aggravating factors such as co-morbidities or ongoing allergen exposure; psychosocial factors may have a role to play, or prescribed medication may simply not be taken.

**Severe asthma**

Once all these issues have been addressed there will be a group of children with severe asthma who remain symptomatic despite conventional therapy. In these children investigation of the underlying pathophysiology reveals different pathological phenotypes. Such distinctions are important to make so that therapy can be targeted to the individual and the side effects of ineffective treatments avoided. The emergence of novel therapies aimed at particular subgroups of patients with asthma makes the pathological classification of the child with difficult asthma ever more important.

**REGIONAL PROBLEMATIC SEVERE ASTHMA (PSA) SERVICE**

This document sets out the requirements of a tertiary Problematic Severe Asthma (PSA) service, both in terms of personnel and facilities available; the assessments which should be undertaken and the role of the specialist PSA service as the gatekeepers for the use of omalizumab and other high cost novel monoclonals currently in development, to prevent inappropriate use, unnecessary risk to patients and spiralling costs to the NHS.

Each region should have a designated Problematic Severe Asthma Service. For some regions this may be supra-regional if no tertiary service exists within that area. Some regions with a large population may have more than one.

**Aims**

* To confirm the diagnosis of asthma
* To identify and treat co-morbidities
* To perform an initial assessment to differentiate severe therapy resistant asthma from difficult asthma (where asthma control improves following attention to the basics of asthma management)
* To assess and address all aspects of asthma care including treatment, treatment effects, psychosocial and school related issues that impact on the child and their family
* To carry out careful characterisation of children with PSA including measures of inflammation, lung function and asthma control to enable a targeted approach to treatment
* To perform an in depth annual review of all children continuing to fulfil the criteria for PSA
* To implement targeted and appropriate pharmacological treatments including omalizumab, steroid sparing agents (such as methotrexate), anti-fungal treatment and novel monoclonals
* To implement targeted and appropriate non-pharmacological treatments such as breathing control exercises
* To monitor and screen for side effects of treatment, in particular long term effects of oral steroids and to implement a steroid sparing management strategy and wean oral steroids safely
* To improve patient adherence to treatment by improving health education and psychological support
* To offer psychological support to all children and their families to address issues including adherence, anxiety, needle phobia and depression
* To liaise with secondary and primary care in terms of the management of individual patients and more widely for education and health service development
* To enter data on all children with PSA onto the National Difficult Asthma registry to inform our knowledge of the prevalence and costs of PSA , the characteristics of children with PSA and identify children who would be eligible to participate in studies of novel therapeutics
* To enhance and coordinate research and regional education in this area.
* To work with regional CCGs and ChiMat to monitor and assess clinical and financial outcome improvements

**Outcomes**

* De-escalation of treatment in those with difficult asthma
* Reduction in exacerbations, hospital admissions and unscheduled health care visits
* Initiation of targeted treatment including novel monoclonals in those with severe therapy resistant asthma
* All children assessed by the tertiary PSA team entered on the National Difficult Asthma Registry (unless consent is withheld)

**Service Description**

* Multi-disciplinary team comprising of a core team: lead Respiratory Paediatrician with an interest in severe asthma, Specialist Respiratory Children’s nurse, specialist respiratory physiotherapist, psychologist, pharmacist; and supported by other professionals including dietician, speech and language therapist, ENT surgeon, paediatric Allergist, paediatric Endocrinologist and social worker / safeguarding nurse
* Comprehensive assessment of children with PSA including review in a Specialist Asthma clinic, nurse led home and hospital visit, physiotherapy review and psychology review (not all children need to be seen by a psychologist, but all children should be discussed with the psychologist and offered an assessment within 4 weeks, if appropriate)
* Assessment of adherence using electronic monitoring devices
* A small number of children may require an inpatient stay of up to 2 weeks for further evaluation
* Some children will have most of their follow up with the PSA service and others will have shared care with their local secondary care service. All children who continue to fulfil the criteria for PSA should have an annual assessment performed by the PSA team, even if the majority of their follow up is in secondary care.
* Regular, minuted team meetings to discuss patients and meetings with shared care partners

**Referral**

**ALL** children who meet the following criteria should be assessed by the regional tertiary PSA service for an initial assessment and then at least annually if they continue to meet any of these criteria.

1. Children prescribed maintenance or frequent courses of oral steroids
2. Children under consideration for biological agents such as omalizumab, other monoclonal antibody or immunosuppressive treatment
3. Ongoing poor control (see below) despite the following treatment:
   * High dose inhaled corticosteroids (budesonide >800μg/day or fluticasone >500μg/day) plus a long acting β2 agonist plus montelukast (or previous failed trial) or trial of other add on therapy such as theophylline

Poor asthma control is defined as (one or more of):

* Persistent chronic symptoms *(most days for >3 months)* or an Asthma Control Test (ACT) or Childhood Asthma Control Test (C-ACT) score of <20
* Persistent airflow obstruction *(FEV1 <80% post bronchodilator)*
* Recurrent severe exacerbations in the past year *(≥2 per year requiring hospital admission or ≥3 per year requiring high dose OCS for at least 3 days)*
* A single PICU admission in the past year

**Assessments**

The following assessments and investigations should be available in the PSA centre although not all assessments will be indicated for every child.

* Assessment of asthma control
  + Asthma control test (ACT), children ≥12 years
  + Childhood asthma control test (C-ACT), children 4-11 years
* Assessment of quality of life and psychological dysfunction
  + Paediatric asthma quality of life questionnaire (PAQLQ)
  + Paediatric anxiety and depression scale (PI-ED) or the Hospital Anxiety and Depression Scale (HADS)
* Inhaler check and grading of technique
* Adherence check
  + Prescription record
  + Electronic monitoring
  + Theophylline levels, prednisolone levels (if applicable)
* Lung function
  + Spirometry
  + Bronchodilator reversibility
  + Tests of airway hyper-responsiveness (methacholine or histamine challenge)
* Inflammomatory
  + Exhaled nitric oxide (FENO)
  + Induced sputum
* Skin prick tests to common aeroallergens and foods
* Blood tests
  + Full blood count
  + Total IgE and specific IgEs
  + Vitamin D
* Monitoring of steroid side effects
  + Synacthen test
  + DEXA scan
* Bronchoscopy
* High resolution CT scan of the chest
* pH study
* Polysomnography
* Dynamic upper airway endoscopy

**Treatment and management options for severe asthma**

**Pharmacological**

Children with severe therapy resistant asthma (STRA) should undergo detailed characterisation so that a targeted and appropriate management plan can be implemented. The following treatments should only be initiated by the PSA service although continuation and ongoing monitoring of these treatments may take place in secondary care. All of these treatments should be given as an initial 16 week trial with careful assessment throughout the treatment period and subjective evidence of benefit. For those who continue on these treatments there should be a continual process of re-assessment

* Omalizumab
* Methotrexate
* Other immunosuppressants including azathioprine and cyclosporine
* Anti-fungal treatment
* Subcutaneous terbutaline
* Novel monoclonals in development including lebrikizumab (anti IL-13), mepolizimab (anti IL-5) and dupilumab (anti IL-4α)
* All children who are ineligible for omalizumab or who have had a failed trial should be offered the opportunity to be entered into a multi-centre clinical trial of novel biologicals if eligible

**Non pharmacological**

Non pharmacological treatment should be considered in addition to conventional therapy for all children with PSA. The following should be available:

* Breathing control exercises implemented by a specialist respiratory physiotherapist
* Psychological support including anxiety management and to cope with depression, denial and disorganisation. Good psychological care to manage anxiety and association with symptoms especially following intensive care admission, and for psychological problems manifesting as asthma symptoms
* Temperature controlled laminar airflow device

All children should be offered the opportunity to be entered into a multi-centre clinical trial of the above therapies if eligible

**Transition**

All paediatric DA services must be aligned to, and work closely with a commissioned adult severe asthma service to ensure the smooth transition of care of young people with severe asthma. Not all young people will require transition to an adult severe asthma service, some will continue to be followed up in their local secondary care asthma clinic and some by their GP. The decision as to the most appropriate setting for on-going care should be made jointly by the adult and paediatric teams.

The process of transition should start some time before the actual transfer of care (from approximately 14 years onwards). During this time the paediatric team should support the young people in gaining greater autonomy and ensuring they have appropriate knowledge of their condition, treatment and self management. This process should continue once the young person has transferred to adult care.

**Recommendations**

Currently, tertiary asthma services are funded as part of the service specification for Paediatric Respiratory Disease which does not include children. In order to be classified as a tertiary severe /difficult asthma service there must be a sufficiently experienced and resourced MDT including respiratory Paediatrician, Clinical Nurse Specialist, psychologist, physiotherapist and input from the Safeguarding team.

**Specialist Paediatric Asthma Commissioning Quality and Innovation (CQUIN)**

Commissioning Quality and Innovation (CQUIN) are designed to incentivise providers to deliver quality and innovation improvements over and above the baseline requirements set out in the NHS standard contract, Users should check with providers for the latest commissioning agreements, such as Local and national CQUIN.

The 2016 Specialist Paediatric CQUIN is designed to be applied to a regional referral or tertiary level centre.

**GOAL:**

* To incentivise the identification of paediatric patients with difficult to control and severe asthma, alone and in combination with other medical conditions,
* To prompt appropriate referral, assessment and follow up after they leave hospital and
* Tto ensure that hospitals deliver high quality care and support to children with difficult to control and severe asthma and their families.

In order to address these issues the management of CYP with difficult to control and severe asthma requires a structured and methodical approach, delivered by a Specialist Paediatric asthma multi- disciplinary team, who should demonstrate the following:

**INDICATORS:**

1. 70 per cent funding to the assessment and investigation of children with difficult to control and severe asthma
2. 10 per cent funding for evidence of a commitment to ongoing education of the networked secondary care units within the region, and be enabled to audit the educational achievement. This should be in close alignment and reportable to the local CCGs / area team.
3. 10 per cent funding for evidence of a commitment to ongoing assessment of networked secondary care unit activity within the region, and data entry into a National Severe paediatric asthma registry. Accountable to local CCGs, and area team.
4. 10 per cent funding for demonstrating a strong communication structure with the CYP secondary and primary care providers, school and above all the child and family.

**DATA SOURCES:**

Secondary Care A&E and admission data via ChiMAT data, and secondary care direct reporting tools,

National Paediatric Asthma registry

**ASSESS, INVESTIGATE AND REPORT (AIR):**

There are three separate stages to this element of the CQUIN:

**Assess**

A detailed re-assessment of the diagnosis should be performed in all patients whose asthma does not appear to be responding to treatment. A focused approach guided by history and physical examination is more appropriate than slavishly performing every possible test on all children. It is crucial to get the diagnosis right.

The most important differential diagnoses and their relevance vary geographically (e.g. tuberculosis). A number of conditions can mimic or coexist with asthma. The list is extensive but includes: bronchiectasis; obliterative bronchiolitis; cystic fibrosis; primary ciliary dyskinesia; extrinsic allergic alveolitis; inhaled foreign body.

**Allergy**: The risk of severe chronic asthma increases with multiple sensitisations and high total Immunoglobulin E (IgE) levels. In fatal childhood asthma, allergens have been linked to the cause of death. This particularly relates to food allergens, such as peanut, but also to airborne allergen exposure such as animal dander, moulds and high pollen levels in combination with physical exercise. Hence, a thorough evaluation of possible allergies and their relevance to clinical disease and severity is mandatory in a child presenting with problematic severe asthma.

It is important to assess the degree of asthma control at each clinic visit. More structured questionnaires can help to improve the decision-making process, and a scoring system can be used as a comparator when management adjustments have been made. The asthma control test is short, simple to administer and has been validated for children over 12 years old.

Special consideration should be given to Vocal cord dysfunction (ENT), and the assessment of dysfunctional breathing.

**Psychosocial factors** can have an important effect on difficult asthma, but the relationship is complex and it is difficult to disentangle cause and effect. Careful evaluation and management are needed. Stressful life events can cause exacerbation of asthma symptoms; asthma in itself, like any chronic illness, can be a cause of psychological morbidity. Psychosocial stressors can cause panic attacks or dysfunctional breathing, which may be mistaken for asthma or can lead to over-reporting of symptoms for secondary gain.

Screening for side effects of high dose medicines: Side effects of high-dose conventional therapies remain a concern along with suppression of growth and final height. Prolonged use of high-dose inhaled corticosteroids (ICS) or oral corticosteroids (OCS) carries a risk of unwanted side effects such as adrenal suppression, growth delay and a decrease in bone mineral density.

**Consideration for novel and high cost drugs**: Novel therapies may be of particular benefit for children with difficult asthma. These are often expensive and also have the potential for side effects. Thus, more precise characterization of the underlying pathological processes in a given individual is needed. It is vital that appropriate children are selected for treatment for good clinical practice and to determine their efficacy. Omalizumab, a recombinant IgG1 monoclonal anti-IgE antibody, has been licensed for use in children over 6 years old with severe persistent IgE-mediated asthma.

**Investigate:** Tests to exclude other diagnoses include, but are not limited to: sweat test and genotyping for cystic fibrosis; nasal nitric oxide and ciliary brushings for primary ciliary dyskinesia; high-resolution computed tomography (HRCT) scan for interstitial lung disease, bronchiectasis and airway malformations; and other relevant tests for systemic disease. Furthermore, a history of severe, persistent, unusual or recurrent infections should prompt immunological investigations including serum immunoglobulin (Ig) G (including subclasses), IgM and IgA, evaluation of antibody response to common antigens and vaccines, and HIV testing.

Measurements of airflow obstruction by spirometry or peak expiratory flow (PEF) are an important part of the evaluation of asthma in terms of diagnosis and in assessing severity. Spirometry and evidence of bronchodilator reversibility add more weight to the diagnosis of asthma. Exercise testing, and the ability to perform overnight sleep assessments should also be available. Invasive measures such as bronchoscopy with endobronchial biopsy and broncho-alveolar lavage (BAL) are considered the gold standard but non invasive tests; induced sputum cytology and exhaled nitric oxide (FeNO) can be performed more easily and repeat measurements can be made. Side effects of high dose ICS and frequent or maintenance OCS should be monitored by assessing adrenal suppression, bone density and growth. The ability to perform long term electronic recording of PEF or FEV1, and assess in conjunction with a severity score.

**Reporting:**

It is essential that the regional team have a timely and accurate reporting structure to the patient, secondary and primary care to ensure continuity in medical advice, and avoid confusion.

The influence of the regional centre cannot be over emphasised. The severe asthma team have a unique overview of the clinical range of paediatric asthma, its diverse presentation according to age, its management and physical and psychological effects. They should share this knowledge with their referring units and provide and coordinate a comprehensive educational program to all secondary care units, with regional meetings and difficult case discussions.

This comprehensive overview should also be used to work in conjunction with the local CCGs to interpret activity and audit data, to formulate a local medium and long term strategy.

**Example: CQUIN Indicator Development Template**

|  |  |
| --- | --- |
| **Indicator Name** |  |
| Indicator Brief Description | Assessment and investigation of children with **difficult to control asthma** within 12 weeks of referral |
| Numerator | Number of patients who undergo a systematic MDT assessment within 12 weeks of referral carried out by a Respiratory Paediatrician, Children’s Respiratory Nurse Specialist, physiotherapist and psychologist  AND issued a detailed management plan  AND have assessments entered onto the Difficult Asthma Database. |
| Denominator | Number of children referred to the service with a suspected diagnosis of difficult to control asthma |
|  |  |
| Sponsor name | Dr Richard Iles – Paediatric Medicine CRG |
| Contact details (organisation, email, phone) | Richard Iles [richard.iles@doctors.org.uk](mailto:richard.iles@doctors.org.uk)  07736351424 |

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| **Rationale: What are the reasons and evidence-base for the scheme?** | |
| Purpose  Summarise the change in behaviour sought and the desired outcome (in terms of cost-savings and/or patient benefit) | It has been demonstrated that a thorough multi-disciplinary assessment of children with problematic severe asthma (PSA) (poor asthma control despite high intensity treatment) can successfully distinguish children with difficult asthma from those with severe therapy resistant asthma. The former group account for approximately 75% of children with PSA. Attention to the basics of asthma management leads to a reduction in exacerbations and reduced treatment burden. The purpose of this CQUIN is to ensure that all children have appropriate and timely assessment and investigation in order to improve asthma control, reduce hospital admissions and avoid inappropriate escalation of therapy including the initiation of expensive monoclonal antibodies. In order to achieve this specialist respiratory services need a dedicated difficult asthma team which requires an appropriate standardised skill sets and strong leadership. |
| Evidence base  Set out, with references to sources, evidence regarding:   * scale of the issue for a typical provider for whom the CQUIN is likely to be suitable, and across England * link between the desired behavioural change and the ultimate outcome; * costs and cost-effectiveness of the intervention; * level of ambition; * counter-factual | There are 20 specialised paediatric respiratory centres in England who see the cohort of “difficult asthma patients”. A specialised centre would expect to see approximately 30 new patients per year who would undergo this assessment. It is likely there are many more children who fit the criteria for PSA but are not referred to the appropriate centre. A more systematic assessment and better organisation of services should lead to a greater number of referrals leading to greater benefit for more patients. At present there are a small number of outstanding centres that have pioneered this approach. This standard should be achievable by all difficult asthma teams.  *A number of units do not see sufficient patients, and are staffed / resourced to an inadequate standard. The collection of data will enable the coalescence of units to maintain adequate resources in line with activity.We expect this numerator to be 30 patients per year.*  *[Scale of the issue: For a typical provider, what is the volume of patients who could benefit each year, and what proportion is*  *Providers need to establish systems and processes within their MDT’s to ensure that patients are seen in a timely way and that a comprehensive management plan is initiated.*  Evidence;  Chung, K., 2014; International ERS/ATS guidelines on the definition, evaluation and treatment of severe asthma. *ERJ -43;343 – 373*  Bracken, M., et al. 2009. The importance of nurse-led home visits in the assessment of children with problematic asthma. *Arch.Dis.Child* 94:780-784  Sharples, J., et al. 2012. Long-term effectiveness of a staged assessment for paediatric problematic severe asthma. *Eur.Respir J* 40:264-267.  See above  *[Link between the desired behavioural change and the ultimate outcome: in most cases, the CQUIN scheme will be targeted at processes so there needs to be evidence (e.g. NICE Clinical Guidelines) to demonstrate that improvements to processes will translate into improved outcomes. What is the potential impact on patient outcomes or experience? What is the impact on costs to the NHS and society in general?*  *[Costs and Cost-effectiveness of the intervention: Evidence that the cost of the intervention is justified by the value of the improved outcomes. To assess this, a realistic assessment of the cost of implementation of the proposal with the corresponding improvement in patient outcomes and/or cost-savings and/or other benefits is required.*  *[Level of ambition: What is a plausible level of improvement in outcomes or experience and over how many years can this be expected to take? How much of this can be achieved in the first financial year of the CQUIN?*  *Over time, this improvement is likely to happen. However using the CQUIN tool will accelerate achievement of improved outcomes for patients, not only medical but also socioeconomic in terms of improved school attendance and reduced time off work for parents..,*  *[Counter-factual: What is likely to happen to patient outcomes if the CQUIN scheme is not selected?* |
| Cost Profile  What is the time frame over which change should be made, when are the costs incurred, and when do any cost savings to the provider accrue. | PSA services will need to have in place the appropriate members of the team to carry out this assessment. Most services will have a medical lead and Children’s asthma nurse. Access to specialist physiotherapy and psychology services may take loner to establish and Trusts would need to find the money to ensure sufficient personnel with the appropriate expertise are employed to enable timely assessment of patients.[  *It is important to be realistic about the period in which costs will actually be incurred and to work through the cash flow implications for providers, to help assessing the appropriate level and duration of the CQUIN payment.*  [*Costs and any costs savings should be set out by quarter for typical provider, scaled by size of quarterly patient cohort.]* |
| CQUIN Appropriateness and Exit strategy  What will secure continued performance once the CQUIN is removed? | *This will be mandated in the service specification and providers will need to derogate with a plan to achieve in 12 months. Regional commissioners will need to consider their commissioning position and ensure that risk mitigation is in place with an achievable action plan for delivery/achievement. [What is it about current arrangements which mean better outcomes are insufficiently motivated at the moment that will be resolved by a temporary financial incentive? E.g. are there one-off service costs required to make the change and/or that those organisations incurring costs do not reap the benefits?*  *[Response here should depend upon the cost profile. If a continuing substantial cost to a provider is envisaged (with benefits accruing to patients or to other agents), then it should be explained how continuing compliance after the CQUIN year(s) should be expected – e.g. through general tariff uplift or through a Best Practice Tariff).]* |

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| **Data and methodology: Is the data and methodology fit for purpose?** | | | |
| Data source and justification  Data availability, timeliness, frequency,: can baseline level of performance can be established readily and prospectively.  Data Quality and Suitability. | | Clinical audit would need to be undertaken to determine number and timing of referrals. The National Registry can then be used to determine the date by which the assessment has taken place.  *[There needs to be a data source identified e.g. Hospital Episode Statistics or clinical audits in order to measure the baseline and changes in performance. Existing data collections should be considered. Any proposed new collections may first need to be submitted to the NHS England Data Operational Group[[4]](#footnote-4) which will help identify alternatives to new collections and endorse the need for new collections that will then need to be submitted for approval by the HSCIC Burden Advice and Assessment Service (BAAS). BAAS has a statutory responsibility to seek to minimise the burden of data collections on the NHS* [*http://www.hscic.gov.uk/baas*](http://www.hscic.gov.uk/baas) *Funding for new collections will need to be identified.*  *[Form in which it is available, who has access, timeliness and frequency including the longevity of the data. If payment is to be linked to performance relative to a base year then the baseline level of performance needs to be established in a timely way to allow organisations to plan and negotiate arrangements.*  *[Data quality refers to the extent to which it is fit for its intended use and covers aspects such as completeness, coverage, accuracy and validity.*  *Suitability: If a scheme uses existing flows, care needs to be taken to ensure that the integrity of the data will not be compromised by attaching financial incentives.* | |
| Actionability and Responsiveness can changes in the value of the measure can be attributed to performance of the change agent. | | *This CQUIN is fully within the gift of the provider unit.*  *The power of the incentive is closely tied to their certainty – those required to change behaviour need to know that the changes in the value of the indicator, and therefore the payment, reflect their actions, and not biased by random variation or changes outside of their control. For example, if the indicator and therefore the payment for a specialised provider is disproportionately affected by other agents beyond their influence.* | |
| Perverse responses | | Use of the National Asthma Database.  [What are the possible perverse responses in terms of data massage or perverse behaviours. Can they be mitigated? | |
| Complementary Initiatives.  Are there other policy initiatives to support the financial incentive. | | *A Paediatric Difficult Asthma Network (PDAN) has been established between 4 centres in the UK. It is envisaged that this network will expand to include all centres eligible for the CQUIN*  *Evidence shows that financial incentives work best when they are supported by other levers such as a national programme.* | |
| Precise Indicator Definition | | 70% of (newly referred) difficult to control asthma patients to achieve all three numerator conditions – i.e.  Numerator:  Number of patients who undergo a systematic MDT assessment within 12 weeks of referral carried out by a Respiratory Paediatrician, Children’s Respiratory Nurse Specialist, physiotherapist and psychologist (units must ensure that they have a robust MDT approach to seeing these patients and whilst there will not a “one size fits all” e.g. one stop clinic approach. However the child should have access to all of these professionals through the most effective MDT arranagement)  AND issued a detailed management plan  AND have assessments entered onto the Difficult Asthma Database.  Denominator:  Number of children referred to the service with a suspected diagnosis of difficult to control asthma  Please note: Providers will be required to produce an end of year CQUIN report which will be standardised across all centres and will include information to support improved outcomes such as reduced DNA’s, reduced hospital admissions etc., This data will be taken from the database and a template for submission of the report will be issued by providers prior to Q1. | |
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| Profiling  The profiling of the payment is realistic relative to the level of improvement that can be plausibly achieved in the period of the CQUIN operating. | | | *The incentives need to be on a meaningful timeframe. Incentivising something on a short time period which requires long term action to have an impact will not work.*  *If appropriate, a multi-year CQUIN can be designed.*  *Past experience has shown that staggering payment to achievable milestones over the year is better than payments only conditional on end of year performance.* |
| Please specify how payment will be linked to performance:  For example: NA   |  |  |  | | --- | --- | --- | |  |  | | |  |  | | |  |  | | |  |  | | |  |  | | |  |  | |  |  | |  |  | | | | |
| **Are there any rules for partial achievement of the indicator at the final indicator period/date?** | NA | | |

**Supporting guidance**

To help complete the above template as fully as possible we recommend that you use the SMART framework when developing your scheme. We have shown how the SMART framework can help avoid some of the common pitfalls of incentives as identified in a seminal paper by Peter Smith[[5]](#footnote-5) at the Centre for Health Economics at York.

**Specific**: Each incentive needs to be clearly defined and aligned to strategic objectives, with an explicit statement of the way in which the incentive is intended to achieve that objective and a statement of the intended costs and benefits (quantified and monetised where possible).

The indicator should therefore be supportive of strategic objectives of NHS England, be proportionate to expected benefits and minimise the risk of:

* Tunnel vision - Concentration on areas included in the indicator to the exclusion of other important unmeasured areas
* Sub-optimisation - The pursuit by managers of their own narrow objectives, at the expense of strategic coordination and the impact on other organisations
* Myopia - Concentration on short-term issue to the exclusion of long-term considerations which may only show up in performance measures in many years’ time
* Misinterpretation - Incorrect inferences about performance brought about by the difficulty of accounting for the full range of potential influences on a performance measurement.

**Measurable**: The threshold for achievement has to be objectively measured though in a way that would avoid:

* Measurement fixation - The pursuit of success as measured rather than intended
* Ossification - Organisational paralysis due to an excessively rigid regime of measurement which may also stifle innovation
* Gaming - Altering behaviour in order to obtain strategic advantage
* Mis-representation - The deliberate manipulation of data by staff ranging from ‘creative’ accounting to fraud - so that reported behaviour differs from actual behaviour

**Attainable**: The threshold for achievement should be realistic but avoid cliff edges, avoid disproportionate redistribution of effort, and be relative to comparative performance of organisations as well as relative to changes in performance over time.

In doing so, the indicator should minimise the risk of:

* Complacency - Lack of ambition for improvement brought about by adequate comparative performance
* Temporary behavioural changes – it should embed the behavioural changes such as with VTE risk assessment which was a CQUIN scheme and has now become a contractual sanction in order to maintain efforts.

**Relevant**: The incentives should be relevant to:

* the strategic priorities of NHS England
* other existing incentives (financial and non-financial) so that the CQUIN is complementary
* agents whose behaviour incentive intended to affect, including down to the level of the individual
* the intrinsic objectives of the organisation so that it reinforces rather than conflicts with them. The incentive will reduce effort if it is not robust to changes that are outside the control of the organisation or are based on small numbers subject to random variation.

**Timely**: The incentives need to be on a meaningful timeframe. Incentivising something on a short time period which requires long term action to have an impact will not work.

1. #### Bush A[, Saglani](http://www.ncbi.nlm.nih.gov/pubmed/?term=Saglani%20S%5Bauth%5D) S (2010).Management of severe asthma in children, The Lancet , Volume 376 , Issue 9743 , 814 - 825

   [↑](#footnote-ref-1)
2. Bracken,M , Fleming, L, Hall, P et al (2009) *The importance of nurse-led home visits in the assessment of children with problematic asthma* Arch D see commissioning sectionis Child 94:780–784. [↑](#footnote-ref-2)
3. Sharples, Gupta et al (2012) Long-term effectiveness of a staged assessment for paediatric problematic severe asthma European Respiratory Journal, 40: 264–278 [↑](#footnote-ref-3)
4. The Data Operational Group is a subgroup of the NHS England Data and Services Panel, with responsibility for managing the detailed approach to data requirements for NHS England. [↑](#footnote-ref-4)
5. P. Smith (1995) “On the unintended consequences of publishing performance data in the public sector”, International Journal of Public Administration, 18(2/3). [↑](#footnote-ref-5)