

Asthma (including children and young people): diagnosis and monitoring

Stakeholder workshop

Monday 18 March 2013

Royal College of General Practitioners, 30 Euston Square, London, NW1 2FB

Group Discussion Notes

The stakeholder scoping workshop is held in addition to the formal consultation on the scope which is taking place from the 10th of April until the 8th of May 2013. The objectives of the scoping workshop were to:

- obtain feedback on the specified population and key clinical issues included in the first draft of the scope
- seek views on the composition of the Guideline Development Group (GDG)
- encourage applications for GDG membership

The scoping group (Technical Team, NICE and GDG Chair) presented a summary of the guideline development process, the role and importance of patient representatives, the process for GDG recruitment and proposed constituency for this group, and the scope. The stakeholders were then divided into four groups which included a facilitator and a scribe and each group had a structured discussion based around pre-defined questions relating to the draft scope. Comments received from each discussion group are summarised below.

Scope section	Comments
4.1 Population: 4.1.1 Groups that will be covered: a) Children and adults who are being investigated for possible asthma, or those persons who have been diagnosed with asthma and are monitored for this condition. b) Specific consideration will be given to subgroups of people in different age categories broadly divided into younger children, older children, and adults.	<i>Is the population appropriate?</i> <ul style="list-style-type: none">• Are there any specific subgroups that have not been mentioned?• Very young children are currently excluded – is there an age cut-off before which diagnosis is difficult to make? GROUP 1 NOTES <ul style="list-style-type: none">• Paediatric diagnosis completely different – many “wheezy” children referred to secondary care.• Difficulty of reporting symptoms by parents (they don’t know what constitutes a productive cough/wheeze) so clinical history taking is often useless – there are no objective markers in this age group.• Children are given a “treatment challenge”/“trial of therapy” with follow up which may mean they

	<p>are getting drugs they don't need? How to decide if this means they have asthma?</p> <ul style="list-style-type: none"> • Rule out test/positive diagnosis needed but doesn't exist – can use FeNO to say if steroids work or not. • Should cover any age. Maybe split 0-6 yrs, then 6-11, then 11 and above. <p>GROUP 2 NOTES</p> <ul style="list-style-type: none"> • Special considerations should be given to: <ul style="list-style-type: none"> ○ The elderly – as they have a different onset and are thus a distinct group. Elderly aged >75 = cut-off for death risk, therefore 'elderly' defined as >75 years of age. ○ Adolescence – to be included and specified (not just to be encompassed within 'older children') – diagnosis wouldn't be different, but monitoring (and adherence) would be. • Majority of participants preferred the words 'older children' than 'adolescence'. <p>GROUP 3 NOTES</p> <ul style="list-style-type: none"> • GPs need most help with under 5s • SIGN guidelines don't have lower age cut off <p>GROUP 4 NOTES</p> <ul style="list-style-type: none"> • The stakeholders agreed that it would be good to cover infancy. Age 2 was suggested by 3 stakeholders. Two people on the table did not want to propose an age cut-off at all, i.e. including neonates.
<p>4.1.2 Groups that will not be covered: a) Infants and very young children.</p>	<p>GROUP 1 NOTES</p> <ul style="list-style-type: none"> • If any age group is excluded then could exclude 0–12 months – 40% infants wheeze but mostly not due to asthma. However, persistent asthmatics often wheeze from early age. Strong evidence that steroids (prednisolone) don't work in children under two years old however they are still given in emergency departments to infants. • Could divide paediatrics into those likely to grow out of asthma and those more likely to continue with asthma in adulthood. <p>GROUP 2 NOTES</p>

	<ul style="list-style-type: none"> • Groups that will not be covered, i.e. cut-off age? <ul style="list-style-type: none"> ○ 12–18 months – as infants with wheezing could be as a result of bronchilitis and not asthma. ○ <1 year – some participants felt that it was not good to ignore young age, as a clinical diagnosis is important, even if diagnosis is not asthma but bronchilitis - at least it excludes asthma; to ignore <1y would be odd if guideline is specifically about asthma diagnosis! ○ 3 years – one pilot study chose 3 years and upwards (Royal College of Child Health), as a lower age will confuse with viral-induced wheeze. Lower the age, the less likely it will be due to allergic asthma. ○ Therefore, to cut-off at 1 year, 2 years or 3 years to age? • Majority of participants agreed that it isn't possible to confidently diagnose asthma in those less than 1 years of age, therefore decided that 12 months should be the cut-off age. <p>GROUP 3 NOTES</p> <ul style="list-style-type: none"> • Under age of 5 would be most appropriate no lower cut off but we should exclude neonates. • Up to three months may be pragmatic <p>GROUP 4 NOTES</p> <ul style="list-style-type: none"> • Two people on the table did not want to propose an age cut-off at all, i.e. including neonates.
b) Occupational asthma.	<p>GROUP 1 NOTES</p> <ul style="list-style-type: none"> • Not to go beyond identification of this through history taking/questionnaire then STOP, i.e. refer to specialist. Full agreement from group. <p>GROUP 2 NOTES</p> <ul style="list-style-type: none"> • Exclusion of occupational asthma? <ul style="list-style-type: none"> ○ Some participants agreed to exclude, as diagnosis is difficult involving specialised tests, but to include in outcomes. However, others pointed out that it is in the Quality Standards guidelines, so why exclude from here? Some suggested addressing this by looking at the value of simple screening tests; they felt that otherwise the guideline will be very side-tracked. • Majority of participants disagreed, as they felt it was important to be aware of work place involvement (in primary care). Therefore, occupational asthma to be included in the guideline.

	<p>GROUP 3 NOTES</p> <ul style="list-style-type: none"> • Occupational asthma: <ul style="list-style-type: none"> ○ Much neglected topic with a small evidence base. ○ Similar presenting symptomatology, patients arrive at GP/hospital with same symptoms. ○ Epidemiology supports 1/6 cases in adults are occupational – would benefit hugely as done poorly in UK currently. ○ Reinforced from intensivists. ○ Huge prognostic implications. Could cure up to 1/3 of cases unique in asthma management. Monitoring would be similar in this group. ○ Primary care perspective: When to refer would be the most important factor GP. ○ We should remember to ask occupational asthma questions in an asthma history. <p>GROUP 4 NOTES</p> <ul style="list-style-type: none"> • SIGN covers occupational asthma. Concerns were raised about an exclusion of occupational asthma. It was felt that it would leave a gap and cause confusion to exclude this topic. • Smoking and asthma was brought up. Misdiagnosis of asthma and people with COPD in this respect was also mentioned particularly in respect of monitoring.
<p>4.2 Healthcare setting a) Primary, secondary and tertiary care settings.</p>	<p>GROUP 1 NOTES</p> <ul style="list-style-type: none"> • No specific discussion. Specialist community care services discussed as an example of a cost effective service used in place of repeated primary care visits. <p>GROUP 2 NOTES</p> <ul style="list-style-type: none"> • Guidance to GPs about reviewing patients with asthma medicines but no guidance on diagnosis of asthma, therefore, a big unmet need is in primary care. • One participant felt that it would be important to specify ambulance-men, as often 1st acute attacks are treated by ambulance-men, who can give nebulisers. • However, the majority of participants felt that this shouldn't be included, as not dealing with hospital monitoring when patient presents with acute attack. • Therefore, a suggestion was made to include the word 'chronic' asthma and not 'acute' so as to exclude ambulance services.

	<ul style="list-style-type: none"> • One participant mentioned the importance of self-management plans, but the majority of participants agreed that we need to truncate the scope and be more focused otherwise this guideline will become too big. • The question: ‘should the word ‘primary’ be changed to ‘community’?’ was raised, as some pharmacists have been contracted/commissioned. However, these are standard NICE wording. In addition, community could include schools etc. • Therefore, the majority agreed that tertiary care should be removed, and wording should be tweaked to ensure that community refers to NHS-related settings only. <p>GROUP 3 NOTES</p> <ul style="list-style-type: none"> • No comment was made on this. <p>GROUP 4 NOTES</p> <ul style="list-style-type: none"> • No changes suggested by the group
<p>4.3 Diagnosis and Monitoring</p>	
<p>4.3.1 Key clinical issues that will be covered: DIAGNOSIS <i>Initial clinical assessment</i> a) The value of specific signs and symptoms such as frequency and severity of difficulties in breathing, wheezing, chest pain / tightness, cough, breathlessness and respiratory symptoms at night or seasonal variation, symptoms in response to exercise and symptoms after taking other medication (including aspirin or other NSAIDs and beta blockers) b) family or personal history of atopic disorders for making a diagnosis of asthma</p>	<p><i>These are the key clinical areas that we propose covering in the guideline. Do you think this is appropriate, acknowledging we must prioritise areas for inclusion?</i></p> <p>GROUP 1 NOTES</p> <ul style="list-style-type: none"> • Asthma diagnosed based on clinical probability on taking a clinical history. Ideal is a standard for formally making a diagnosis of asthma. These standards may be different in primary/secondary/tertiary care. • Does further testing add anything? Tests often unable to show anything useful. • Misdiagnosis – discussion by group of their clinical experience of conditions being treated as if they were asthma but on further testing or consultation from specialist identified as something else (e.g. TB or COPD) which could have been treated properly earlier if identified. A primary care standard diagnosis may avoid this. • Much asthma is related to allergies – lack of UK specialism / NHS services. Skin/allergy testing should be considered. Skin test in primary care if asthma severe – not in majority. Cost issues: Skin prick test compared with unnecessary drugs

- Paediatricians have allergy assessment training, adult services less so.
- Key to diagnosis is multiple symptoms on repeat assessment in conjunction with family history, pets. Key symptoms are productive cough, eczema, wheeze – even then based on probabilities.
- Key signs that are negative for asthma – light headedness/dizziness, unproductive cough or cough on its own.
- **Differential diagnosis** - important to flag the symptoms/signs that should be taking you away from a diagnosis of asthma. These include co-existing conditions (bronchiectasis, COPD, etc.). Asthma is a difficult diagnosis to NOT make (e.g. primary care may diagnose as asthma as it's easy – no tests etc. and there are drugs available), so need to exclude as much as possible.
- Seasonal effects – thunder storms, hay fever associated: these may lead to avoidable deaths, but not commonly identified as a key risk. Need to be emphasised to primary care more than currently.
- Documentation key to diagnosis – ideal if followed up by same person each time in primary care however this is unlikely.
- **Education/training** – fewer specialist asthma nurses in primary care. Could have specialist community team – e.g. Southampton. Support for primary care. Skill set required.

GROUP 2 NOTES

- The following were discussed:-
 - If you have rhinitis, have high chance of having asthma
 - Difficult to use tests in young children
 - Should we consider breathing dysfunction, etc. to distinguish asthma from various other conditions?
 - Symptoms in response to treatment are not accurate, as patients will get better over time.
 - Would monitoring by review (i.e. review of symptoms) and having a list of misdiagnosed conditions would be useful.
 - Viral-induced wheeze can be mistaken for asthma therefore should 'take away' diagnosis of asthma – important to be able to 'take away' asthma diagnosis. i.e. 'grown out' of asthma)
- The majority agreed with b) as it is stated.

GROUP 3 NOTES

- No comment was made on this.

	<p>GROUP 4 NOTES</p> <ul style="list-style-type: none"> • It was mentioned that there might not be that many symptoms and that they therefore could all be considered independently (i.e. nocturnal cough). • Wheezing as a symptom which often leads to misdiagnosis was mentioned (several people focused on this symptoms). • Primary care and assessment of symptoms was highlighted - and an algorithm was seen as an important aspect of the guideline. • Maybe symptoms that could exclude a diagnosis of asthma could be a focus. • Group members were not aware of many (with the exception of the Yung checklist) validated tools. • Wheezing, nocturnal cough and exercise was mentioned as possible priorities in way of symptoms. • Birth history was mentioned as something that was missing such as low birth weight. • Reactions to ACE inhibitors (not to be included) and NSAIDS was mentioned and whether this could be excluded was queried.
<p><i>Objective tests</i></p> <p>c) Measures of lung function and airway obstruction including peak expiratory flow (PEF) variability, bronchodilator response (using PEF or FEV1), bronchial reactivity/airway challenge (eg methacholine), exhaled nitric oxide, induced sputum eosinophil count, airway responsiveness to methacholine or histamines, and indirect challenges such as mannitol</p> <p>d) Biomarkers of airway inflammation using tests of exhaled nitric oxide or sputum eosinophils.</p> <p>e) Measures of exercise induced bronchoconstriction, such as cold air</p>	<p>GROUP 1 NOTES</p> <ul style="list-style-type: none"> • Tests – Who to test? Tests aren't sensitive enough. Need to be done by specialist so secondary care / specialist team. • Order of tests? Sequencing? • Practical thing for primary care is FeNO test for responsiveness to steroids – no response to treatment and/or atypical history. Cost effectiveness not proven. Expensive? • Flow volume loop important and commonly used as a predictor of asthma – used in secondary care/specialist community care. • Blood eosinophil – widely used, should include • Sputum eosinophil test– specialist asthma centres ONLY. • Exercise/cold air – mannitol a substitute for this. Set up for cold air isn't very common or practical? Exercise may be more useful/practical/pragmatic (paediatrician identified exercise challenge as a commonly used tool). How useful is it? In what patients? Done in different ways. • KEY ISSUES – 1) Early diagnosis (as early as possible); 2) Appropriate hierarchy of tests for “grey” cases; 3) Red flags for referral to secondary care.

challenge.

GROUP 2 NOTES

- Lots of tests missing including, CT scanning; cough monitoring (questionnaire), allergy-testing, skin-testing, oxygen saturation monitoring.
- Important to include tests that 'rule in' asthma.
- **The majority agreed that there was no need to include ALL, as guideline will become too large? They also agreed that it is important to keep 'reviewing' pt that they still have asthma, as diagnosis is difficult.**

GROUP 3 NOTES

- Triggers: Occupational historical features, animals in home environment. Sensitizers or allergens. Allergens e.g. (House dust mite)
- Setting: Initial Presentation separating by settings; could be for the first time in AE
- Historical features: History of hospitalisation features
- Specific diagnostic tests missing: -
 - Peripheral blood eosinophilia utility
 - Specific IgE
 - Skin prick/RAST testing
 - Eucapnic voluntary hyperventilation: ?Gold standard assessment tool for exercise induced asthma: Costly? Cost-implications? Could result in a change in practice

GROUP 4 NOTES

- Mechanisms of tests were highlighted as something that was not mentioned.
- Supervision of test procedures such as spirometry (as the gold standard) was also mentioned and should be a priority.
- Self monitoring which was not specifically mentioned was seen to be important.
- Exercise tests in children was also considered important.
- Exhaled nitric oxide is in use for monitoring whereas induced sputum was implicated in diagnosis more than monitoring.
- Steroid sensitive vs. steroid insensitive asthma would also be worth looking at and other people joined in saying that this was diagnosis rather than management related.
- Chest x-ray was also seen as an issue that should be covered (currently used in secondary and tertiary care).

	<ul style="list-style-type: none"> • Skin testing for atopy was also seen as missing. • Cold air challenge might be an issue that could be excluded. • Peak flow as a method of diagnosis was not seen as being routinely used.
<p>MONITORING <i>Patient-reported symptoms:</i> f) Assessment of asthma control using self / parental reports, such as symptom scores / diaries and validated asthma control questionnaires such as asthma control test (ACT), asthma control questionnaire-7 (ACQ-7), and RCP3. g) Use of tele-healthcare as a route of assessment <i>Lung function:</i> h) Assessments of asthma control using tests / measures, including PEF and lung function tests (eg spirometry) and bronchial reactivity/airway challenge (eg methacholine, histamine, adenosine, cold air, etc), <i>Airways inflammation:</i> i) Assessments of asthma control using tests / measures, including exhaled nitric oxide, and sputum eosinophilia.</p>	<p>GROUP 1 NOTES</p> <ul style="list-style-type: none"> • Adherence is integral to monitoring. Patients not keen to accept treatment as they feel diagnosis based on clinical history is not confirmed/based on hunch – patients prefer a conclusive test, however for asthma there isn't one. • Inhaler technique a key issue – asthma won't improve if patient not using correctly • Prescribing practice – monitor numbers of prescriptions? • Objective assessment of patient symptoms...asthma control list (ACT) is validated It is quick and easy to do. • Primary care – RCP 3 questions more commonly used • Tele healthcare – novel way of reporting to GP. Thought to be a big money saver, however it's a variable disease so could be a waste of time. • Monitor usage/prescription of specific drugs – number of short acting beta agonists/ single device long acting beta agonists. Might be a way of using routine data to identify patients most at risk of adverse outcomes/increased mortality. <p>GROUP 2 NOTES</p> <ul style="list-style-type: none"> • It was discussed that:- <ul style="list-style-type: none"> ○ A combination of monitoring techniques may be best. ○ Environmental assessment (e.g. damp homes for children, smoke, pets) should be considered – have diagnostic tests that can be done in relation to these. ○ Children's asthma control test (CACT) should be included – questionnaires are useful as something written down ensures correct questions are being asked. ○ Adherence and compliance should be included, i.e. adherence to medicine data useful. Data on prescription collections could also be important for monitoring. ○ Patient education/training: is this management? Important to include? ○ Inhaler technique essential as part of monitoring. But what is the clinical question we can ask? Are those patients who were taught how to use inhalers associated with better outcome than those not taught? BUT DO WE need to look at this in this guideline as it's a given? May be

	<p>important to include if focusing on primary care only.</p> <ul style="list-style-type: none"> ○ It is important to include patients of highest risks of hospital admission, death, etc. ie include ‘risk assessment’. ○ Education is part of intervention for monitoring and is part of self-management. ○ Assessment of co-morbidities, e.g. side-effects of drugs is done routinely with all diseases, so not to include. ○ Growth affected by steroids, therefore need to include height measurement – important in children? BUT, physicians will always measure height, so no need to include in guideline. ○ Long-term measure of lung function important as is a planned review. <p>GROUP 3 NOTES</p> <ul style="list-style-type: none"> ● Inhaler technique: Adherence, prescription pick up as outcome and a measure of monitoring. <p>GROUP 4 NOTES</p> <ul style="list-style-type: none"> ● Peak flow was seen as important in monitoring. ● Children's checklists were currently not directly mentioned such as C-ACT 4-11 and parent related symptoms. ● Current research in Edinburgh was also mentioned related to PROMs. ● Overuse and the incorrect use, adherence of inhalers was mentioned related to monitoring - also considering cost effectiveness. ● Pharmacists might be involved in monitoring, too (checking prescriptions). ● Asthma management plans were also mentioned as missing from the scope. ● Tele-healthcare might be less important than adherence and incorrect use of inhalers.
<p>4.3.2 Key clinical issues that will not be covered: a) Management of asthma.</p>	<p>GROUP NOTES</p> <ul style="list-style-type: none"> ● None of the four groups commented on this.
<p>4.4 Main outcomes a) Diagnostic test accuracy measures b) Frequencies of hospitalisations and / or ITU admissions c) Frequency of asthma attacks</p>	<p>GROUP 1 NOTES Missing outcomes included:-</p> <ul style="list-style-type: none"> ● Asthma deaths ● Time away from work/school

<p>d) Need for oral corticosteroids e) Health-related quality of life</p>	<p>GROUP 2 NOTES</p> <ul style="list-style-type: none"> • To consider adding the following outcomes:- <ul style="list-style-type: none"> ○ no. of days off school (important in monitoring) – but is this reported in papers? ○ death ○ unscheduled GP attendance (and out of hours) ○ use of beta-2 ○ asthma control <p>GROUP 3 NOTES</p> <p>Missing outcomes included:-</p> <ul style="list-style-type: none"> • Mortality/Asthma deaths • ‘Need for emergency treatment’ • Time of school/work • Hospitalisation • Prescription pick up • Measure of asthma control: RCP3, ACT (paeds) ? Need to note: (Language- Equalities) <p>GROUP 4 NOTES</p> <ul style="list-style-type: none"> • Asthma deaths was missing from the list. • ED admissions were also suggested. • Time off school and work on the list. • Need for oral corticosteroids was queried. • Stepping up and down also related to this and an important outcome. • Inhaler consumption as an outcome was also suggested by one group member. • Links from monitoring to management should be made and cross-reference to the BTS guideline should be made. Isle of Wight trial was mentioned, but also the focus on randomised controlled trials was queried. • Measuring children's growth as an outcome should be included.
<p>GDG composition</p>	<p>GROUP 1 NOTES</p> <p>To consider including:-</p> <ul style="list-style-type: none"> • GP commissioner or someone from a Clinical Commissioning Group

	<ul style="list-style-type: none"> • Pharmacist • Allergist (specifically Respiratory Allergist) • 2 x paediatricians (1 x paediatrician with interest in asthma and 1 x specialist asthma paediatrician) • Specialist respiratory nurse should be paediatric <p>GROUP 2 NOTES</p> <ul style="list-style-type: none"> • The group agreed with most of the composition, with the exception of the following points:- <ul style="list-style-type: none"> ○ To consider having 2 Specialist Respiratory Nurses; an adult and a paediatric one ○ To include Pharmacists, as currently lots of pharmacists are involved with monitoring, perhaps as a co-optee. ○ To include an Allergist, perhaps as a co-optee. <p>GROUP 3 NOTES</p> <p>To consider including:-</p> <ul style="list-style-type: none"> • Paediatric nurse specialist? • Pharmacist (as a Co-Optee?) • Respiratory Physiologist (as a Co-optee) • Occupational asthma specialist (as a co-optee?) <p>GROUP 4 NOTES</p> <p>To consider including:-</p> <ul style="list-style-type: none"> • Pharmacist • Paediatric / adult nurse specialist and two practice nurses. • One adult one parent representative
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The meeting was closed with an outline of the next steps and a reminder to attendees of the scope consultation dates and process, and that GDG recruitment would happen simultaneously. Further comments on the scope and applications for GDG membership were encouraged.