

Clinical Standards ~ *March 2007*

Asthma Services for Children and Young People

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Contents

| | | |
|----------|--|-----------|
| 1 | Background on NHS Quality Improvement Scotland | 2 |
| 2 | Development of NHS Quality Improvement Scotland standards | 3 |
| 3 | An introduction to asthma services for children and young people | 5 |
| 4 | Development of the clinical standards for asthma services for children and young people | 7 |
| 5 | Clinical standards for asthma services for children and young people | 11 |
| | Standard 1 Organisation of asthma care | 12 |
| | Standard 2 Healthcare professional training and education | 14 |
| | Standard 3 Schools | 15 |
| | Standard 4 Linking care | 16 |
| | Standard 5 High risk asthma groups | 17 |
| | Standard 6 Clinical review | 18 |
| | Standard 7 Emergency care | 19 |
| 6 | Appendices | 21 |
| | Appendix 1 Membership of the clinical standards for asthma services for children and young people project group | 22 |
| | Appendix 2 Evidence base | 23 |
| | Appendix 3 Glossary | 26 |
| | Appendix 4 List of useful websites | 30 |
| | Appendix 5 Diagnosis of asthma in children | 31 |

1 Background on NHS Quality Improvement Scotland

NHS Quality Improvement Scotland (NHS QIS) was set up by the Scottish Parliament in 2003 to take the lead in improving the quality of care and treatment delivered by NHSScotland.

We achieve our objectives through five key functions that link together:

- providing clear advice and guidance on effective clinical practice
- setting clinical and non-clinical standards of care
- reviewing and monitoring the performance of NHS services
- supporting NHS staff in improving services, and
- promoting patient safety and implementation of clinical governance.

We deliver our commitments to the public and to NHSScotland by following an approach that is:

- **independent** – we reach our own conclusions and report on what we find
- **open and transparent** – we explain what we do, how and why we do it, and what we find, using language and formats that are easy to understand and to access
- **sensitive and professional** – we recognise needs, beliefs and opinions and respect and encourage diversity.

Our work is:

- **partnership-focused** – we work with patients and the public, NHSScotland and many organisations to improve the quality of care and avoid duplication
- **evidence-based** – we base our conclusions and recommendations on the best evidence available
- **quality-driven** – we make sure our own work is monitored and evaluated, internally and externally.

2 Development of NHS Quality Improvement Scotland standards

Basic principles

A major part of our remit is to develop and run a national system of quality assurance of clinical services. Working in partnership with healthcare professionals and members of the public, we set standards for clinical services, assess performance throughout NHSScotland against these standards, and publish the findings. The standards are based on the patient's journey as he or she moves through different parts of the health service. A wide range of conditions and services have already been addressed, including blood transfusion and cancer services.

In fulfilling our responsibility to develop and run a system of quality assurance, we take account of the principles set out in *Fair for All* and *Partnership for Care*, to ensure that 'our health services recognise and respond sensitively to the individual needs, background and circumstances of people's lives'.

We will ensure that consideration of equality and diversity issues feature prominently in the design, development and delivery of all our functions and policies.

The standards are developed in accordance with the commitments of the National Health Service Reform (Scotland) Act 2004 which state that 'individual patients receive the service they need in the way most appropriate to their personal circumstances and all policy and service developments are shown not to disadvantage any of the people they serve'.

Process

For each set of standards we develop, we appoint a group representing a range of stakeholders, including healthcare professionals and members of the public, to:

- oversee the development of, and consultation on, the standards and self-assessment framework, and
- recommend an external peer review process.

The way in which standards are developed is a key element of the quality assurance process. Project groups working on behalf of NHS QIS are expected to:

- adopt an open and inclusive process involving members of the public, voluntary organisations and healthcare professionals
- work within NHS QIS policies and procedures, and
- test the measurability of draft standards by undertaking pilot reviews.

The standards are clear and measurable, based on appropriate evidence, and written to take into account other recognised standards and clinical guidelines. The standards are:

- written in simple language and available in a variety of formats
- focused on clinical issues and include non-clinical factors that impact on the quality of care
- developed by healthcare professionals and members of the public, and consulted on widely
- regularly reviewed and revised to make sure they remain relevant and up to date, and
- achievable but stretching.

Format of standards and definition of terminology

All our standards follow the same format.

- Each standard has a **title**, which summarises the area on which that standard focuses.
- This is followed by the **standard statement**, which explains the level of performance to be achieved.
- The **rationale** section provides the reasons why the standard is considered to be important.
- The standard statement is expanded in the section headed **criteria**, which states exactly what must be achieved for the standard to be reached. Criteria are **essential**, in that it is expected that they will be met wherever a service is provided. Other criteria are **desirable**, in that they are being met in some parts of the service and demonstrate levels of quality, which other providers of a similar service should strive to achieve. The criteria are numbered for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority.

Clinical governance and risk management standards

Every patient using healthcare services should expect these to be safe and effective. The NHS QIS standards for clinical governance and risk management will ensure NHS boards can provide assurance that clinical governance and risk management arrangements are in place, and are supporting the delivery of safe, effective, patient-focused care and services.

The clinical governance and risk management standards underpin all care and services delivered by NHSScotland and provide the context within which NHS QIS service and condition-specific standards apply. They should be read in conjunction with all our standards.

The clinical governance and risk management standards are available on request from NHS QIS or can be downloaded from the website (www.nhshealthquality.org).

Assessment of performance against the standards

The framework for the NHS QIS review process is as follows.

- Once the standards have been finalised, each relevant NHS board/service is asked to undertake a self-assessment of its service against the standards.
- A review team visits the NHS board/service on behalf of NHS QIS to follow up this self-assessment exercise with an external peer review of performance in relation to the standards.
- NHS QIS reports the findings for the NHS board/service, based on the self-assessment exercise and on the external peer review.

Our processes are subject to internal and external evaluation, to help improve the quality assurance system.

3 An introduction to asthma services for children and young people

In August 2003, NHS QIS established a children's health services steering group. The remit of this group was to consider the work of NHS QIS and other organisations, and to scope the area of children's health services generally. Furthermore, the group was to produce recommendations as to how NHS QIS could best support services which would improve the quality of care for children, young people and their families¹.

This work was completed in the context of the strategic direction set by the Scottish Executive Health Department (SEHD). In light of this, the group made recommendations on work that could be carried out during the development of the strategic framework. One of those recommendations was the development of standards for the management of long-term conditions in childhood. Asthma requires a co-ordinated approach across primary, secondary and specialist healthcare, and was selected as the exemplar condition.

Definition of children and young people

The Children (Scotland) Act 1995² defines a child or young person as being under the age of 18 years old. It is recommended by the Scottish Executive in Building a Health Service Fit for the Future³ that the age limit for admitting children and young people to acute care in paediatric facilities is up to their 16th birthday, with additional flexibility and choice for young people between the ages of 16 and 18 years. It is important to recognise that it is the developmental stage of a young person and not just their age which should be considered when identifying the most appropriate care environment.

Introduction to asthma

In the UK, asthma is the most common long-term respiratory condition in childhood and affects one in eight children⁴. There is evidence that the prevalence of childhood asthma has increased over the past two decades. Respiratory disease was reported to be the most frequent cause for children to consult a GP, with diagnosed asthma accounting for 15% of consultations for respiratory disease and 5% of all consultations⁴. Asthma is the most common cause of emergency hospital admission in childhood, and the rates are particularly high in children under the age of five⁵.

Symptoms of asthma

Asthma is a condition that affects the airways – the small tubes that carry air in and out of the lungs. Children and young people who have asthma usually have inflamed airways. These airways can become narrowed and airflow is limited when airways are exposed to various risk factors. Common risk factors in childhood asthma include respiratory viral infections, exercise, tobacco smoke and exposure to allergens, such as dog and cat hair.

The usual symptoms of asthma are:

- wheezing
- difficulty breathing
- chest tightness, and
- coughing, particularly at night or in the early morning.

Asthma severity can vary. It can be mild, moderate or severe. The symptoms of asthma can be physically and psychologically disabling and have a considerable impact on quality of life. Severity varies amongst individuals and can change in one individual over time.

Diagnosis of asthma in children

Diagnosis in young children can be difficult. The diagnosis of asthma is based on the presence of key features in the child's history and careful consideration of alternative diagnoses (see Appendix 5)⁶.

Repeated reassessment of the child and their response to treatment is important in confirming the diagnosis of asthma.

Treatment of asthma

Although there is no cure for asthma, symptoms can be controlled. With the right treatment and care, there is no reason why most children and young people with asthma cannot enjoy a healthy and active life.

Many children and young people have to take medication daily to control symptoms and to prevent attacks. Children and young people with mild to moderate asthma use a preventer inhaler on a regular basis and a reliever inhaler as and when they experience difficulty breathing, persistent coughing and/or wheeze. The preventer treatment can only have an impact if taken on a regular basis. If the treatment is stopped the underlying inflammation in the airways, which causes the symptoms, will return. Children and young people may be prescribed a short course of steroid tablets at the time of a bad asthma attack.

Management of asthma in children and young people

The management of a child's asthma takes place mainly in the community. Children and young people with asthma and their parents/carers/families require the support and co-operation of both healthcare professionals, such as the GP, practice nurse, hospital specialist, pharmacist, physiotherapist and school nurse, and non-healthcare professionals, including nursery staff, school teachers and other care workers. Communication between all these individuals is essential in order to provide optimum care for a child or young person with asthma.

4 Development of the clinical standards for asthma services for children and young people

In October 2004, Dr Kate McKay, Consultant Paediatrician and Clinical Director, Community Paediatrics, NHS Greater Glasgow and Clyde, joined the standards development team as clinical advisor to the asthma services for children and young people project and undertook a detailed scoping exercise over a 6-month period. The primary purpose of the scoping exercise was to review current evidence relating to asthma services for children and young people, and use clinical knowledge and expertise to provide clear direction over which areas standards should be set, ensuring appropriate links with policy and other relevant work. The exercise included the review of a number of user surveys of patient and carer experiences, as well as existing guidelines and standards.

In June 2005, NHS QIS established a project group, with a remit to develop a set of national standards and an accompanying self-assessment framework for asthma services for children and young people. The group, chaired by Dr John Haughney, General Practitioner, NHS Lanarkshire, consists of a variety of healthcare professionals who are involved in the care of children and young people with asthma, parent representatives and representatives from both Asthma UK Scotland and the British Lung Foundation (Scotland). The group's full membership can be found in Appendix 1. The group considered the findings of the scoping exercise, along with a number of other issues relating to children and young people with asthma and their parents/carers/families, and identified the following seven critical areas for clinical standards:

- organisation of asthma care
- healthcare professional training and education
- schools
- linking care
- high risk asthma groups
- clinical review, and
- emergency care.

External consultation with children, young people and parents

The group agreed that, following the production of draft standards, there should be a full consultation with children and young people, who have asthma, and parents. NHS QIS commissioned Asthma UK Scotland and Children in Scotland to take forward this piece of work. The information collected has been a significant driver for the content of these standards. The children, young people and parents involved in the consultation process were also asked for their views on the format of the final clinical standards to ensure that they are accessible.

Your Asthma Services Tell Us What You Think: Report of Consultation with Children, Young People and Parents⁷ was produced in May 2006. The key points from participants in the consultation process were detailed as follows.

Key points: Children and young people

- Having well-controlled asthma is important to children and young people.
- Children and young people want good services that are designed around their needs.
- Children and young people want professionals to respect them, talk to them and listen to them.
- Waiting times are a major problem, particularly in terms of emergency care.
- Children and young people want local paediatric asthma services.
- Lack of teacher training and education about asthma is a problem.
- Having consistent, good practice policies in place in school, that enable children and young people to carry their inhaler with them at all times, is central to asthma care at school.
- Children and young people would welcome an increase in information provision about asthma.
- Children and young people suggested posters as the preferred method to receive the clinical standards.

Key points: Parents

- Parents expressed the need for a supportive network between parents that links into a formal partnership with providers of paediatric asthma care.
- Parents would like their experience and expertise to be taken seriously by healthcare professionals as partners in care and as service-users.
- Parents considered that a central database would increase communication between healthcare professionals leading to the delivery of a higher standard of care.
- Healthcare professionals require training in interpersonal skills to help them communicate effectively with children. They should be able to explain asthma treatment and education to children and parents.
- Parents would like asthma policies to be consistent and transparent within schools. They would like communication between healthcare professionals and school staff to be well organised and consistent.
- Parents would like school staff to be educated about asthma.
- Parents would like the transition from child to adult services to be less stressful. This requires both services to overlap prior to a young person being moved to adult services.
- For parents living in a rural and remote area, poor access and availability of local services is a barrier to receiving standardised care.
- Parents think that the needs of children who may be at risk of poorly controlled or acute severe asthma should be monitored and targeted by direct provision of services at a local level.
- Parents want access to information about local asthma services and asthma education at the time of diagnosis.
- Parents would like everyone diagnosed with asthma to have access to a paediatrician either at time of diagnosis or at a later stage.
- Parents would like easier access to emergency care within primary care and consistent protocols for emergency care across primary and secondary care.
- Parents would like to feel that healthcare professionals are taking their child's asthma seriously when their child is experiencing an exacerbation.
- Parents would prefer the clinical standards to be brief and concise, in a paper-based form with language that is easy to understand and no health service jargon.

The asthma services for children and young people project group would like to thank all the children, young people and parents, who took part in the consultation events, for their time and input.

5 Clinical standards for asthma services for children and young people

Standard 1 Organisation of asthma care

Standard 2 Healthcare professional training and education

Standard 3 Schools

Standard 4 Linking care

Standard 5 High risk asthma groups

Standard 6 Clinical review

Standard 7 Emergency care

Standard 1: Organisation of asthma care

Standard Statement 1a

There are formal partnerships established with all local providers of asthma care for children and young people to determine local service provision and develop consistent protocols for care and advice.

Rationale

Multi-agency co-operation and joint working is required to plan, design, commission and deliver high quality integrated services for all children.

Improvements in the health of children and young people can only be achieved by professionals and agencies working in partnership with one another and with children, young people and their parents/carers/families.

References: 8, 9

Essential Criteria

- 1a.1 There is an established multidisciplinary group at NHS board level to oversee asthma services for children and young people, which meets at least annually and includes representatives from primary, secondary, emergency, tertiary care (where appropriate), and children and young people or their representatives.
- 1a.2 The group is responsible for ensuring that there is a protocol in place covering diagnosis, treatment and care, reporting arrangements and accountability, which is disseminated across the NHS board.
- 1a.3 Minimum agenda items for the group to discuss on an annual basis include:
 - the number of children and young people with a recorded diagnosis of asthma
 - mortality rates of children and young people due to asthma
 - the number of children and young people in the NHS board area who are admitted to intensive care unit (ICU), high dependency unit (HDU) or paediatric intensive care unit (PICU) due to asthma
 - the number of children and young people who have more than one emergency hospital admission due to asthma
 - the number of children and young people who have three or more attendances at a department of emergency medicine or out-of-hours services due to asthma
 - the number of children and young people who have more than three unscheduled healthcare contacts with a GP due to asthma
 - the number of children and young people who are prescribed inhaled steroids at doses higher than those recommended in the product licence, and
 - a needs assessment of asthma training and education.
- 1a.4 The group publishes minutes of meeting(s), which include the minimum agenda items.

Standard Statement 1b

There are electronic systems in place to record core information about the care of all children and young people with a diagnosis of asthma for use in direct patient care and service audit.

Rationale

Information systems need to facilitate seamless packages of care which include not only specialist hospital care, but also the patient's outpatient care and their primary care and community-based needs.

Evidence suggests that guidelines alone do not affect clinical practice. Feedback based on audit is useful, both as part of an implementation strategy and for longer term positive influence on practice.

Data collection and audit facilitate effective healthcare since outcomes can be monitored and lead, where necessary, to improvements in the quality of treatment and care.

Computerisation allows for quick and accurate review, targeting and audit.

References: 6, 8, 10

Essential Criteria

- 1b.1 There are up-to-date electronic records of all children and young people with a diagnosis of asthma.
- 1b.2 There is a system in place to collate the total number of children and young people with a recorded diagnosis of asthma.

Standard 2: Healthcare professional training and education

Standard Statement 2a

Children and young people with asthma and their parents/carers/families have contact with healthcare professionals who have received appropriate training and ongoing education in paediatric asthma care.

Rationale

Minimum standards can be reproduced more consistently through the use of appropriate training.

Services delivered by healthcare professionals trained in asthma management improve diagnosis, prescribing, education, monitoring, and continuity of care for children and young people with asthma.

References: 6, 11

Essential Criterion

- 2a.1 The NHS board has undertaken a needs assessment of training and education for all healthcare professionals involved in paediatric asthma care and implemented appropriate training and education programmes.

Standard 3: Schools

Standard Statement 3a

There are clear and effective partnership arrangements in place between the NHS board and the local authorities for the management of children and young people with asthma within the primary and secondary school setting.

Rationale

Co-operation between schools, parents/carers/families, healthcare professionals and other agencies is crucial to provide a suitably supportive environment for pupils with healthcare needs to enable them to participate fully in all educational activities.

The National Health Service (Scotland) Act 1978 states that NHS boards have a statutory responsibility for the medical inspection, supervision and treatment of pupils in schools, and local authorities have a responsibility to help them to discharge their duty.

The Children (Scotland) Act 1995 refers to Children's Services Plans as a means for ensuring that there are partnership arrangements between NHS boards and local authorities.

The Scottish Executive asked NHS boards and local authorities to draw together their existing planning for children and young people into a single Integrated Children's Services Plan which describes local improvement objectives and delivery strategies across universal and targeted services for children and young people.

MEL(1996)71 and the report, Health Services in Schools: A Report of Policy Review, make it clear that there should be a joint agreement between NHS boards and local authorities covering a range of issues including the administration of medicines in schools.

The Education (Additional Support for Learning) (Scotland) Act 2004 states that agencies such as health, social work services and others, are expected to be involved, where necessary, in providing education authorities, when requested, with advice and information including reports and formal assessments to help them identify a child or young person's additional support needs and requirement for a co-ordinated support plan.

References: 2, 12, 13, 14, 15

Essential Criterion

- 3a.1 There is an agreed joint policy in place between the NHS board and local authorities, which guides, monitors and improves the management of asthma within the primary and secondary school setting.

Desirable Criterion

- 3a.2 All children and young people with asthma within the primary and secondary school setting have an individual healthcare plan, as appropriate to their needs.

Standard 4: Linking care

Standard Statement 4a

There are effective referral systems in place to ensure the smooth transition of children and young people with asthma moving between primary care and specialist services and from paediatric asthma care to secondary care adult respiratory services.

Rationale

There is some evidence that properly planned transition programmes result in better disease control and improved patient satisfaction.

Clear referral criteria and pathways facilitate access to suitable healthcare services, and early diagnosis and treatment can reduce levels of morbidity.

Prompt referral, assessment and treatment result in increased user and carer satisfaction with services.

Delays in referral, assessment and treatment can adversely affect a patient's condition and wellbeing.

References: 16, 17

Essential Criteria

- 4a.1 There is an agreed, written local protocol in place for shared care, referral and discharge between primary care and specialist services, which is jointly reviewed at least annually.
- 4a.2 When a child is transferred to secondary care adult respiratory services, their paediatric asthma consultant provides a written handover summary to a named secondary care adult respiratory consultant, the patient's GP and the patient.

Standard 5: High risk asthma groups

Standard Statement 5a

There is an agreed NHS board-wide system in place to identify and manage the needs of children and young people who may be at high risk of poorly controlled or acute severe asthma.

Rationale

A register of children and young people at risk of acute deterioration may help primary care healthcare professionals to identify children and young people who are more at risk of death from their asthma.

The safety of inhaled steroids needs consideration. The balance between benefits and risk for each child or young person needs to be assessed.

Children and young people with severe or poorly controlled asthma are at a higher risk of developing fatal or near fatal episodes.

Recognising children and young people at risk of life-threatening asthma should lead to appropriate targeting of care.

Recurring attendance of children and young people for emergency care or advice may indicate particular vulnerability. Therefore all emergency sites must be able to identify recurring attendance.

References: 6, 18, 19, 20, 21, 22

Essential Criteria

- 5a.1 There is a system in place to identify and manage children and young people with asthma who have more than one emergency hospital admission within a year.
- 5a.2 There is a system in place to identify the number of children and young people with asthma in the NHS board area who are admitted to HDU, ICU and PICU within a year.
- 5a.3* There is a system in place to identify and manage children and young people with asthma who have had three or more attendances at a department of emergency medicine or out-of-hours services within a year.
- 5a.4* There is a system in place to identify and manage children and young people with asthma who have had three or more unscheduled healthcare contacts with a GP within a year.
- 5a.5 There is a system in place to identify and manage children and young people prescribed inhaled steroids at doses higher than those recommended in the product licence.

* For the purpose of these criteria, the number of attendances chosen is based on the expert clinical consensus of the project group.

Standard 6: Clinical review

Standard Statement 6a

All children and young people with a diagnosis of asthma are offered an annual review, or more frequent examination where clinically indicated, to monitor the management and progression of their condition.

Rationale

General practices need to maintain a list of children and young people known to have asthma in order to offer each child or young person a regular, structured clinical review.

Proactive structured review, as opposed to opportunistic or unscheduled review, is associated with reduced exacerbation rates and days lost from normal activity.

Reference: 6

Essential Criterion

- 6a.1 There is a protocol in place, which specifies that all children and young people with a diagnosis of asthma are offered the following at annual clinical review:
- assessment using a structured assessment tool
 - review of any emergency or unscheduled asthma care
 - discussion of asthma symptoms, triggers and treatments, peak flow, if appropriate, and particular action to be taken in case of an emergency (eg asthma action plan)
 - review of treatment/medication
 - consideration of steroid dosage
 - an accurate height measurement
 - assessment of ability to use medication device/inhaler technique
 - assessment of their understanding of asthma and its treatment. (Parents/carers/families may also be assessed, where appropriate.)
 - consideration of immunisation, and
 - health education on smoking, diet and exercise.

Standard 7: Emergency care

Standard Statement 7a

All children and young people with an acute asthma emergency are managed according to a written local protocol, which is based on national guidelines.

Rationale

The acute complications of asthma can cause distress, disability or death. Appropriate initial management can improve outcome from the event and subsequent management may prevent readmission with similar problems.

The effective medical care of children and young people who present with an acute illness requires the provision of services which ensure timely, high quality assessment, diagnosis and treatment.

In order to maximise clinical outcomes, it is important to identify optimal care processes and treatment, using evidence-based practice where possible. This ensures that children and young people receive a consistent high quality of emergency care wherever they are seen.

References: 6, 16, 20

Essential Criteria

- 7a.1 There is a written local protocol in place, based on national guidelines, for children and young people with an acute asthma emergency, which specifies:
- acute asthma management
 - asthma education to be provided
 - treatment following discharge, and
 - communication with the patient's GP or asthma nurse regarding follow-up care, which should be arranged as soon as possible.
- 7a.2 The acute asthma emergency protocol is in use for individual patient management in all healthcare settings where emergency care for children and young people is provided.

6 Appendices

Appendix 1 Membership of the clinical standards for asthma services for children and young people project group

Appendix 2 Evidence base

Appendix 3 Glossary

Appendix 4 List of useful websites

Appendix 5 Diagnosis of asthma in children

Appendix 1: Membership of the clinical standards for asthma services for children and young people project group

| Name | Title | NHS board area/ Organisation |
|--|---|--|
| Dr John Haughney (Chair) | General Practitioner and Research Fellow | NHS Lanarkshire/ University of Aberdeen |
| Dr Ian Bashford | Senior Medical Officer – Advisor in Child and Maternal Health | Scottish Executive Health Department |
| Mrs Elaine Carnegie (from February 2006) | Policy Officer | Asthma UK Scotland |
| Mrs Betsy Craig | Public Health Nurse (Schools) | NHS Forth Valley |
| Dr Anne Devenny | Consultant in Paediatric Respiratory Medicine | NHS Greater Glasgow and Clyde |
| Dr Kate McKay (NHS QIS Clinical Advisor) | Consultant Paediatrician and Clinical Director | NHS Greater Glasgow and Clyde |
| Mrs Mary Malarkey | Parent Representative | |
| Dr Patricia O'Connor | Consultant in Emergency Medicine | NHS Lanarkshire |
| Ms Cathy Orr | Child Health Commissioner | NHS Lothian |
| Dr James Paton | Reader in Paediatric Respiratory Disease | NHS Greater Glasgow and Clyde |
| Mr Andrew Powrie-Smith | Head of British Lung Foundation (Scotland) | British Lung Foundation (Scotland) |
| Dr Iain Small | General Practitioner | NHS Grampian |
| Mr James Wallace | Director of Pharmacy | NHS Greater Glasgow and Clyde |
| Ms Elizabeth Watson | Professional Lead Nurse - Health Visiting and School Nursing | NHS Highland |

Support from NHS QIS is provided by the Standards Development Unit: Mr Moray Baylis (Project Administrator to October 2006); Ms Hilary Davison (Team Manager); Miss Stacey Macindoe (Project Officer); and Miss Joanne Storrar (Senior Project Officer to December 2006).

Appendix 2: Evidence base

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Appendix 3: Glossary

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| accountability | Answerability. Responsibility to someone for an activity or service performed. |
| acute | Describes a disease or infection of rapid onset, severe symptoms and brief duration. |
| acute asthma emergency | A sudden asthma attack which is potentially life-threatening. |
| acute care | A pattern of healthcare in which a patient is treated for an acute (immediate and severe) episode of illness, for the subsequent treatment of injuries related to an accident or other trauma, or during recovery from surgery. Acute care is usually given in a hospital by specialised personnel using complex and sophisticated technical equipment and materials. Acute care is often necessary for only a short period of time. |
| acute sector | Hospital-based health services which are provided on an inpatient or outpatient basis. |
| assessment | The process of measuring patients' needs or the quality of an activity, service or organisation. |
| asthma | A long-term lung disease caused by inflammation of the airway. |
| asthma action plan | A plan agreed with the individual patient and held by them, which sets out how they can manage their asthma and what to do if it becomes more severe, or acute. |
| asthma nurse | A nurse whose specialised area is treating asthma. Sometimes employed in a doctor's surgery and may run specialist asthma clinics. |
| audit | Systematic review of the procedures used for diagnosis, care, treatment, rehabilitation, examining how associated resources are used and investigating the effect care has on the outcome and quality of life for the patient. |
| clinical effectiveness | The extent to which specific clinical interventions, when deployed, do what they are intended to do, ie maintain and improve health, securing the greatest possible health gain from the available resources. |
| clinical governance | The system through which NHS organisations are accountable for continuously monitoring and improving the quality of their care and services, and safeguarding high standards of care and services. |
| clinical guidelines | Systematically developed statements, which help in deciding how to treat particular conditions. |
| co-ordinated support plan | An educational plan for a child or young person who has additional support needs arising from one or more complex, or multiple factors. Such a plan may be required when those needs are likely to continue for more than one year and require significant additional support to be provided by the education authority or by one or more appropriate agencies. |
| diagnosis | Identification of an illness or health problem by means of its signs and symptoms. This involves ruling out other illnesses and possible causes for the symptoms. |
| evaluation | The study of the performance of a service (or element of treatment and care) with the aim of identifying successful and problem areas of activity. |
| guidelines (non-clinical) | A document which presents operational good practice in a way that can guide day-to-day activities within an organisation. |

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| healthcare plan | A document drawn up by healthcare professionals which details the action required to promote the optimal physical, emotional and psychological health and development of the child or young person. |
| healthcare professional | A person qualified in a health discipline. |
| immunisation | An artificial way of creating protection against certain infections, by using relatively harmless antigens that come from, or are similar to the micro-organisms that cause the diseases. |
| individual healthcare plan | A healthcare plan tailored to the needs of a child or young person, whilst in a school setting, which has been agreed between the school health services, the child or young person and their parents/carers. |
| inhaler | A portable device for administering medicine through drawing it in by breathing. |
| monitoring | The systematic process of collecting information on the performance of clinical or non-clinical activities, actions or systems. Monitoring may be intermittent or continuous. It may also be undertaken in relation to specific incidents of concern or to check key performance areas. |
| morbidity | How much ill health a particular condition causes. |
| multidisciplinary | An approach combining the knowledge, skills and expertise of a range of organisations and professionals. |
| national guidelines | Guidelines defined at national level. See guidelines (non-clinical) and clinical guidelines. |
| NHS board | There are 22 NHS boards of two types: 14 territorial boards responsible for healthcare in their areas and eight special boards, which offer supporting services nationally. |
| NHS board (territorial) | There are 14 territorial boards, the mainland being covered by 11 and the island groups (Orkney, Shetland and the Western Isles) by three. They are responsible and accountable for strategic planning, service delivery, performance management and governance within their local areas. |
| outcome | The end result of care and treatment and/or rehabilitation. In other words, the change in health, functional ability, symptoms or situation of a person, which can be used to measure the effectiveness of care and treatment, and/or rehabilitation. |
| paediatric | Relating to the care and medical treatment of children and young people. |
| paediatric specialist services | Within healthcare services there are staff trained to meet the special requirements of children. |
| peak expiratory flow rate (PEFR) | The maximum rate that air is expired from the lungs when blowing into a peak flow meter or a spirometer. The rate is given in the form of litres per minute. |
| peer review | Review of a service by those with expertise and experience in that service, either as a provider, user or carer, but who are not involved in its provision in the area under review. In the NHS QIS approach, all members of a review team are equal. |
| policy | The highest level statement of intent and objectives within an organisation. A policy can also be a required process or procedure within an organisation. |
| preventer | Medication taken regularly which stops symptoms developing. |

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| primary care | The conventional first point of contact between a patient and the NHS. This is the part of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS. Primary care encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners. |
| procedure | Operational instructions to regulate activity. |
| protocol | Operational instructions to regulate activity. Protocols may be national, or agreed locally to take into account local requirements. |
| quality assurance (QA) | Improving performance and preventing problems through planned and systematic activities including documentation, training and review. |
| rationale | Scientific/objective reason for taking specific action. |
| referral | The process by which a patient is transferred from one professional to another, usually for specialist advice and/or treatment. |
| referral pathway | How a patient is assessed by a healthcare professional and the steps which follow if they are identified as needing specialised examination and treatment. A referral pathway should be set out in a formal document. |
| review | Examine or assess (something) formally with the possibility or intention of instituting change if necessary. |
| risk management | Systematic approach to the management of risk, staff and patient/client/user safety, to reducing loss of life, financial loss, loss of staff availability, loss of availability of buildings or equipment, or loss of reputation. Risk management involves identifying, assessing, controlling, monitoring, reviewing and auditing risk. |
| Royal College of Paediatrics and Child Health (RCPCH) | The professional and advisory body overseeing education and qualifications of paediatricians. Website address: www.rcpch.ac.uk |
| scoping exercise | Before a project can begin, its purpose and targets need to be agreed. This also means looking in an organised way at the range and depth of work to be undertaken, planning, assessment of risks, and the resources and expertise required. |
| Scottish Executive | The devolved government for Scotland. |
| Scottish Executive Health Department (SEHD) | The Scottish Executive Health Department is responsible for health policy and the administration of NHSScotland. Website address: www.show.scot.nhs.uk/sehd |
| Scottish Intercollegiate Guidelines Network (SIGN) | To help improve the quality of healthcare, SIGN develops national clinical guidelines aimed at reducing variations in clinical practice and in outcomes for patients. Founded in 1993 by the Academy of Royal Colleges and Faculties in Scotland, SIGN became part of the national clinical effectiveness body, NHS QIS, on 1 January 2005. The evidence base for many of the clinical standards developed by NHS QIS has been drawn from SIGN guidelines. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Secretariat, 28 Thistle Street, Edinburgh, EH2 1EN. Website address: www.sign.ac.uk |
| secondary care | Care provided in an acute sector setting. See acute sector. |
| secondary care adult respiratory services | Hospital-based adult specialist respiratory services for patients with asthma, which are provided on an inpatient or outpatient basis. |

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| self-assessment | Assessment of performance against standards by the individual/ clinical team/NHS operating division/NHS board providing the service to which the standards are related. See assessment. |
| shared care | Care of a service user shared between primary and secondary care services. |
| steroid | Medication that reduces swelling and inflammation available in pill, cream and inhaled forms. |
| tertiary care | Specialised care, usually on referral from primary or secondary medical care personnel, by specialists working in a centre that has the personnel and facilities for special investigation and treatment. |
| transition | Moving or preparing to move from one service to another, eg paediatric to adult services. |

Appendix 4: List of useful websites

1 <http://www.asthma.org.uk>

Asthma UK is the charity dedicated to improving the health and wellbeing of people with asthma. This is a comprehensive online resource for all people in the UK whose lives are affected by asthma.

2 <http://www.lunguk.org/asthma.asp?chi=3>

This is a useful link to the British Lung Foundation information about children and young people with asthma.

3 <http://www.sign.ac.uk/pdf/sign63.pdf>

A British guideline on the management of asthma in both primary and secondary care, which was developed jointly by the Scottish Intercollegiate Guidelines Network (SIGN) and the British Thoracic Society (BTS).

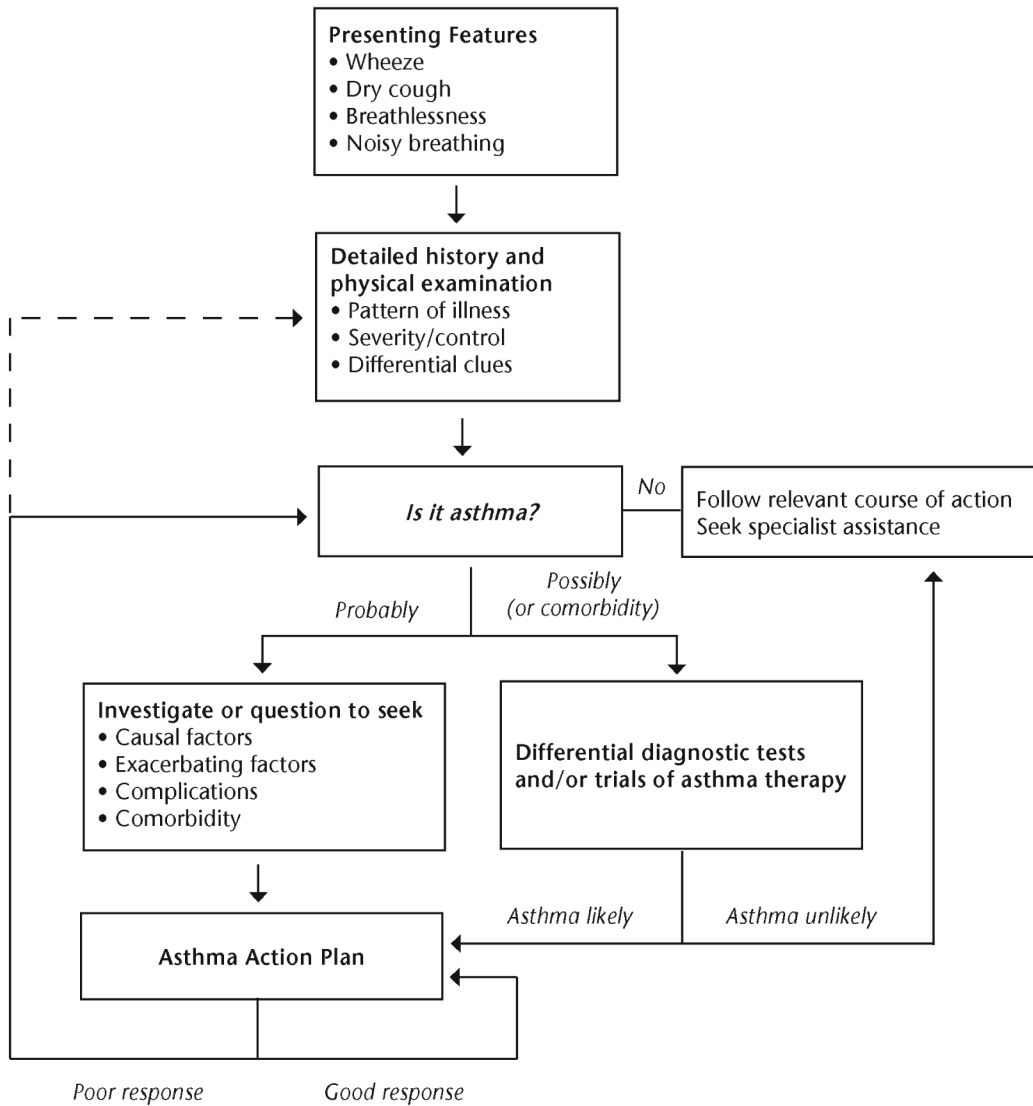
4 <http://www.nice.org.uk>

This is a useful link for both healthcare professionals and patients, providing guidance on inhalers for childhood asthma. The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance in England and Wales on the promotion of good healthcare and the prevention and treatment of ill health.

5 <http://www.ginasthma.org>

The Global Initiative for Asthma (GINA) is a collaboration of the National Heart, Lung, and Blood Institute, National Institutes of Health, USA, and the World Health Organisation. GINA works with healthcare professionals and public health officials around the world to reduce asthma prevalence, morbidity and mortality.

Appendix 5: Diagnosis of asthma in children⁶



Appendix 5: Diagnosis of asthma in children (continued)⁶

Indications for referral for specialist opinion/further investigation

- Diagnosis unclear or in doubt
- Symptoms present from birth or perinatal lung problem
- Excessive vomiting or possetting
- Severe upper respiratory tract infection
- Persistent wet cough
- Family history of unusual chest disease
- Failure to thrive
- Unexpected clinical findings
eg focal signs in the chest, abnormal voice or cry, dysphagia, inspiratory stridor
- Failure to respond to conventional treatment
(particularly inhaled corticosteroids above 400 µg/day or frequent use of steroid tablets)
- Parental anxiety or need for reassurance

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We can also provide this information:

- by email
- in large print
- on audio tape or CD
- in Braille, and
- in community languages.

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