

FOREWORD

The Government consultation document "A First Class Service - Quality in the new NHS", published in 1998, emphasised three essential aspects of ensuring delivery of high quality of care by the National Health Service: setting, delivering and monitoring standards. It also discussed the importance of partnership between the Government and the clinical professions and patients in achieving such quality.

This series of 10 reports concerns the third aspect - monitoring standards. It represents the culmination of work that was started several years ago under the auspices of the Clinical Outcomes Group, chaired jointly by the then Chief Medical Officer, Sir Kenneth Calman, and the Chief Nursing Officer, Dame Yvonne Moores. The work was commissioned by the former Central Health Outcomes Unit of the Department of Health. The Unit has since moved and is now called the National Centre for Health Outcomes Development (NCHOD), based jointly at the Institute of Health Sciences, University of Oxford and the London School of Hygiene and Tropical Medicine, University of London.

The background to the work was the need to ensure that the NHS is driven by considerations of quality and outcome. The Department wanted to build on an earlier set of Population Health Outcome indicators, which had been limited by the constraints of existing routine data. It therefore commissioned systematic work on ten clinical topics, to be undertaken by a Working Group on each, tasked to make recommendations on 'ideal indicators' for each condition. 'Ideal indicators' were defined as statistical measures of what should be known, and realistically could be known, about the outcomes of the condition in routine clinical practice. The Groups were asked to consider a wide spectrum of possible uses of outcome indicators, from national monitoring of NHS performance by government to the periodic assessment of local services by clinicians and users.

The work of the Working Groups was coordinated by Michael Goldacre, University of Oxford. A particular feature of the work is that the Groups have recommended definitions and technical specifications for each indicator. It is hoped that people interested in monitoring the topic covered by each indicator will use the same definitions so that comparisons can be facilitated. Moreover, the methodology adopted by the Working Groups is applicable to developing health outcome indicators for many other conditions.

The publication of these reports, however, is only one further step on a long road of quality assessment in health care. The reports present 'menus' of suggestions for ways in which outcomes might be monitored in a variety of settings, by a variety of organisations and people. It goes without saying that NCHOD will welcome feedback on the reports and on the development and use of outcome indicators.

I believe that the work described here shows the value and potential of partnerships between various parties. Each working group had members who brought together perspectives of all the relevant clinical professions plus patients, NHS managers, policy makers, researchers and others as appropriate. The recommendations of the Working groups show quite clearly how these various perspectives may contribute to a broader and more balanced monitoring of standards. I would personally like to congratulate and thank everyone who has worked so hard and well to bring this initiative to fruition.

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OUTCOME INDICATORS FOR ASTHMA

CONTENTS OF REPORT	Page
Summary of recommendations	1
Sections:	
1. Background to the work	3
2. Health outcome model for asthma	9
3. Methods for choosing candidate indicators	17
4. Choice of candidate indicators	21
5. Candidate indicator specifications	27
6. Recommendations	73
Appendices:	
A. Workshop held in January 1995	79
B. Asthma Working Group	81
C. Work commissioned from NHS Centre for Reviews and Dissemination	83
D. Guidance notes for indicator specifications	111
E. Work commissioned from UK Clearing House for Information on Health Outcomes	115
F. References to text and all appendices	145

SUMMARY OF RECOMMENDATIONS

Using a variety of check lists including a health outcome model, the Group identified outcome indicators which were fully specified in a standard format and are included in this Report. Outcome indicators were grouped together under headings relating to the aim of intervention. The numbers given to the outcome indicators correspond to the specifications in Section 5.

Recommendations for implementation were made for each indicator using the following categories:

- A.** To be implemented generally on a routine basis.
- B.** To be implemented where local circumstances allow on a routine basis.
- C.** To be implemented where local circumstances allow by periodic survey.
- D.** To be implemented following IT development on a routine basis.
- E.** To be implemented following IT development by periodic survey.
- F.** To be further developed either because the link with effectiveness is not clear or the indicator specification is incomplete.

Category	Page	
		<i>Indicators related to reduction or avoidance of risk of asthma</i>
A	28	1. Hospital admission rate for asthma per general population.
B	35	4. General practice consultation rate per general population.
		<i>Indicators related to early detection of asthma</i>
F	37	5. General practice consultations before diagnosis of asthma is first made.
		<i>Indicators related to reducing or avoiding acute attack</i>
F	30	2. Emergency admission rate per population of people with asthma.
D	39	6. Accident and emergency attendance rate for asthma related problems per population of people with asthma.
B	41	7. British Thoracic Society (BTS) treatment step profile.
F	43	8. Incidence of progression to British Thoracic Society (BTS) treatment step 3 and greater.
E	48	10. Current lung function as percentage of individuals' best lung function.
C	50	11. Loss of best lung function over time.
B	60	15A. Patient-assessed impact measure: <i>at consultation.</i>
F	63	15B. Patient-assessed impact measure: <i>questionnaire-based.</i>
F	66	15C. Patient-assessed impact measure: <i>computer-based.</i>
F	68	16. Patient satisfaction with asthma care.
F	71	17. Awareness of asthma management.

Indicators related to reducing risk of death

A	52	12. Age-specific mortality rate.
A	54	13. Years of life lost.
F	56	14. Case-fatality rate within a defined period of hospital admission.

Indicators related to assuring return to function after acute attack

B	33	3. Emergency re-admission rate per population of in-patients discharged with asthma.
C	45	9. Compliance with British Thoracic Society (BTS) guidelines for acute asthma care.
E	48	10. Current lung function as percentage of individuals' best lung function.
C	50	11. Loss of best lung function over time.
B	60	15A. Patient-assessed impact measure: <i>at consultation.</i>
F	63	15B. Patient-assessed impact measure: <i>questionnaire-based.</i>
F	66	15C. Patient-assessed impact measure: <i>computer-based.</i>
F	68	16. Patient satisfaction with asthma care.

Indicators related to reducing impact of asthma on general population

F	30	2. Emergency admission rate per population of people with asthma.
B	41	7. British Thoracic Society (BTS) treatment step profile.
F	43	8. Incidence of progression to British Thoracic Society (BTS) treatment step 3 and greater.
E	48	10. Current lung function as percentage of individuals' best lung function.
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F	71	17. Awareness of asthma management.

1. BACKGROUND TO THE WORK

Summary

1.1 Over the last few years a major component of the Department of Health's and NHS Executive's strategy has been to promote the development and use of measures of health outcome. In July 1993 the Central Health Outcome Unit (CHOU) was set up within the Department of Health (DoH). In 1993 a feasibility study of potential outcome indicators was published by the Faculty of Public Health Medicine and a package of indicators was published by the University of Surrey for consultation. Following these two phases of development, a third phase of work was initiated by the CHOU. Its remit is to report on 'ideal' health outcome indicators. Asthma was chosen as the first condition for the Phase 3 work.

Central Health Outcome Unit

1.2 The CHOU is an internal DoH unit whose goal is 'to help secure continuing improvement in the health of the people of England through cost-effective and efficient use of resources' (Lakhani 1994). The objectives of the Unit are to:

- encourage and co-ordinate the development of health outcome assessment, particularly in respect of the development of appropriate methods, appropriate data collection systems, expertise, analytical skills, and interpretation
- encourage and support the use of health outcome assessment and information in making policy about health interventions and in the planning, delivery and monitoring of services.

1.3 Several national committees have a special interest in outcomes and are kept informed of progress:

- Clinical Outcomes Group
- Public Health Network
- Chief Medical Officer's Working Group on Information Management and Technology.

Feasibility study on population health outcome indicators

1.4 The Faculty of Public Health Medicine was commissioned to undertake a feasibility study of potential indicators which reflect health end-points for health services and which cover topics in which health care has an important contribution to make. This work was limited because the set of indicators were to:

- be based on routinely collected data
- reflect health service interventions rather than the wider influences on health.

- 1.5 The report of the feasibility study (McColl and Gulliford 1993) was issued as a consultative document to the NHS with EL (93) 79.

Consultative package of indicators from first phases of work

- 1.6 The University of Surrey was commissioned to produce a package of comparative statistics based on the outcome measures recommended in the feasibility study. Forty indicators were chosen, 18 for maternal and child health, 3 for mental health and the rest for other topics in adult health. The publication contained indicator definitions, maps and scatter plots showing geographical variations, and tables presenting the rates, with corresponding observed numbers and confidence intervals when appropriate.
- 1.7 The report of the Surrey work (Department of Health 1993a) was also issued under cover of EL (93) 79. The Faculty of Public Health Medicine then completed and reported on work on the feasibility of a further set of indicators (Phase 2). Revised and updated indicators based on the 1993 consultation, as well as the Phase 2 recommendations, are now published annually as part of the Public Health Common Dataset.

The 'Phase 3' work : 'ideal' indicators of health outcome

- 1.8 In the third and current phase of the work on health outcomes a number of research institutions were commissioned to assist in developing a structured approach to identify indicators to cover a number of clinical topics. The prime contractor is the Unit of Health-Care Epidemiology, Department of Public Health and Primary Care, University of Oxford. Support activities were commissioned as an integral part of the work from the University of York NHS Centre for Reviews and Dissemination; the UK Clearing House on Health Outcomes, Nuffield Institute of Health, University of Leeds; CASPE Research, London; and the Royal College of Physicians' Research Unit. The work also received continuing input from the CHOU and its activities on disease modelling.
- 1.9 In the previous work a key criterion for selection of indicators was the requirement to base the work on routinely available data. This practical constraint meant that the recommended indicators were a selected and opportunistic set rather than an ideal set. This inevitably led, as the DoH acknowledged, to a bias towards outcomes which may be measurable now but which may not necessarily be those which are most appropriate and most needed. The aim of Phase 3 is to advise on and develop 'ideal' outcome indicators without confining recommendations to data which have been routinely available.

1.10 The initial task of the Phase 3 work was to select clinical topics for detailed study. In order to ensure that the work would be manageable, and that the NHS would have the capacity to absorb it, the CHOU decided to limit the activity to 10 clinical topics in the first two years.

1.11 A workshop to initiate the work was held in 1995 and was attended by over 70 individuals representing a wide range of interests. A report of the proceedings has been published (Goldacre and Ferguson 1995). The main aims of the workshop were:

- to identify the criteria which should be used to choose clinical topics for the Phase 3 work (see Appendix A)
- to suggest a list of clinical topics which workshop participants would like to be included in the Phase 3 work (see Appendix A).

1.12 Following further consultation within and outside the DoH, the CHOU decided in June 1995 to include the following topics in the first two years of the Phase 3 work:

- First year:
 - Asthma
 - Stroke
 - Severe mental illness
 - Cataract
 - Fracture of neck of femur.
- Second year:
 - Myocardial infarction
 - Diabetes mellitus
 - Breast cancer
 - Pregnancy and childbirth
 - Incontinence.

The Asthma Working Group

1.13 The Asthma Working Group was formally constituted in July 1995 and met three times, completing its work in February 1996. The Report was completed in August 1996. The terms of reference were:

- to advise on indicators of health outcomes of the prevention and treatment of asthma
- to make recommendations about the practicalities of the compilation and interpretation of the indicators, and to advise if further work is needed to refine the indicators and/or make them more useful.

1.14 It was considered that a fundamental aspect of the work should be to draw together a wide range of clinical and non-clinical perspectives, including those of patients. The composition of the Group included the major professional and managerial groups and representatives of patients and carers. It is shown in Appendix B.

1.15 The respective roles of the supporting organisations were as follows:

- Unit of Health-Care Epidemiology, University of Oxford, to provide epidemiological and managerial support to the Group and co-ordinate the input of the other agencies.
- NHS Centre for Reviews and Dissemination, University of York, to produce reviews of the literature on the effectiveness and cost-effectiveness of relevant interventions.
- UK Clearing House on Health Outcomes, Nuffield Institute of Health, University of Leeds, to provide support in identifying measures and instruments to be used for assessing outcomes.
- CASPE Research, London, to provide technical advice with regard to the indicators and their data sources and prepare the detailed indicator specifications.
- Royal College of Physicians' Research Unit, London, to co-ordinate the clinical input and, if deemed necessary, to undertake pilot studies.

Uses of outcome information

1.16 The Group was influenced in its work by considering the potential uses of outcome information, as follows:

- for clinical decision-making and audit of clinical work, including:
 - audit and management of health professionals' practice
 - research
- for informing decisions about the strategic and operational development of services
- for comparisons of organisations in the delivery of services which may be:
 - provider based
 - population based
- for assessing progress towards standards or targets for health outcomes, agreed locally or nationally, which may be:
 - identified from the research literature
 - set by clinical and managerial decisions.

1.17 Current managerial interests which are relevant to the use of health outcome information include:

- The NHS goal 'to secure, through the resources available, the greatest improvement in the physical and mental health of people in England'
- clinical audit
- evidence-based commissioning.

1.18 An important purpose of this work has been to recommend indicators which, if possible, would allow 'health gain' to be assessed alongside information used to measure health service input. Our particular focus has been to make recommendations about aggregated, statistical information about people with asthma which could be used to:

- enable providers of care to review the outcomes of care of their patients
- make comparisons of health outcomes against locally agreed targets and/or between different places and/or over time.

1.19 Information for outcome indicators may be obtained from continuous data collection systems but, when having continuously collected information is unnecessary, or when the cost or complexity of this is high, use can be made of sample survey techniques or periodic surveys.

1.20 Health indicators are more likely to be successful if they fit naturally into the everyday work of health care professionals than when they have to be collected as a separate activity. The aim is to have indicators that are:

- *Relevant*, because professionals use them everyday in treating their patients and will record them accurately.
- *Reliable*, in that they can be validated or cross-checked from other sources.
- *Responsive*, because they readily identify changes in patients' state of health.
- *Research-based*, because there is a plausible link between processes of care and outcome.

1.21 In common with the approach taken to other types of indicators by the NHS, we recognise that useful outcome indicators should be capable of identifying circumstances worthy of investigation but that, in themselves, they may not necessarily provide answers to whether care has been 'good' or 'bad'. In particular, we recognise that there may be difficulties in drawing causal conclusions - say, that a particular aspect of prevention or care caused a particular outcome - from indicators derived from non-experimental clinical settings. Nonetheless, the vast majority of clinical care is delivered in routine rather than experimental settings. The assessment of its outcomes entails, by definition, the use of observational rather than experimental data.

1.22 To be useful, work on 'ideal' outcome indicators must incorporate considerations of practicability. It is a time of rapid change in information technology. What may be feasible now in some places may not be feasible everywhere. What may not be practical today may become so in a year or two.

2. HEALTH OUTCOME MODEL FOR ASTHMA

Definitions and scope of the work

- 2.1** Asthma is a disorder characterised by inflammation and narrowing of the airways. It is frequently defined clinically as reversible airway limitation but the methods of measuring such reversibility, the criteria for deciding what degree of reversibility is significant, and the use of objective measurements are variable. The severe asthma patient is easy to recognise and include on an asthma register. The mildest asthma patients merge imperceptibly with the normal healthy population and may fluctuate between normal and asthmatic states.
- 2.2** The Group decided that it was not possible to work with one single definition for the condition. Different definitions are needed for specific indicators depending on the purpose for which the information is to be used. Various practical definitions were identified. These were intended primarily to aid the working of the Group and thus were taken from existing work as follows:
- i. Patients diagnosed as having asthma in general practice, as included or eligible for inclusion on an asthma register which many practices are now maintaining.
 - ii. Adults diagnosed as having asthma in general practice, with a response to bronchodilators of at least 60 litres/minute improvement in Peak Expiratory Flow (PEF). In children the response to bronchodilators indicative of asthma would be an improvement in PEF of 15% or more above baseline. We took these values for our purposes but accept that others may wish to work with slightly different ones.
 - iii. Patients prescribed inhaled drugs for asthma for whatever period.
 - iv. Patients with asthma specified as a diagnosis on a hospital record.
 - v. People who had asthma certified as the underlying cause of death on a death certificate.
- 2.3** The Group recognised that there are particular problems in identifying and diagnosing asthma in both the young and the old.
- 2.4** Under the age of five years it is very difficult with any degree of certainty to differentiate wheezing attacks due to asthma from other conditions such as those associated with viral infections. Measurements of respiratory function may be difficult and the very young respond differently to many of the available drugs. In the light of this, the Group agreed that work would not be done specifically on information about the under-fives, although the importance of this topic was recognised. However, many of the indicators developed should be appropriate for this age group.

2.5 In the elderly the influence of smoking is a major factor because smoking-related chronic obstructive pulmonary disease (COPD) can have similar clinical features to chronic asthma. However, the interventions in the two conditions are broadly similar and a significant proportion of asthma morbidity and mortality occurs in the older age groups. The Group agreed that on balance the scope of the work should not be constrained by an upper age limit. It acknowledged, however, that its recommendations for the use of a particular indicator might include restriction to particular age limits and would, in any case, generally be compiled as age-specific rates.

Developing a health outcome model for asthma

2.6 Although some original work was commissioned by the Group, the greater part of the input to the development of the asthma outcome model came from already published national reviews including:

- *Asthma : an epidemiological overview*, published by the Central Health Monitoring Unit (Department of Health 1994).
- *Health needs assessment for lower respiratory disease*, one of the 19 epidemiologically based reviews commissioned by the Department of Health (Anderson et al. 1994).
- *Guidelines for the management of asthma in adults* initiated by the British Thoracic Society (BTS), Research Unit of the Royal College of Physicians, King's Fund Centre and National Asthma Campaign and modified with others in 1993 (British Thoracic Society et al. 1993), and a draft of the revised guidelines subsequently published in 1997 (General Practitioners in Asthma Group et al. 1997).
- *Asthma and outdoor air pollution*, a report of the Committee on the Medical Effects of Air Pollutants (Department of Health 1995).

2.7 The health outcome model for asthma was developed as an aid to help Group members identify potential indicators. The model contained:

- an overview of the epidemiology of the disease
- a review of causes and risk factors
- a review of the course, complications and consequences
- a review of relevant interventions.

Overview of epidemiology

2.8 As already noted in paragraphs 2.1 to 2.5 there are some difficulties in interpreting asthma statistics because of variations in the definition of the disease. Despite this, it is possible to summarise the impact of the disease in terms of its prevalence, toll of ill-health and mortality.

- 2.9** On the basis of data obtained from population surveys and research studies it has been estimated that the prevalence of asthma is sufficiently severe to require regular medical supervision in at least 4 - 6% of children and in at least 4% of other age groups (Department of Health 1994).
- 2.10** Asthma is certified as the underlying cause of death in over 1,600 deaths per year, accounting for about 0.3% of all deaths in England (Department of Health 1994). Deaths occur mainly in elderly people : 60% of all asthma deaths occur in people aged 65 and over. The age standardised mortality rate for asthma, adjusting for changes over time in the age structure of the population, has fallen by more than 10% since the mid-1980s. The number of deaths from asthma among people aged under 65 fell by 20% between 1984-86 and 1990-92. There is no clear geographical pattern of mortality in England although health authorities with a high mortality in people under 65 are more likely to be in the north rather than the south of the country. Standardised mortality ratios for asthma, comparing people in different social classes, are significantly lower in Social Classes I and II than in other classes for both men and women.
- 2.11** Prescriptions for asthma-related drugs increased by 80% between 1983 and 1993. Prescriptions for asthma currently account for about 7% of all NHS prescriptions and their net ingredient cost, £350 million in 1993, was 11% of the net ingredient cost of all prescriptions (Department of Health 1994).
- 2.12** The GP consulting rate for asthma increased by 191% between 1983 and 1994/5. Consultation rates for children are much higher than those for adults (Department of Health 1994).
- 2.13** The number of hospital in-patient admissions for asthma nearly doubled between 1983 and 1994/5 although the increase flattened off in the latter years. Part of the increase was due to changes in the basis of the statistics. Children are much more likely than adults to be treated as in-patients and children under 15 currently account for about half of all 'finished consultant episodes' for asthma (Department of Health 1994).
- 2.14** There has been a marked increase in the recorded treatment of asthma in the last decade. There is strong evidence that the prevalence of asthma has increased in recent years but the increase in recorded asthma is probably not wholly explained by this. Other probable influencing factors include:
- changes in the basis of the statistical data collection
 - an increased use of the term asthma for respiratory conditions
 - changes in treatment practices
 - changes in the tendency of people, particularly the parents of children, to seek medical care.

Causes and risk factors

2.15 The precise causes of asthma are as yet unidentified. It results from an interaction between genetically susceptible individuals and environmental factors which may initially help to determine whether a person develops asthma or may precipitate an attack once a person has asthma.

2.16 Environmental factors which have been suggested as risk factors for the onset of the disease in childhood include (Department of Health 1994; Anderson et al. 1994):

- exposure to tobacco smoke
- viral infection
- components of diet
- exposure to allergens during pregnancy and the first months of life
- artificial feeding of neonates.

2.17 Environmental factors which have been suggested as precipitating factors for asthma attacks are (Department of Health 1994; Anderson et al. 1994):

- respiratory infections
- exposure to tobacco smoke
- exposure to cold
- pollens
- allergens of animal origin such as house dust mites and pets
- fungal spores and mould
- emotional upsets or stress
- air pollution
- occupational causes such as isocyanates, flour, wood dusts.

2.18 The Group decided that it was not necessary to commission new work about the relationship between the suspected environmental factors and asthma. Major studies have been commissioned by the Department of Health on air pollutants and the MRC has a working group reviewing the environmental determinants of asthma.

2.19 Evidence of the relationship of air pollutants to asthma is still weak (Department of Health 1995) in that:

- while there is laboratory evidence that air pollution could potentially have a role in the initiation of asthma, there is no firm epidemiological evidence that this has occurred
- while there is epidemiological evidence that air pollution may provoke acute attacks or aggravate chronic asthma the effect, if any, is small
- there is no constant relationship between trends in the prevalence of asthma and trends in emissions or ambient concentrations of air pollutants.

2.20 On the evidence available to the Group, it was decided that no work should be done by the Group to develop indicators for monitoring specific environmental policies to reduce causes and risk factors. Extensive work has already been done on smoking indicators which takes into account the importance of reducing environmental tobacco smoke (Anderson et al.1994). Air pollution indicators will be the subject of European legislation. It was considered that the relationships of the other aetiological factors with asthma were not strong enough to develop indicators to monitor them. The Group felt, however, that indicators of changes in the occurrence and/or severity of asthma should help identify possible changes in aetiological factors.

Course, complications and consequences

2.21 It is common for the severity of asthma in individuals to wax and wane over time. It commonly starts in childhood and may improve spontaneously in early adult life (Lane 1996).

2.22 Longitudinal studies have demonstrated that half or more of children with asthma when aged 7 years will outgrow their disease (especially those with mild asthma) and be symptom-free in their thirties. Those with more severe asthma as a child are more likely to have symptoms later in life and the presence of severe eczema indicates a poorer prognosis (Sears 1994).

2.23 Against the background of long-term variation in an individual's symptoms, there are short-term exacerbations which may be triggered by recognisable factors. Severe attacks can at worst be life threatening and require hospital treatment and at best interfere with normal activities such as work and leisure. One aim of ongoing care and treatment is to prevent severe attacks or catch them at an early stage (Woolcock 1987). Another is to prevent lesser degrees of morbidity and preserve the ability to pursue work/school and leisure activities. A third aim is to try and reduce the 60-70% of deaths in people under 65 years which have been shown to be potentially preventable.

2.24 In some individuals asthma may become chronic and persistent. Airways obstruction becomes increasingly severe and progressively less responsive to treatment. Breathlessness, wheezing and nocturnal sleep disturbance interferes with the ability to work or perform daily activities and may progress to severe disability. Patients may experience the emotional and social effects of long-standing illness and side effects of their medication. Death in such patients may follow from intercurrent infection, respiratory failure or heart failure (Woolcock 1987).

Relevant interventions

2.25 The Group reviewed the relevant interventions for asthma using the following classification of aims of intervention:

- reduce or avoid risk of asthma
- detect asthma early
- reduce or avoid acute attacks
- reduce risk of death
- assure return to function after acute attack
- reduce impact of asthma on general well-being, including:
 - reduce or avoid complications
 - achieve a target level of lung function
 - improve long-term prognosis.

2.26 The reduction of exposure to environmental factors to **reduce the risk of asthma and asthma attacks** could be aimed either at the whole population or targeted to individuals with asthma or known to be at risk. As noted previously, the evidence linking specific environmental factors to the cause of asthma or onset of attacks is not conclusive. Similarly there is little evidence in England of the effectiveness of reducing exposure to them, in particular:

- house dust mites can be controlled by various procedures but, unless these are sustained, there is recolonisation (Anderson et al. 1994)
- evidence of improvement after patients leave damp or mouldy premises is only anecdotal (Anderson et al. 1994).

2.27 The current evidence about the effectiveness of reducing environmental risks is weak (Anderson et al. 1994; Department of Health 1995). Therefore, the Group decided that no indicators relating to specific risk factors should be developed.

2.28 Previously unrecognised asthma may be **detected early** by simple questionnaires. Uncontrolled trials of such an intervention, followed by treatment when indicated, have shown a temporary improvement in morbidity (Anderson et al. 1994). Increased bronchial reactivity in subjects without symptoms may be predictive of later asthma but the identification of this cannot be recommended for screening because few of the criteria for adopting a screening programme can be satisfied. The Group reviewed this evidence and considered that it was not appropriate to identify indicators related to screening for the early detection of disease.

2.29 The consensus statement published by the British Thoracic Society and others (British Thoracic Society et al. 1993) describes the interventions currently thought to be most effective in **managing acute attacks and reducing the risk of death**. The mainstay of treatment is by drugs, the chief types being sympathomimetics, steroids, xanthines and disodium cromoglycate. Drugs given by the inhaled route are associated with fewer side effects for a given therapeutic effect. In severe attacks hospital admission for oxygen, high dose bronchodilators and steroids and, in a few, assisted ventilation may be required.

2.30 There is no clear evidence about the benefits of antibiotics or physiotherapy in managing an acute attack, although these are frequently prescribed (Anderson et al. 1994).

2.31 The consensus statement also describes the interventions currently thought to be most effective in **assuring return to function after an acute attack and reducing the impact of asthma**. Drugs are again the mainstay of treatment. However, there are few data about long-term outcomes of treatment. There are no long-term data to balance the medically-expected benefits of drug treatment against patients' concerns about possible side effects (Anderson et al. 1994).

2.32 The Group noted that:

- surveys consistently report high proportions of patients with disabling symptoms, despite or without treatment
- there may occasionally be a conflict between the aims of doctors and their patients, with patients preferring to live with a certain level of symptoms rather than have the extra burden of treatment or lose financial benefits obtained as a result of their illness.

2.33 There is no clear evidence to support the general use of desensitisation, physiotherapy, acupuncture or hypnotherapy. However, these treatments are often sought by patients, sometimes without the knowledge of their medical practitioners. Some of the indicators recommended may prove useful in evaluating outcomes in patients who seek such treatments.

2.34 Two other factors which may assure return to function and reduce the impact of the condition were considered by the Group:

- the role of patient education
- the organisation of care services.

2.35 Self care is an indispensable aspect of the domiciliary care of asthma (Lane 1996). Education aims to improve self care by educating patients about the illness, its treatment, the performance of therapeutic techniques, and by helping them monitor the illness and make appropriate decisions about adjusting treatment and seeking assistance.

2.36 The evidence from a meta-analysis of published trials suggests that education alone, whilst it may increase knowledge, does not necessarily improve clinical outcome (Anderson et al. 1994). However, recent clinical trials have now shown that giving control of the condition to patients by means of self management plans can reduce morbidity (D'Souza et al.1994; Lahdensuo et al. 1996).

2.37 As no recent review of the effect of the organisation of care services was available, the Group commissioned the NHS Centre for Reviews and Dissemination, University of York, to review the organisational methods of delivery of asthma care. This report is available as a separate paper which has been reproduced in Appendix C (Eastwood and Sheldon 1996). Conclusions from it are summarised in paragraphs 2.38 - 2.40.

2.38 In summary, 27 studies were reviewed but the conclusions that can be drawn are limited by the poor quality of the methodology used in many of them. Only one third were randomised controlled trials and many had a small sample size. The studies covered different settings for care management, the involvement of a variety of specialist and generalist health professionals, and alternative arrangements for access to care. No conclusive evidence was found in favour of any particular form of organisation.

2.39 The Group noted that:

- it was difficult from the evidence to distinguish between the individual effects of the settings or forms of delivery of care and the characteristics of the staff who delivered it
- most interventions which aimed to provide more education and information to patients or parents appeared to succeed in improving knowledge and confidence but not necessarily morbidity, although there were difficulties in the methods used for measuring morbidity
- the characteristics of the deliverer of care may be more important than the setting in which it is provided and, although no study has addressed it specifically, it seems likely that health professionals with asthma expertise (wherever they practice) may obtain better health outcomes than others for their patients
- most studies of interventions have not addressed issues of cost-effectiveness and the identification of robust indicators should help encourage such studies.

2.40 As a result of the commissioned review the Group decided not to specify organisational factors which could be used as proxy indicators of outcomes. However, it was agreed to consider indicators associated with patient or parent education in view of the recent published work (see paragraph 2.36).

3. METHODS FOR CHOOSING CANDIDATE INDICATORS

3.1 The work of the Group had three main components:

- use of the health outcome model and the development of check-lists to assist members choose 'candidate indicators', by which is meant potential indicators worth detailed consideration
- specification of 'candidate indicators' in detail
- recommendations about the implementation of indicators.

Check-lists for identifying candidate indicators

3.2 The Group noted that indicators could be related to:

- i. environmental factors in the general population or relating to the individual
- ii. knowledge, attitudes, behaviour in the general population
- iii. knowledge, attitudes including satisfaction with service delivery, behaviour of individual patients with asthma
- iv. patients' symptoms, function, health status, well-being
- v. patients' clinical state
- vi. patients' pathological/physiological state
- vii. events occurring to patients as endpoints of earlier occurrence of disease and/or interventions e.g. health service contacts with general practitioners, issuing of prescriptions, out-patient visits, in-patient admissions, death.

3.3 The data sources for the indicator entities noted in paragraph 3.2 will differ. It is likely that:

- indicators for (i) and (ii) would come from population surveys
- indicators for (iii) and (iv) would come from patients either opportunistically or when specifically requested
- indicators for (v) and (vi) would come from doctors and other health professionals
- indicators for (vii) would come from administrative information systems.

3.4 Four characteristics of an outcome indicator were identified and classified. They are:

- specificity (see paragraph 3.5)
- perspective: whose perspective the indicator measures (see paragraph 3.6)
- time-frame (see paragraph 3.7)
- outcome relationship, in that the indicator is either a direct measure or an indirect, proxy measure of outcome (see paragraph 3.8).

- 3.5** We have used the term ‘specificity’ of an indicator to describe the degree to which it is specific or generic in application. For example, the measurement of peak expiratory flow is specific to lung function and fairly specific to chest disease. The measurement of exercise tolerance or physical activity is much less specific and would be influenced for example by heart disease or arthritis as well as chest disease. Condition-specific indicators have the advantage that their relative insensitivity to other conditions is likely to increase their sensitivity to changes in the condition of interest. Generic measures provide outcomes relevant to a wide range of conditions. A comprehensive indicator set would contain examples of both generic and specific indicators.
- 3.6** For the Group’s purpose the measurement perspective was classified as patient-based, clinical or population-based. In the treatment of asthma, for example, a measure of quality of life may be most relevant to the patient’s perspective while more immediate clinical concerns may properly focus on measures of pulmonary function. The population perspective has a broader view, best addressed by measures able to assess the burden of the disease as a whole. Of course, these perspectives are not necessarily in opposition and will often be associated with shared goals. Where possible, a set of indicators should be developed which satisfies all three measurement perspectives.
- 3.7** The measurement time-frame relates to whether the indicator is:
- cross-sectional and thus an indicator at a single point in time for any one individual
 - a longitudinal measure of progression over time for any one individual.
- 3.8** The Group’s main task has been to develop direct indicators of health outcome although in many areas it may be very difficult to identify or obtain such information. It recognised that some care processes are so closely related to the production of benefits that the successful completion of the intervention might be used as a proxy measure of the actual outcome. Where direct outcome indicators are difficult to compile, some proxy indicators were therefore considered.
- 3.9** With the assistance of the check-lists and a knowledge of the disease supplemented by commissioned work, the Group addressed the following key questions:
- What are health professionals trying to achieve for each patient?
 - What can each patient realistically expect will be achieved for him/herself?
 - What should be achieved for the population as a whole in respect of the prevention, care or cure of the disease?

Specification of candidate indicators

3.10 The Group agreed a set of attributes which should be specified for each candidate indicator. Further definition of each attribute is provided in the indicator specification guidance notes at Appendix D.

- Title
- Aims of health intervention (see paragraph 2.25)
- Characteristics (see paragraph 3.4)
- Indicator definition
- Rationale for use
- Condition definition
- Potential uses
- Potential users
- Possible confounding variables
- Data sources
- Data quality
- Any relevant comments
- Further work required
- Conclusion and priority for implementation
- References.

3.11 Where the data required to derive the candidate indicators were already available consideration was given to any constraints in data:

- collection
- availability
- cost
- reliability in terms of coverage, accuracy, validity and timeliness.

Types of recommendation

3.12 The Group reviewed the specifications of the candidate indicators and made final recommendations. The Group's recommendations can be categorised as those which:

- can be implemented generally throughout the NHS as there are systems available which can provide the requisite data
- could be implemented now where local circumstances allow and more generally in the near future once expected developments are in place
- will not be possible to implement in the near future but, because of their desirability, they should be considered in the future development of clinical and management information services
- require further work before a recommendation can be made.

3.13 The recommendations have been further categorised as to whether the requisite indicators should be available:

- routinely on a universal and continuous basis
- from periodic surveys, either at different points in time nationally or in geographical areas when there is a particular need and/or by sampling.

4. CHOICE OF CANDIDATE INDICATORS

- 4.1** To assist the Group in choosing the candidate indicators, a literature review of asthma outcome measures was commissioned and a matrix was developed to ensure the coverage of all relevant aspects of health outcomes.

Literature review

- 4.2** The Group commissioned the UK Clearing House for Information on Health Outcomes at University of Leeds to carry out a review of asthma outcome measures in the published literature. This report has been published as a separate paper (Dixon et al. 1996) which is reproduced in Appendix E.

- 4.3** The work covered two main areas:

- a review of asthma outcomes which are summarised in Exhibit 1
- a review of instruments used for measuring asthma outcomes.

EXHIBIT 1 : OUTCOMES IDENTIFIED IN THE COMMISSIONED REVIEW

Patient education and knowledge

- medication and its effects and use of inhalers and relief bronchodilators
- use of self administered peak expiratory flow readings
- avoidance of attacks and what to do in the event of an attack.

Patients' symptoms, functioning, satisfaction and health status

- chest tightening and daytime/nocturnal dyspnoea and wheezing
- feelings of coping and self control, depression and fatigue
- confidence in care and carers and impact on others
- concerns for general health
- fears of asthma attack
- limiting of a range of physical activities
- limiting of a range of social activities.

Measurement of patients' clinical or physiological state

- point estimates such as % peak expiratory flow of best or predicted
- fluctuations in peak expiratory flow over time.

Events occurring to patients

- emergency admissions
- deaths.

Outcomes matrix

4.4 To ensure that all aspects of outcomes were considered a matrix, shown in Exhibit 2, was drawn up using the two dimensions:

- aims of interventions (see paragraph 2.25)
- perspectives of measurement (see paragraph 3.6).

4.5 For each part of the matrix, consideration was given to possible indicators. Using the information in the health outcome model, candidate indicators were identified as shown in the paragraphs which follow. The numbers in the text relate to the Exhibit and indicator definitions in the next section.

4.6 In view of the overall lack of firm evidence on specific risk factors, it was agreed that measures of the occurrence of asthma would be used as proxies for **reduction and avoidance of risk**. The two candidate indicators chosen for specification were:

- 1:** hospital admission rate for asthma per general population
- 4:** general practice consultation rate per general population.

EXHIBIT 2 : MATRIX FOR ASTHMA OUTCOME INDICATORS

Aim of health intervention	Primary measurement perspective		
	Population	Clinical	Patient
Reduce or avoid risk of asthma	1,4		
Detect asthma early		5	
Reduce or avoid acute attacks		2,6,7,8,10,11,	15 (A,B & C) 16,17
Reduce risk of death	12,13,14		
Assure return to function after acute attack		3,9,10,11	15 (A,B & C), 16
Reduce impact of asthma on general well-being		2,7,8,10,11	15 (A, B & C) 16,17

- 4.7 The **early detection** of asthma contributes significantly to ensuring appropriate treatment and reduced morbidity. While the difficulties in identifying the timing of a diagnosis are recognised, the following candidate indicator was chosen for specification:
- 5: number of general practice consultations before the diagnosis of asthma is first made.
- 4.8 Indicators chosen to measure the success of health services in **avoiding acute attacks of asthma** or in reducing their likelihood were of two types. The first group measures the occurrence of emergency contacts with hospitals as 'end points' of ambulatory care. These candidate indicators were:
- 2: emergency admission rate per population of people with asthma
6: accident & emergency attendance rate for asthma related problems per population of people with asthma.
- 4.9 The second group includes clinical indicators that assess the results of individual patient management or that of a group of patients. It was considered valuable to classify patients using the treatment step recommendations in the British Thoracic Society (BTS) guidelines. The measurement of lung function was strongly supported by clinicians. The use of PEF rather than FEV1 acknowledges the widespread accessibility of equipment to measure PEF. The candidate indicators within this group were:
- 7: BTS treatment step profile
8: incidence of progression to BTS treatment step 3 and greater
10: current lung function as percentage of individuals' best lung function
11: loss of best lung function over time.
- 4.10 The reduction of the risk of acute attacks should not only be examined through clinical measures but also for its impact on the patient, and from their perspective. The choice of instruments is probably for local decision, since their application depends on purpose, depth of enquiry and resources available. Similar issues arise when considering the development of patient satisfaction and patient awareness instruments. The candidate indicators were:
- 15: patient-assessed impact measures
16: patient satisfaction with asthma care
17: awareness of asthma management.
- 4.11 The Group selected three candidate indicators by which to assess the outcome of health interventions aimed at **reducing the risk of death**. These were:
- 12: age-specific mortality rate
13: years of life lost
14: case-fatality rate within a defined period of hospital admission.

4.12 The Group considered that it was important to measure the **return to function after an acute asthma attack**. Four clinical indicators were proposed. Two of these relate to the measurement of lung function, the rationale for which has been described in paragraph 4.9. The other two attempt to measure the outcome of a secondary care episode. Both are process based proxy measures, the first measuring the adverse outcome of antecedent care, while the second assesses the level of compliance with professional guidelines about the process of care. The candidate indicators chosen to address this aspect of care were:

- 3:** emergency re-admission rate per population of in-patients discharged with asthma
- 9:** compliance with BTS guidelines for acute asthma care
- 10:** current lung function as percentage of individuals' best lung function
- 11:** loss of best lung function over time.

4.13 Similarly, indicators were selected to address the successful return to function after an acute asthma attack from the perspective of the patient. The two candidate indicators chosen were drawn from those listed in paragraph 4.10 and were:

- 15:** patient-assessed impact measures
- 16:** patient satisfaction with asthma care.

4.14 A final set of health interventions considered by the Group is described by the aim of **reducing the impact of asthma on general well-being**. Indicators similar to those selected for assessing the avoidance or reduction of risk of acute attacks were selected, the differences within the specifications being related to the timing and mode of application for each indicator. The candidate indicators selected were:

- 2:** emergency admission rate per population of people with asthma
- 7:** BTS treatment step profile
- 8:** incidence of progression to BTS treatment step 3 and greater
- 10:** current lung function as percentage of individuals' best lung function
- 11:** loss of best lung function over time.

4.15 With the same rationale, indicators using information provided by patients were also selected to address this health aim. Similar comments apply to the need to consider and validate the appropriateness of wording, timing and mode of application of each of these instruments in this situation. The patient-assessed indicators selected were:

- 15:** patient-assessed impact measures
- 16:** patient satisfaction with asthma care
- 17:** awareness of asthma management.

4.16 The Group decided that there was not enough evidence available to warrant development of indicators for specific risk factors for asthma. Those considered in particular were:

- Air pollution for which, as noted in paragraph 2.19, the evidence linking specific components to the cause or aggravation of asthma is weak and not conclusive. Indicators of air pollution for more general use will be available from other work undertaken for Government and thus were not selected for development as candidate indicators by us.
- Occupational causes of asthma, although important, are not widespread. Any further work on specific indicators of occupational risk should be developed either locally for high-risk populations or on an industry-wide basis.
- The evidence relating to house dust mites in precipitating asthma attacks is getting stronger but evidence of the long-term effectiveness of interventions in England is lacking. Routine measurement of house dust mites levels on a large scale is impractical. For these reasons no indicators were specified for this factor.
- Active smoking adversely affects the occurrence of asthma in children and young adults and smoking indicators are part of the Health of the Nation data set.
- There is good observational evidence of the benefits of reducing environmental tobacco smoke. There are, however, practical difficulties with data collection and therefore no indicators are specified to monitor passive smoking.

5. CANDIDATE INDICATOR SPECIFICATIONS

- 5.1** This section contains the detailed specifications of the candidate indicators chosen by the Group. To facilitate ease of reference indicators derived from broadly similar data have been grouped together.
- 5.2** Guidance notes which explain the attributes used in the specifications are included in Appendix D.
- 5.3** The detailed work on the specifications was carried out by Moyra Amess, Robert Cleary and James Coles of CASPE Research.

Candidate indicator 1

Title	Hospital admission rate for asthma per general population
Intervention aim	Reduce or avoid risk of asthma.
Characteristics	Specificity : Condition-specific Perspective : Population Time-frame : Cross-sectional Outcome relationship : Proxy for occurrence.
Indicator definition	For a given population, age and sex band: <i>the number of provider spells with asthma as a primary diagnosis at discharge divided by the number of people resident in the population of interest.</i>
Rationale	In-patient admission is one of the routinely available measures of treated morbidity. Alongside a modest rise in admission in young adults (Alderson 1987), asthma admissions in children have increased dramatically (Anderson 1989). Although some of this increase could be explained by a shift towards the hospital as the preferred place to treat acute asthma in children, epidemiological factors could also be contributing (Burney et al. 1980). Providing that admission thresholds are appropriate, and not subject to significant variation, this measure should be a reasonable proxy for variation in the occurrence of serious disease. There is some evidence suggesting that improved primary care will lead to fewer hospital admissions.
Asthma definition	Asthma as specified on a hospital record - In-patient diagnosis (ICD-9 493 or ICD-10 J45-J46)
Potential uses	Assessment of regional and national trends over time. Population based geographical comparisons. For more local monitoring, data are currently collected with postcodes and GP identifiers and trends in admission rates could be mapped by electoral ward (using population census as denominators) or practice (using practice population as denominators) to identify areas or practices with the greatest problems and to monitor changes in rates.
Potential users	National and regional policy makers, commissioners, provider management, consumers and the public.
Possible confounders	This indicator is aimed at disease occurrence and severity but will also be influenced by referral thresholds, admission thresholds, supply of hospital care, patients' expectations and the quality of care.
Data sources	The numerator may be obtained from HES data with a primary diagnosis of asthma, and the denominator from census data (or GP practice) for the population concerned.

Data quality	The indicator relies on the accuracy of disease coding and may be affected by respiratory diagnoses other than asthma, such as chronic obstructive pulmonary disease or wheezy bronchitis.
Comments	<p>Despite the limitations outlined above, this is a useful indicator especially when supported by other information. The value of the indicator will be enhanced when the new NHS number is implemented and allows episodes of care to be distinguished from individuals admitted. When such distinctions can be made, it will be useful to distinguish between:</p> <ul style="list-style-type: none">- episode based incidence, counting each admission- person based incidence meaning each person's first ever admission- treated period prevalence, meaning counts of people admitted per annum.
Further work	None recommended.
Conclusion & priority	<p>Priority very high. The data required to compile the indicator are routinely available. The indicator can be compiled, from existing data, at low cost.</p> <p>A - To be implemented generally on a routine basis.</p>
References	<p>Alderson, M. R. (1987). Trends in morbidity and mortality from asthma. <i>Population Trends</i>, 49,18-23.</p> <p>Anderson, H. R. (1989). Increase in hospital admissions for childhood asthma. Trends in referral, severity and re-admissions from 1970 to 1985 in a health region of the United Kingdom. <i>Thorax</i>, 44, 614-619.</p> <p>Burney, P.G., Chinn, S., and Rona, R.J. (1990). Has the prevalence of asthma increased in children? Evidence from the national study of health and growth 1973-86. <i>British Medical Journal</i>, 300, 1306-1310.</p>

Candidate indicator 2

Title	Emergency admission rate per population of people with asthma
Intervention aim	Reduce or avoid acute attacks; reduce impact of asthma on general well-being.
Characteristics	Specificity: Condition-specific Perspective: Clinical Time-frame: Cross-sectional Outcome relationship: Process based proxy.
Indicator definition	For a given GP, or group thereof, period of time, and patient age band: <i>the number of emergency in-patient episodes with a primary diagnosis of asthma divided by the number of patients with asthma in GP population</i> . The numerator and denominator are to be reported as well as the derived rate.
Rationale	Emergency admissions may sometimes be adverse outcomes of antecedent health care. Comparisons of levels of such admissions may also have a role in identifying a high risk population within a practice, on which to focus care.
Asthma definition	<i>Numerator:</i> Asthma as specified on a hospital record - In-patient diagnosis (ICD-9 493 or ICD-10 J45-J46) <i>Denominator:</i> Asthma as defined by GP and recorded in the patients' notes or on an asthma register (Read code (5 character) H33).
Potential uses	Population based comparisons of the effectiveness of primary care provision. The likely low frequency of emergency admissions could make it difficult to draw valid conclusions from comparisons based on individual practices. The value of the indicator for audit within a single practice would be limited for the same reason. As one of a group of indicators it may have a role in identifying a high risk population within a practice, on which to focus care (Jones et al. 1992a).
Potential users	Provider management, commissioners, clinicians.
Possible confounders	Comparisons should be made in the context of information on the relative severity of asthma in the GP populations. The BTS treatment step classification provides a comprehensive process based proxy for severity. This approach would, however, fail to identify practices with a relatively large number of brittle asthma cases (BTS 1993) or differences in levels of patient risk taking. Alternatives to emergency in-patient care such as health clinics or community hospital day care, may be a confounder of this indicator. In-patient admissions recorded using this indicator may therefore underestimate emergency events in asthma requiring specialised care.

Data sources

The numerator may be obtained from HES data with a primary diagnosis of asthma, an emergency method of admission (via GP, bed bureau, out-patients or domiciliary visit, coded 22, 23, 24, 25 respectively) and one of a given set of registered GP codes (based on Prescription Pricing Authority identification). The denominator would be available from those GPs with matching PPA codes who maintain a register of asthma sufferers which includes both diagnostic and prescription information. Where a GP register is capable of identifying an emergency admission to hospital, and the primary diagnosis associated with that admission, it could act as an alternative source of numerator data. This method of recording could be facilitated by adding an explicit record of relevant admissions in the Chronic Disease Management (Band III) dataset. Severity information would only be available from those GPs with a register from which the BTS treatment step can be derived. Where numerator data are obtained from HES, and a breakdown of the indicator by treatment step is desired, record linkage via the NHS number would be required.

Data quality

The validity of the indicator will depend on the quality of HES diagnoses which is unlikely to be uniformly high yet. There may also be incomplete recording of the registered (as distinct from referring) GP within HES data. Deriving the numerator from GP data may be hampered by incomplete recording of emergency admissions, or their association with a given diagnosis. GP based data collection using patient reports of admissions might overcome some of the difficulties in this area. Denominator and severity data would be subject to the general concerns regarding the availability and accuracy of asthma registers.

Comments

There is some evidence that increased use of inhaled steroids is associated with reduced emergency admissions (Price 1995). As a subset, consideration should be given to monitoring rates of 'emergency in-patient admissions for asthma lasting two days or longer'. This may help interpret whether variation in admission rates are due to variation in severity or variation in admission threshold. It may be useful to report, separately, emergency admissions resulting from general practice referrals and self referrals to hospital accident and emergency departments.

Further work

Further assessment of quality of data held on GP asthma registers, and the feasibility of extending the Chronic Disease Management dataset.

Conclusion & priority

An emergency admission is an adverse event and often the outcome of poorly controlled asthma in the community. Hence this indicator has high 'face validity'. However, patterns of care are changing and emergency admissions are increasing for all conditions, making interpretation of these data increasingly difficult.

F - To be further developed because the indicator specification is incomplete.

References

British Thoracic Society, British Paediatric Association, Research Unit of the Royal College of Physicians of London, King's Fund Centre, National Asthma Campaign, Royal College of General Practitioners, General Practitioners in Asthma Group, British Association of Accident and Emergency Medicine, British Paediatric Respiratory Group (1993). Guidelines for the management of asthma. *Thorax*, **48**, Supplement S1-24.

Jones, K. P., Bain, D. J. G., Middleton, M., and Mullee, M. A. (1992a). Correlates of asthma morbidity in primary care. *British Medical Journal*, **304**, 361-364.

Price, D. B. (1995). Patterns of prescribing of inhaled steroids over a seven year period in a general practice and its implications. *Thorax*, **50**, 443P.

Candidate indicator 3

Title	Emergency re-admission rate per population of in-patients discharged with asthma
Intervention aim	Assure return to function after acute attack.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Clinical</p> <p>Time-frame: Cross-sectional</p> <p>Outcome relationship: Process based proxy.</p>
Indicator definition	For a given hospital, or hospital group, period of time, and patient age band: <i>the number of emergency re-admissions to hospital as in-patient with a primary diagnosis of asthma within three months of a previous admission (planned or emergency) where asthma was the primary diagnosis, divided by the total number of patients who were admitted with a primary diagnosis of asthma.</i> Patients who died in the previous admission or who died within the three months would be excluded from the denominator. The numerator and denominator are to be reported as well as the derived rate.
Rationale	Emergency re-admissions can be seen as an adverse outcome of antecedent health care. Adult asthma patients currently have a 40% probability of re-admission over two years (Trent Health 1993).
Asthma definition	Asthma as specified on a hospital record - In-patient diagnosis (ICD-9 493 or ICD-10 J45-J46).
Potential uses	Provider based comparisons of the effectiveness of secondary care provision and clinical audit within the provider unit. The validity of inter-unit comparisons may be affected by factors including small numbers of cases within the groups being compared, the accuracy of source data and the presence of confounding factors.
Potential users	Provider management, commissioners, clinicians.
Possible confounders	Comparisons should be made in the context of information on the relative severity of asthma in the patient populations. The quality of primary care provision is also important.
Data sources	PAS data on emergency admissions (coded 21, 22, 23, 14, 28) could be used to identify re-admissions by matching episodes with the same patient number and primary diagnosis of asthma within the reference period. Re-admissions to other hospitals or specialties would rely on routine use of the new NHS number.
Data quality	The validity of the indicator will depend on the quality of PAS diagnosis which is unlikely to be uniformly high.

Comments

This indicator was considered to be a useful indicator of failure to get asthma under control following an admission and possibly an indicator of poor discharge planning. At the moment it is not possible to calculate this indicator universally on a routine basis because of difficulties in linking episodes of care to individual patients in different hospitals.

Indicators based on re-admission rates may need careful interpretation. Two or more admissions for an individual person may or may not be related; and when related, the re-admission may or may not be avoidable (Henderson et al. 1989). One observational study has shown that re-admission rates in children were reduced where effective discharge procedures were in place (Madge and Paton 1995). However, an earlier randomised controlled study investigating the use of an asthma liaison nurse in children admitted to hospital found that this intervention resulted in an increase in re-admissions (Mitchell et al. 1986). Another controlled trial among adults decreased re-admissions (Mayo et al. 1990). Methodological issues in the use of re-admission rates have been discussed in detail by Henderson et al. (1989, 1993) and by Clarke (1990) and Milne and Clarke (1990).

Further work

None recommended.

Conclusion & priority

High priority should be given to implementation as soon as information systems allow.

B - To be implemented where local circumstances allow on a routine basis.

References

Clarke, A. (1990). Are re-admissions avoidable? *British Medical Journal*, **301**, 1136-1138.

Henderson, J., Goldacre, M.J., Graveney, M.J., and Simmons, H.M. (1989). Use of medical record linkage to study re-admission rates. *British Medical Journal*, **299**, 709-713.

Henderson, J., Graveney, M.J., and Goldacre, M.J. (1993). Should emergency re-admissions be used as health service indicators and in medical audit? *Health Services Management Research*, **6**, 109-116.

Madge, P., and Paton, J. Y. (1995). Impact of structured nurse-led discharge planning on outcome in children hospitalised with acute asthma. *Thorax*, **50**, 464P.

Mayo, P.H., Richman, J., and Harris, H.W. (1990). Results of a program to reduce admissions for adult asthma. *Annals of Internal Medicine*, **112**, 864-871.

Milne, R., and Clarke, A. (1990). Can re-admission rates be used as an outcome indicator? *British Medical Journal*, **301**, 1139-1140.

Mitchell, E.A., Ferguson, V., and Norwood, M. (1986). Asthma education by community child health nurses. *Archives of Diseases in Children*, **61**, 1184-1189.

Trent Health (1993). *Focus on asthma: an aid to contracting*. Trent Health, Sheffield.

Candidate indicator 4

Title	General practice consultation rate per general population
Intervention aim	Reduce or avoid risk of asthma.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Population</p> <p>Time-frame: Cross-sectional</p> <p>Outcome relationship: Proxy for occurrence.</p>
Indicator definition	For a given population, age and sex band and time period: <i>the number of consultations within general practice(s) where the primary diagnosis is asthma divided by the number of people within the practice population.</i>
Rationale	The RCGP data show there has been an increase in asthma related patient consulting between 1970/71 and 1980/81 accompanied by a fall in consultations per patient consulting (Fleming and Crombie 1987). This is consistent with the postulated increase in prevalence or severity of asthma. Monitoring of consultation trends as a proxy for prevalence may be helpful in the evaluation and planning of services.
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register.
Potential uses	Trends over time in national and regional populations. Population or provider based regional comparisons.
Potential users	National and regional policy makers, clinicians, consumers and the public.
Possible confounders	This indicator is aimed at reflecting disease prevalence and severity, but will be influenced also by diagnostic fashion and health behaviour by patients.
Data sources	The numerator may be obtained from GP Read-coded information systems. Such data are also collected every ten years for the General Practice Morbidity Survey. The weekly returns service of the Royal College of General Practitioners also collects data on asthma consultations but from a limited sample of practices (Birmingham Research Unit 1995). The denominator may be obtained from the practice or health authority.
Data quality	The indicator relies on the accuracy and completeness of data held on general practitioners' information systems. This may be of variable quality outside special surveys.

Comments

Despite the limitations outlined above, this is a useful indicator when interpreted alongside other information. The data are collected already in national surveys. With future developments in general practice information systems this indicator may become more widely collectable. Where it is possible to enumerate all patients in a practice with asthma (e.g. those practices with asthma registers) consideration should be given to compiling two additional indicators:

- GP consultation rate for asthma per practice population *not previously diagnosed* with asthma (as a measure of incidence)
- GP consultation rate per population of people with asthma.

Further work

Need to consider standardisation on what is meant by a consultation for asthma, e.g. whether a visit to collect a prescription counts as a consultation. Different computer systems in current use will need some modification to permit compilation of the indicators.

Conclusion & priority

High priority.

B - To be implemented where local circumstances allow on a routine basis.

References

Birmingham Research Unit of the Royal College of General Practitioners (1995). *Weekly returns service report for 1994*. Birmingham Research Unit.

Fleming, D. M., and Crombie, D. L. (1987). Prevalence of asthma and hay fever in England and Wales. *British Medical Journal*, **295**, 279-283.

Candidate indicator 5

Title	General practice consultations before diagnosis of asthma is first made
Intervention aim	Detect asthma early.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Clinical</p> <p>Time-frame: Cross-sectional</p> <p>Outcome relationship: Process based proxy.</p>
Indicator definition	For a given GP, or group of GPs, and patient age band: <i>the mean number of consultations associated with specific respiratory symptoms (cough, wheeze, chest tightness & difficulty in breathing, chest infections), per patient with a subsequent diagnosis of asthma, in the 12 months before the diagnosis of asthma was made.</i>
Rationale	For a patient with asthma to consult their doctor on a number of occasions before a diagnosis is reached is not unusual. There is some concern however, that an unduly delayed diagnosis may delay appropriate treatment (Levy and Bell 1995; Gellert et al. 1990; Jones and Sykes 1990). An accurate diagnosis is more likely to lead to appropriate treatment.
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register, and asthma as defined by those who are prescribed inhaled drugs for asthma for whatever period (For example Read codes: cromoglycate c71% - c72%; beta agonists c1%; inhaled steroids c61% - c64%). The use of the dual definition is intended to focus the indicator on cases with a clear, rather than possible, diagnosis of asthma.
Potential uses	Clinical audit and medical education; population-based trends over time. The validity of such comparisons will be affected by factors including the numbers of cases within the groups being compared, the accuracy of source data and the presence of confounding factors.
Potential users	Clinicians, commissioners.
Possible confounders	The indicator should be reported separately for patients under 5, aged 5-54, and 55 years and over. This is because of the increased prevalence, relative to intermediate age group, of viral-associated transient wheeze in patients younger than 5, and COPD in patients older than 55. An awareness of the frequency of consultations for upper respiratory tract infections in the local population (especially in older patient age-groups) may be helpful in interpreting this indicator.
Data sources	Data should be collected from Read-coded consultation records on GP information systems. Patients with a diagnosis of asthma should be identified, when first made for each patient, and any previous consultations involving reports of asthma-related symptoms one year prior to the date of diagnosis traced and noted. Where routine data in GP systems are not readily available, periodic surveys using a nationally agreed audit tool.

Data quality	Accuracy of data would depend on the quality of documentation yielded by GP information systems.
Comments	An alternative to the number of consultations prior to first diagnosis may be the actual period of time which passed between the initial consultation when respiratory symptoms were reported and the consultation when the asthma diagnosis was given. Monitoring of this indicator could raise awareness of the need to consider asthma in patients attending frequently with respiratory symptoms and help target treatment effectively. Insensitive use of this indicator could lead to perverse incentives to overdiagnose asthma.
Further work	It will not yet be possible to collect these data easily with current GP computer systems. Manual collection (at a cost) will probably be needed in the short term. Numbers of new cases per year in a practice may be too small to be useful. Whether aggregated data will be useful as a monitoring tool is unknown. A formal study is needed to evaluate the utility of this indicator.
Conclusion & priority	Medium priority. Data definition study needed; collection costs could be significant; value of indicator needs to be proven. F - To be further developed because specification is incomplete and link with effectiveness is not clear
References	Gellert, A. R., Gellert, S. L., and Illiffe, S. R. (1990). Prevalence and management of asthma in a London inner city general. <i>British Journal of General Practice</i> , 40 , 197-201. Jones, A., and Sykes, A. (1990). The effect of symptom presentation on delay in asthma diagnosis in children in a general practice. <i>Respiratory Medicine</i> , 84 , 139-142. Levy, M. L., and Bell, L. C. (1984). General practice audit of asthma in childhood. <i>British Medical Journal</i> , 289 , 115-116.

Candidate indicator 6

Title	Accident and emergency attendance rate for asthma related problems per population of people with asthma
Intervention aim	Reduce or avoid acute attacks.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Clinical</p> <p>Time-frame: Cross-sectional</p> <p>Outcome relationship: Process-based proxy.</p>
Indicator definition	For a given GP, or group of GPs, period of time, and patient age band: <i>the number of patients attending accident and emergency, and given a diagnosis of asthma, divided by the number of patients with asthma in the practice population.</i> The numerator and denominator are to be reported as well as the derived rate.
Rationale	Emergency attendances may be an adverse outcome of antecedent health care. Comparisons of levels of such attendances reflecting the effectiveness of primary care provision may have a role in identifying a high risk population, within a practice, on which to focus care (Jones et al. 1992a).
Asthma definition	<p><i>Numerator:</i> Asthma as specified on a hospital record - A&E record.</p> <p><i>Denominator:</i> Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register.</p>
Potential uses	Population based comparisons of the effectiveness of primary care provision. The validity of such comparisons will be affected by factors including the numbers of cases within the groups being compared, the accuracy of source data and the presence of confounding factors.
Potential users	Provider management, commissioners, clinicians.
Possible confounders	Comparisons should be made in the context of information on the relative severity of asthma in the populations. The BTS treatment step classification provides a comprehensive process based proxy for severity. This approach would, however, fail to identify practices with a relatively large number of brittle asthma cases (BTS 1993) or differences in levels of patient risk taking. Other factors to consider are whether the A&E attendances are the result of self referrals or GP referrals; the proximity and organisation of A&E departments; and patients' thresholds for seeking care. There is evidence for a trend away from GP domiciliary visits and towards A&E attendance (Strachan and Anderson 1991). Therefore, it may be advisable to report by referral type. Alternatives to accident and emergency care, such as health clinics or community hospital day care, may be a confounder of this indicator. Accident & emergency attendances recorded using this indicator may therefore underestimate emergency events in asthma.

Data sources A full data set specification exists for the collection of accident and emergency activity. Patients seen and diagnosed with an asthma related condition could be identified by CMDS codes 251 (respiratory condition - bronchial asthma). Currently this data set is not mandatory and therefore has limited use for comparisons. Further work currently underway with the Information Management Group suggests there may be a change to the collection status of this data set.

The denominator would be available from those GPs with matching Prescription Pricing Authority (PPA) codes, who maintain a register of asthma patients which includes both diagnostic and prescription information.

Data quality The validity of the indicator will depend on the quality of diagnoses which would need to be assessed when such records are collected. Denominator and severity data would be subject to the general concerns regarding the availability and accuracy of asthma registers.

Comments The whole practice population could act as an alternative denominator for the indicator on the assumption that a given proportion of any practice's population has asthma, whether diagnosed / registered or not. There is some evidence that increased use of inhaled steroids is associated with reduced emergency admissions (Price 1995). The patients admitted following an A&E attendance could be identified separately from those that were not.

Further work Assessment of the dataset for A&E following its development. Further assessment of quality of data held on GP asthma registers, and the feasibility of extending the Chronic Disease Management dataset.

Conclusion & priority Attendance at A&E is an adverse event in the life of an asthmatic patient. This indicator should be interpreted with indicators 2 and 3. Routine data are not available at the moment on the number of A&E attendances by patients with asthma from particular GP's lists. This information would be useful in order to complement the picture of consultations for asthma in general practice.

D - To be implemented following IT development on a routine basis.

References British Thoracic Society, British Paediatric Association, Research Unit of the Royal College of Physicians of London, King's Fund Centre, National Asthma Campaign, Royal College of General Practitioners, General Practitioners in Asthma Group, British Association of Accident and Emergency Medicine, British Paediatric Respiratory Group (1993). Guidelines for the management of asthma. *Thorax*, **48**, Supplement S1-24.

Jones, K. P., Bain, D. J. G., Middleton, M., and Mullee, M. A. (1992a). Correlates of asthma morbidity in primary care. *British Medical Journal*, **304**, 361-364.

Price, D. B. (1995). Patterns of prescribing of inhaled steroids over a seven year period in a general practice and its implications. *Thorax*, **50**, 443P.

Strachan, D. P., and Anderson, H. R. (1991). Trends in hospital admission rates for asthma in children: change in prevalence or medical care? *British Medical Journal*, **304**, 819-820.

Candidate indicator 7

Title	British Thoracic Society (BTS) treatment step profile
Intervention aim	Reduce or avoid acute attacks; reduce impact of asthma on general well-being.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Clinical</p> <p>Time-frame: Cross-sectional</p> <p>Outcome relationship: Process-based proxy.</p>
Indicator definition	For a given GP, or group of GPs, and patient age band: <i>the percentage of asthma patients within each step of the BTS treatment classification (BTS 1992)</i> as obtained by patient census. In addition to the percentages, the numerators (number of patients at each treatment step) and the denominators (all people in the practice with asthma) should be reported. It may be presented also as population based-rates of people at each step of treatment.
Rationale	By documenting current treatment patterns, in the context of comparisons with other providers, it may indicate areas for detailed local review. It could also be used as a proxy measure for severity.
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register, and asthma as defined by those who are prescribed inhaled drugs for asthma for whatever period. (Read codes: cromoglycate c71%-c72%; beta agonists c1%; inhaled steroids c61%-c64%).
Potential uses	As a proxy measure of case-mix when comparing other indicators. Local management of clinical practice; clinical audit; provider-based comparisons of treatment patterns; assessments of regional/national trends. The value of the indicator for these purposes may be influenced by factors including the number of relevant cases, the accuracy of source data and the presence of confounding factors.
Potential users	Clinicians, commissioners
Possible confounders	Patients with chronic obstructive pulmonary diseases undiagnosed as asthma may confuse interpretation of this indicator. There is a large variability in the approach of GPs to the management of the condition. The treatment step profile may not necessarily reflect good symptom control nor the appropriateness of therapy. Correlating this measure with other indicators such as 15A, B and C may assist in its interpretation.
Data sources	The required data may be obtained from asthma registers holding the relevant prescription information. An analysis of such information from 100 practices using the AAH Meditel system has produced usable reference information on the prevalence of each treatment step within the GP asthma population (Pearson, personal communication). The Chronic Disease Management Band III data set revised to allow for annual review of asthma patients when stable may be useful.

Data quality	The indicator is reliant on the quality of prescription data. It must also be recognised that the prescription of a given dose may not accurately reflect the dose taken.
Comments	Given the proportion of patients at step 2 or greater, a broad estimate of the rate at which inhaled steroids are being prescribed may be made. This is likely to be a slight over-estimate, in view of the likely use of alternative drugs (eg cromoglycate) in a small proportion of cases. The BTS treatment classification is slightly different for children under 5 and this should be taken into account in the use of this indicator.
Further work	Examination of the feasibility of extending the Chronic Disease Management data set. This indicator may be derived from some general practice computer systems but others may need to develop the necessary software tools. Before routine implementation a study will be needed to assess the utility of this indicator and how it should be interpreted.
Conclusion & priority	The BTS step profile was thought to be an important indicator in describing the current 'burden' of asthma within a given GP population. Its value as an outcome indicator lies in comparative analysis, either over time or with others. However, the interpretation of this indicator needs further work. B - To be implemented where local circumstances allow on a routine basis.
Reference	British Thoracic Society, British Paediatric Association, Research Unit of the Royal College of Physicians of London, King's Fund Centre, National Asthma Campaign, Royal College of General Practitioners, General Practitioners in Asthma Group, British Association of Accident and Emergency Medicine, British Paediatric Respiratory Group (1993). Guidelines for the management of asthma. <i>Thorax</i> , 48 , Supplement S1-24.

Candidate indicator 8

Title	Incidence of progression to British Thoracic Society (BTS) treatment step 3 and greater
Intervention aim	Reduce or avoid acute attacks; reduce impact of asthma on general well-being.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Clinical</p> <p>Time-frame: Longitudinal</p> <p>Outcome relationship: Process based proxy.</p>
Indicator definition	For a given GP, or group thereof, and patient age band: <i>the proportion of asthma patients who, having been at step 2 of the BTS treatment classification (BTS 1992) one year previously, are now at step 3, 4 or 5.</i> In addition to the incidence, the numerator (those who progressed to step 3) and denominator (number at step 1 or 2 at start of period) should be reported.
Rationale	Treatment step 3 introduces the use of higher dose inhaled steroids and as such is an indication of greater severity of disease. However, the decision to prescribe such levels of steroids has implications, such as adverse side effects with long term use which may deter both clinicians and patients.
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded on an asthma register and asthma as defined by those who are prescribed inhaled drugs for asthma for whatever period (Read codes: cromoglycate c71%-c72%; beta agonists c1%; inhaled steroids c61%-c64%).
Potential uses	Provider based comparisons of the effectiveness of primary care provision in controlling disease severity. The validity of such comparisons will be affected by factors including the numbers of cases within the groups being compared, the accuracy of source data and the presence of confounding factors.
Potential users	Clinicians, commissioners.
Possible confounders	Any differences between groups of patients in severity of disease when at steps lower than 3 and their potential to progress; patients' compliance with care and level of risk taking behaviour; presence of any exacerbating environmental factors.
Data sources	The required data may be obtained from asthma registers holding the relevant prescription information. An analysis of such information from 100 practices using the AAH Meditel system has produced usable reference information on the prevalence of each treatment step within the GP asthma population (Pearson, personal communication).
Data quality	The indicator is reliant on the quality of prescription data. It must also be recognised that the prescription of a given dose may not accurately reflect the dose taken.

Comments

In addition to the casemix factors noted earlier, this indicator is likely to be influenced by variations in clinicians' practice and/or patients' preferences with respect to the risks and benefits of inhaled steroids. For some patients, treatment is started on high levels of medication with the aim of reducing when indicated. Current understanding of fluxes between treatment steps is fairly rudimentary.

Further work

Further assessment of the quality of relevant data within asthma registers. The availability of prescription data from two sources offers the opportunity to compare them and study their validity.

Conclusion & priority

The development of this indicator was of considerable clinical interest. However, there are many technical difficulties in operationalising such an indicator, such as whether change is of a temporary or permanent nature.

F - To be further developed because specification is incomplete and link with effectiveness is not clear.

Reference

British Thoracic Society, British Paediatric Association, Research Unit of the Royal College of Physicians of London, King's Fund Centre, National Asthma Campaign, Royal College of General Practitioners, General Practitioners in Asthma Group, British Association of Accident and Emergency Medicine, British Paediatric Respiratory Group (1993). Guidelines for the management of asthma. *Thorax*, **48**, Supplement S1-24.

Candidate indicator 9

Title	Compliance with British Thoracic Society (BTS) guidelines for acute asthma care
Intervention aim	Assure return to function after acute attack.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Clinical</p> <p>Time-frame: Cross-sectional</p> <p>Outcome relationship: Combination of process-based proxy and direct measures.</p>
Indicator definition	<p>For a given hospital, or hospital group and time period: <i>the proportion of episodes of acute asthma care meeting each of the following eight care guidelines as defined by the British Thoracic Society national audit minimum dataset (Pearson et al. 1995):</i></p> <p style="padding-left: 40px;"><i>On admission:</i></p> <ol style="list-style-type: none"> 1. PEF measured 2. Arterial blood gases measured or oxygen saturation >92% 3. Treated with systemic steroids <p style="padding-left: 40px;"><i>Management in hospital:</i></p> <ol style="list-style-type: none"> 4. Peak flow variability reduced to <25% before discharge <p style="padding-left: 40px;"><i>On discharge:</i></p> <ol style="list-style-type: none"> 5. Oral steroids prescribed 6. Inhaled steroids prescribed 7. Out-patient appointment planned 8. Self-management plan provided. <p>The indicator should report:</p> <ul style="list-style-type: none"> - the percentage compliance rate for each individual recommendation - the mean number of recommendations complied with per episode.
Rationale	<p>Items 1, 2, 3, 5, 6, 7, 8 are amongst elements of the process of care identified by the British Thoracic Society as making up the most appropriate management of an acute episode - and as such most likely to produce the desired outcomes for the episode (BTS et al. 1990; BTS et al. 1993). Item 4, arises from the same national guidelines, and is an intermediate outcome for which there is conflicting evidence that where the standard is not met, there is a greater chance of emergency re-admission (Udwadia and Harrison 1990; Bucknall et al. 1992; Williams et al. 1994).</p>
Asthma definition	<p>Asthma as specified on a hospital record - In-patient diagnosis (ICD-9 493 or ICD-10 J45-J46).</p> <p>Patients admitted electively for stabilisation are to be excluded.</p>

Potential uses	Clinical audit and provider-based comparisons. The validity of such comparisons will be affected by factors including the numbers of cases within the groups being compared, the accuracy of source data and the presence of confounding factors.
Potential users	Clinicians, provider management, commissioners.
Possible confounders	Comparisons should be made in the context of information on the relative severity of asthma in the patient populations and lung function measurements are a component of the guideline. The BTS step classification, once validated, could provide additional information about severity.
Data sources	Periodic use of the BTS acute asthma audit tool to collect the minimum dataset.
Data quality	The minimum dataset has been collected with apparent success at 36 hospitals between 1990 and 1995 (Pearson et al. 1995). The completeness and accuracy of supplied data have yet to be examined.
Comments	These values are a mixture of specific therapies (such as oral steroids) and administrative arrangements for care (such as out-patient appointment planned). These are important factors in care and could be used as indicators of quality or completeness of care, which in turn bear some relation to subsequent experience of illness.
Further work	Validation of routine collection of the BTS national audit minimum dataset. Value of indicator also needs to be examined.
Conclusion & priority	Knowing about current practice within a hospital is useful both from a professional and organisational view. The monitoring of the BTS guidelines provides this information quickly.

C - To be implemented where local circumstances allow by periodic survey.

References	<p>British Thoracic Society, Research Unit of the Royal College of Physicians of London, King's Fund Centre and National Asthma Campaign (1990). Guidelines for the management of asthma in adults : 2. acute severe asthma. <i>British Medical Journal</i>, 301, 797-800.</p> <p>British Thoracic Society, British Paediatric Association, Research Unit of the Royal College of Physicians of London, King's Fund Centre, National Asthma Campaign, Royal College of General Practitioners, General Practitioners in Asthma Group, British Association of Accident and Emergency Medicine, British Paediatric Respiratory Group (1993). Guidelines for the management of asthma. <i>Thorax</i>, 48, Supplement S1-24.</p> <p>Bucknall, C.E., Robertson, C. Moran, F., and Stevenson, R.D.(1992). Why uncritical criterion based audit is not enough: analysis of PFR data from a prospective asthma audit. <i>Thorax</i>, 48, 884P.</p>
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Pearson, M., Ryland, I., and Harrison, B.D.W. (1995). National audit of acute severe asthma in adults. *Quality in Health Care*, **4**, 24-30.

Udwadia, Z.F., and Harrison, B.D.W. (1990). An attempt to determine the optimal duration of hospital stay following a severe attack of asthma. *Journal of the Royal College of Physicians of London*, **24**, 112-114.

Williams, T. J., Spencer, J., Fahey, T., and Harris, L. (1994). Timing of discharge from hospital of patients admitted with asthma: a district general hospital experience. *Journal of the Royal College of Physicians London*, **28**, 306-309.

Candidate indicator 10

Title	Current lung function as percentage of individuals' best lung function
Intervention aim	Reduce or avoid acute attacks; assure return to function after acute attack; reduce impact of asthma on general well-being.
Characteristics	Specificity: Condition-specific Perspective: Clinical Time-frame: Cross-sectional Outcome relationship: Direct.
Indicator definition	For a given GP, or group of GPs, and patient age band: <i>current PEF expressed as a percentage of best PEF achieved per patient measured, based on the most recent recording when patient was stable, and aggregated as the average in the patient population. Best function is accepted as defined by Connolly et al. (1994).</i>
Rationale	Measurements of pulmonary function are well-established clinical measures in asthma care, and provide information on the severity of disease and quality of symptom management. Such measurements of severity can give an indication of the success of current management. Although some studies suggest that there is a relatively low correlation between volumetric measurement and patient perceptions of symptoms, other work (Marks et al. 1992) has resolved these contradictions by more precise analyses of the relation between symptoms and pulmonary function which suggest that breathlessness and patients' concerns have strong correlations with measurements of PEF.
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register.
Potential uses	Aggregated data for this variable could be used as standards for use in clinical audit (eg within a GP practice); and as a basis for effectiveness comparisons between individual GPs or practices. The validity of such comparisons will be affected by factors including the numbers of cases within the groups being compared, the accuracy of source data and the presence of confounding factors.
Potential users	Clinicians, provider management, commissioners.
Possible confounders	Any differences between groups of patients in the severity of their disease.
Data sources	Peak flows should be recorded as part of the minimum data set of the Chronic Disease Management programme band III.

Data quality	The indicator could be heavily biased by opportunistic data collection by the GP, ie collecting 'current lung function' when the patient presents with what may be an asthma-related problem. Better data would come from a regular review at some fixed period or when the patient has been identified as stable. The age and reliability of peak flow meters need to be comparable at the time the measurements are made. Standardisation and calibration of meters is therefore important. A single measurement of PEF is likely to have limited reliability. This problem could be overcome by recasting the indicator as some measure of pulmonary function over a period of, say, two weeks. However, repeated visits by the patient for assessment are likely to be impractical. Best function must also be recalibrated periodically.
Comments	Although FEV1 based measures have major long term advantages, the accessibility of PEF as a measure outweighs this. Annual reviews of peak flow may provide a 'best function' assessment. The wider availability of peak flow meters, including portable ones, opens up the possibility of the routine monitoring of pulmonary function, without surgery visits. The prescription of peak flow meters is currently patchy, and there are concerns about their contribution to effective self-medication (GRASSIC 1994). It is unclear to what extent patients would be prepared to support routine monitoring of pulmonary function through self-assessment and self-report.
Further work	Investigation of implications of best-function-based measurement for interpretation of aggregate indicator data.
Conclusion & priority	Best function is better as an outcome indicator, while recorded peak flow divided by predicted peak flow (on the basis of age, sex and height) is useful in clinical diagnosis. A decline in best function over a period of years would indicate progression of asthma with irreversible lung disease.
	E - To be implemented following IT development by periodic survey.
References	<p>Connolly, C. K., Prescott, R. J., Alcock, S. M., and Gatnash, A. A. (1994). Actual over best function as an outcome measure in asthma. <i>Respiratory Medicine</i>, 8, 453-459.</p> <p>Marks, G. B., Dunn, S. M., and Woolcock, A. J. (1992). A scale for the measurement of quality of life in adults with asthma. <i>Journal of Clinical Epidemiology</i>, 45, 461-472.</p> <p>GRASSIC (1994). Effectiveness of routine self monitoring of peak flow in patients with asthma. <i>British Medical Journal</i>, 308, 564-567.</p>

Candidate indicator 11

Title	Loss of best lung function over time
Intervention aim	Reduce or avoid acute attacks; assure return to function after acute attack; reduce impact of asthma on general well-being.
Characteristics	Specificity: Condition-specific Perspective: Clinical Time-frame: Longitudinal Outcome relationship: Direct.
Indicator definition	For a given GP, or group of GPs, and patient age band: <i>the loss of best lung function as defined by Connolly (Connolly et al. 1994)</i> . The measure in an individual patient is the loss of best lung function per year (i.e. current value expressed as percentage of best lung function). The indicator, compiled from measures on a number of patients, is the median value of the 'percentage loss' in the group. 'Best lung function' needs to be referenced to that predicted from each patient's age and height.
Rationale	The development of irreversible airflow obstruction registered by loss of best function can give an indication of the success of long term management. This outcome measure would show the average annual decline in best function (which should be 0 for many patients) and could prompt further assessment for some patients.
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register.
Potential uses	Aggregated data for this variable could be used as standards for use in clinical audit (eg within a GP practice); and as a basis for effectiveness comparisons between individual GPs or practices. The validity of such comparisons will be affected by factors including the numbers of cases within the groups being compared, the accuracy of source data and the presence of confounding factors.
Potential users	Provider management, commissioners, clinicians.
Possible confounders	Any differences between groups of patients in the severity of their disease.
Data sources	This measure would be reviewed in conjunction with indicator 10 (current lung function) and would be derived from the same source, by review of serial observations. Peak flows should be recorded for inclusion on the asthma register which is part of the Chronic Disease Management programme.
Data quality	Dependent on acceptance of value of best function as a useful tool, and its measurement in an agreed manner.

Comments

Although FEV1 based measures have some long term advantages, the accessibility of PEF as a measure outweighs this. Annual reviews of peak flow may provide a best function assessment. The wider availability of peak flow meters, including portable ones, opens up the possibility of routine monitoring of pulmonary function, without surgery visits. The prescription of peak flow meters is currently patchy, and there are concerns about their contribution to effective self-medication (GRASSIC 1994). It is unclear to what extent patients would be prepared to support routine monitoring of pulmonary function through self-assessment and self-report.

Further work

Validation study required to test utility, practicality, robustness.

Conclusion & priority

This could be an important indicator and should have medium priority to be implemented within five years. The validation study should have high priority to enable this.

C - To be implemented following IT development by periodic survey.

References

Connolly, C. K., Prescott, R. J., Alcock, S. M., and Gatnash, A. A. (1994). Actual over best function as an outcome measure in asthma. *Respiratory Medicine*, **8**, 453-459.

GRASSIC (1994). Effectiveness of routine self monitoring of peak flow in patients with asthma. *British Medical Journal*, **308**, 564-567.

Candidate indicator 12

Title	Age-specific mortality rate
Intervention aim	Reduce risk of death.
Characteristics	Specificity: Condition-specific Perspective: Population Time-frame: Cross-sectional Outcome relationship: Direct.
Indicator definition	Adapted from Public Health Common Data Set indicator CDS- C3B (Department of Health 1993b). For a given population, age band and sex: <i>deaths in residents of an area from asthma (ICD 493 or J45-J46) per 100,000 resident population.</i>
Rationale	Variations in asthma mortality may be partly explained by variations in the prevalence of asthma and its severity (McColl and Gulliford 1993). Given that the latter variables are unmeasured for the whole population, geographical differences in this indicator may not easily be interpreted as reflecting differences in health service provision. A substantial proportion of asthma deaths are recognised as avoidable and, within a region, the effectiveness of interventions aimed at preventing them should be reflected by changes in the indicator over time (McColl and Gulliford 1993).
Asthma definition	Asthma as the underlying cause on death certificate ie. ICD-9 493 or ICD-10 J45-J46.
Potential uses	Population-based comparisons; trends over time. The validity of such comparisons will be affected by factors including the numbers of cases within the populations being compared, the accuracy of source data and the presence of confounding factors.
Potential users	National and regional policy makers, commissioners, clinicians, consumers and the public.
Possible confounders	The Public Health Common Data Set reports this indicator by age and sex. A wide range of other patient variables have a potential influence on the indicator.
Data sources	Office for National Statistics.
Data quality	The indicator depends on the reliability of recording the underlying cause of death by the death certificate. (British Thoracic Association 1984; Goldacre 1993).
Comments	It would be useful to have systematic information on the extent of variation in death certificate practice for adults.
Further work	None.

Conclusion & priority

This indicator should be used for monitoring trends over time and for comparing large populations. The data on which the indicator is based are collected routinely.

A - To be implemented generally on a routine basis.

References

British Thoracic Association (1984). Accuracy of death certificates in bronchial asthma. *Thorax*, **39**, 505-509.

Department of Health (1993b). *Public health common dataset Part 1: indicator definition*. Institute of Public Health, University of Surrey.

Goldacre, M.J. (1993). Cause-specific mortality: understanding uncertain tips of the disease iceberg. *Journal of Epidemiology and Community Health*, **47**, 491-496.

McColl, A. J., and Gulliford, M. C. (1993). *Population health outcome indicators for the NHS - a feasibility study for the Department of Health*. Faculty of Public Health Medicine of the Royal College of Physicians, London.

Candidate indicator 13

Title	Years of life lost
Intervention aim	Reduce risk of death.
Characteristics	Specificity: Condition-specific Perspective: Population Time-frame: Cross-sectional Outcome relationship: Direct.
Indicator definition	Public Health Common Data Set indicator CDS-C7 (Department of Health 1993b). For a given population and age band: <i>years of life lost (YLL) up to the age 75 due to asthma (ICD 493 or J45/J46), calculated as: $YLL = (74.5 - y) * N_y$</i> ; summed over ages 0 to 74, where y is age at death and N_y is the number of deaths associated with ICD 493 or J45/J46 within a given time period.
Rationale	Variations in asthma mortality may be partly explained by variations in the prevalence of asthma and its severity (McColl and Gulliford 1993). Given that the latter variables are unmeasured for the whole population, geographical differences in this indicator may not easily be interpreted as reflecting differences in health service provision. A substantial proportion of asthma deaths are recognised as avoidable and, within a region, the effectiveness of interventions aimed at preventing them should be reflected by changes in the indicator over time (McColl and Gulliford 1993).
Asthma definition	Asthma as a primary cause on death certificate ie. ICD-9 493 or ICD-10 J45-J46.
Potential uses	Population based comparisons; trends over time.
Potential users	National and regional policy makers, commissioners, clinicians, consumers and the public.
Possible confounders	Public Health Common Data Set reports this indicator by sex. A wide range of other patient variables have a potential influence on the indicator.
Data sources	Office of National Statistics.
Data quality	The indicator depends on the reliability of recording the underlying cause of death by the death certificate (British Thoracic Association 1984; Goldacre 1993).
Comments	It would be useful to have systematic information on the extent of variation in death certificate practice for adults.
Further work	None recommended.

Conclusion & priority

This indicator should be used for monitoring trends over time and for comparing large populations. The data on which this indicator is based are collected routinely.

A - To be implemented generally on a routine basis.

References

British Thoracic Association (1984). Accuracy of death certificates in bronchial asthma. *Thorax*, **39**, 505-509.

Department of Health (1993b). *Public health common dataset Part 1: indicator definition*. Institute of Public Health, University of Surrey.

Goldacre, M.J. (1993). Cause-specific mortality: understanding uncertain tips of the disease iceberg. *Journal of Epidemiology and Community Health*, **47**, 491-496.

McColl, A. J., and Gulliford, M. C. (1993). *Population health outcome indicators for the NHS - a feasibility study for the Department of Health*. Faculty of Public Health Medicine of the Royal College of Physicians, London.

Candidate indicator 14

Title	Case-fatality rate within a defined period of hospital admission
Intervention aim	Reduce risk of death.
Characteristics	Specificity: Condition-specific Perspective: Population Time-frame: Longitudinal Outcome relationship: Direct.
Indicator definition	For a given provider unit, or group thereof, and time period: <i>the proportion of in-patients with a primary diagnosis of asthma who die within 30 days of their admission.</i> The numerator and denominator are to be reported as well as the derived rate.
Rationale	Mortality in hospital, or within 30 days of admission, may in part represent an adverse outcome of antecedent health care. Comparisons of mortality rates, with suitable casemix controls, across providers may reflect the effectiveness of care within individual provider units. In particular, comparisons in large populations over time may indicate whether care is resulting in improved outcomes.
Asthma definition	Asthma as the underlying cause of death on death certificate ie. ICD-9 493 or ICD-10 J45-J46.
Potential uses	Provider based comparisons of the effectiveness of secondary care provision. Clinical audit of individual fatal cases within the provider unit. Trends over time. The validity of comparisons between providers will be affected by many factors including the rarity of the event, the accuracy of source data and the presence of confounding factors.
Potential users	Provider management, commissioners, clinicians.
Possible confounders	Comparisons should be made in the context of information on the relative severity of asthma in the patient populations. The BTS treatment step classification provides a comprehensive process based proxy for severity. Alternatively, a measure of 'best' lung function could provide a more direct measure of severity (Connolly et al. 1994).
Data sources	For in-hospital mortality, the numerator and denominator data may be obtained from HES data with a primary diagnosis of asthma and discharge method coded as death (coded 4). Identification of all deaths, including those outside hospital, within a defined time-period such as 30 days would require linkage between hospital records and death certificates. Severity data will require linkage with GP information on prescribing and / or lung function.

Data quality	Any problems with accuracy of items in HES and availability of GP severity data may be overcome by abstraction from clinical notes, in view of the small number of deaths in any one locality.
Comments	There are 1,600 deaths ascribed to asthma per year in the UK and only a minority of these occur soon after an in-patient episode. However, this indicator may provide useful information, particularly comparing trends in large populations over time, when used in conjunction with total mortality rates from asthma (Candidate 12) and hospital admission rates (Candidate 1).
Further work	Further work could be usefully undertaken using data which are already available to investigate the use and interpretation of this indicator.
Conclusions & priority	<p>The data are already available for mortality in hospital, but the indicator is probably of limited local use due to the rarity of its occurrence. Its value in monitoring long-term trends over time in a large, defined population (eg nationally) is worth exploring, as is its value for study as a sentinel event.</p> <p>F - To be further developed because utility of this indicator is not clear.</p>
Reference	Connolly, C. K., Prescott, R. J., Alcock, S. M., and Gatnash, A. A. (1994). Actual over best function as an outcome measure in asthma. <i>Respiratory Medicine</i> , 8 , 453-459.

Candidate indicators 15 (A, B and C)

Title	Patient-assessed impact measures: <i>detailed specifications are provided on the three indicator sheets which follow.</i>
Intervention aim	Reduce or avoid risk of asthma; assure return to function after acute attack; reduce impact of asthma on general well-being.
Characteristics	Specificity: Condition-specific Perspective: Patient Time-frame: Cross-sectional or longitudinal Outcome relationship: Direct.
Indicator definition	<p>Within this indicator there are <i>three alternative versions</i> which offer an opportunity for patient-assessed impact measurement. These differ in their mode of data collection. Each version, while addressing similar areas of patient concern, represents a trade-off between ease of administration and depth of questioning.</p> <p>The first (15A) is a <i>consultation based questionnaire</i> which is short and suitable for a busy clinic setting. Its advantages are that it could easily be integrated with a consultation or other patient contact and is undemanding in terms of data collection. However, its simplicity does mean that it has limited detail.</p> <p>The second (15B) is a <i>longer battery of questions</i> which is more suitable for use in a postal survey. The additional questions allow collection of information at a greater level of detail. The questions may also be divided into subsets for separate analysis.</p> <p>The third (15C) is a <i>computer-based questionnaire</i> which provides an opportunity to collect an even greater level of detail but more specifically tailored to the needs of the individual. Such a method of questioning allows capture of individual concerns which will therefore identify disabilities which are important to a patient in terms of handicap.</p>
Rationale	Patient assessed measures which reflect the impact of asthma on the lifestyle of the individual asthma sufferer can make a significant contribution to the management of their care. Alongside clinical indicators such as lung function, capturing patients' subjective feelings will be more likely to provide valid information on symptom control, functional health status and quality of life.
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in patients' notes or on an asthma register.
Potential uses	Formal monitoring of these symptoms, with reference to normative data, may be valuable in highlighting the need for alteration in the management of individual cases of asthma - eg appropriateness of medication and organisation of self-care. Aggregated data for this variable could be used for norms, as above; standards for use in local audit (eg within a GP practice); and as a basis for effectiveness comparisons between individual GPs or practices.

Comments

The body of developmental work in the field of patient assessed outcomes allows clear recommendations to be made regarding the broad structure of the consultation-based and postal questionnaires. Indeed, in each case it has been possible to identify an example of an instrument or instruments that are already yielding encouraging results regarding practicality, validity etc.. However, the rationale for selecting a single measure from among the available alternatives is less clear. Little comparative information is currently available to assist the selection process. Thus the research needs associated with these indicators relate to the selection of specific items and testing of their measurement properties within the context of the potential uses outlined above. The proposals for the computer-based questionnaire remain more speculative at this time and the required research investment is likely to be higher.

Conclusion

The Group has yet to decide on a patient assessed outcome measure for asthma. The advantage of a question that measures, say, sleep disturbance or exercise tolerance is that it is clear what the outcome indicator relates to. However, single symptoms do not really give a total picture of a patient's condition. Combined symptom scores, which develop a severity index, do have the advantage of taking several symptoms into consideration at once but suffer the disadvantage of being more complex and lacking face validity as to what the number actually means or is measuring. There are also some problems associated with collecting large amounts of such patient assessed data in a systematic way. At the moment the likely role of patient assessed measures will be in specially commissioned surveys, research and audit, rather than as part of routine information systems. However, with developments in information technology some of these problems may be overcome in the future.

Candidate indicator 15A

Title	Patient assessed impact measure: at consultation
Intervention aim	Reduce/avoid risk of asthma; assure return to function after acute attack; reduce impact of asthma on general well-being.
Characteristics	Specificity: Condition-specific Perspective: Patient Time-frame: Cross-sectional or longitudinal Outcome relationship: Direct.
Indicator definition	<p>For an individual asthma patient, the measure is defined by the <i>patient's response to a small set of questions</i>. The following morbidity index revised from Jones et al. (1992b) is given as a field-tested example.</p> <p>Example: Morbidity index</p> <p>During the last four weeks:</p> <p><i>Have you been in a wheezy or asthmatic condition at least once per week?</i> Yes/No</p> <p><i>Have you had time off work or school because of wheeze or asthma?</i> Yes/No</p> <p><i>Have you suffered from attacks of wheezing during the night?</i> Yes/No</p> <p>Scoring:</p> <p>No to all questions = low morbidity One yes = medium morbidity Two or three yeses = high morbidity.</p> <p>The indicator would be compiled for a given GP, or group of GPs, and patient age band as the response rate mean scores and score profile per practice population of patients with asthma.</p>
Rationale	<p>The questions in this example are sufficiently brief to be used during a consultation as a simple global measure of the patient's assessment of their morbidity. The advantages are that three of the five areas identified by the Working Group as particularly relevant for patient assessment are covered (the others are fear as a result of asthma, and impact of asthma on activities beyond school or work). In the example the response required is a simple yes or no. There are other measures which prompt the patient for the number of days in which the patient has experienced different symptoms (Steen et al. 1994) or have a different reference period, eg a year rather than the last four weeks.</p>
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register.

Potential uses	Formal monitoring of these symptoms, with reference to normative data, may be valuable in highlighting the need for alteration in the management of individual cases of asthma - eg appropriateness of medication and organisation of self-care. Aggregated data for this variable could be used for norms, as above; standards for use in local audit (eg within a GP practice); and as a basis for effectiveness comparisons between individual GPs or practices. The validity of such comparisons will be affected by factors including the numbers of cases within the groups being compared, the response rate obtained and the presence of confounding factors.
Potential users	Clinicians, commissioners.
Possible confounders	Interpretation of this indicator may be aided if it, and its associated norms, are broken down by BTS treatment step - acting as a proxy for disease severity. It is also possible that patient assessment of symptoms may vary systematically with age and sex and therefore that consideration should be given to compiling indicators which are age-sex-specific.
Data sources	Self report - orally. The set of questions would be asked during visits to the surgery and documented in the patient's records. To encourage documentation of this information, these questions could form part of an extended minimum data set for the Chronic Disease Management Programme band III.
Data quality	No particular points.
Comments	<p>The focus of the example indicator on the 'last month' represents a sensible compromise between the need for reliability and the limitations of respondents' memories. The indicator could be heavily biased by opportunistic data collection by the GP, ie when the patient presents with what may well be an asthma related problem. Better data would come from an annual review. As a compromise between these alternatives, data collection could be based around some other regular contact with the surgery, such as the collection of a repeat prescription. As another alternative, stable patients might be targeted for questioning - thus avoiding any patients with a current acute exacerbation of their symptoms. This would however entail the reliable identification of stable patients.</p> <p>As mentioned, the morbidity index (Jones et al. 1992b) covers three of the five topics identified as particularly important for self-assessment. Two further questions could be added to cover fear due to asthma and social activities beyond work and school. Examples of such questions, which might be adapted to the requirements of the indicator, are available from the literature (Steen et al. 1994; Health Outcomes Institute 1994).</p>

Further work

The morbidity index provides an example of the kind of brief validated instrument that would be suitable for routine use within consultations (Jones et al. 1992a; Jones et al. 1992b). The value of an additional question, relating to fear due to asthma, is currently being assessed. Alternative items, compatible with the format of the index, could be tested alongside the standard instrument to assist in the identification of an optimal selection.

Conclusions & priority

High priority should be given to implementing a simple symptom based indicator. Work is required to define the most suitable questions. They can easily be asked; and the information is relevant to patient well being.

B - To be implemented where local circumstances allow on a routine basis.

References

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Steen, N., Hutchinson, A., McColl, E., Eccles, M. P., Hewison, J., Meadows, K. A., Blades, S.M., and Fowler, P. (1994). Development of a symptom based outcome measure for asthma. *British Medical Journal*, **309**, 1065-1068.

Candidate indicator 15B

Title	Patient-assessed impact measure: questionnaire-based
Intervention aim	Reduce/avoid risk of asthma; assure return to function after acute attack; reduce impact of asthma on general well-being.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Patient</p> <p>Time-frame: Cross-sectional or longitudinal</p> <p>Outcome relationship: Direct.</p>
Indicator definition	<p>For an individual asthma patient, the measure is defined by <i>the patient's response to a longer, more detailed questionnaire</i>. The asthma health status measure for ambulatory care (Hutchinson et al. 1995) is given as a validated example. Each of the four sections yields a separate sub-score. Sections may be used independently or combined. For a given group of patients, eg. all those with asthma in a clinician's practice, the indicator would be compiled from scores on individuals to give aggregate scores for the group. The scores and/or subscores should be reported in the context of the number responding to the question, the response rate and the standard deviation of the responses.</p> <p>Asthma Health Status Measure for Ambulatory Care.</p> <p>Example questions:</p> <p><i>In the past month, on how many days have you been short of breath when you were not exercising?</i></p> <p>Never/On one or a few days/On several days/On most days/Every day.</p> <p><i>For how much time during the past month did you feel full of life?</i></p> <p>All of the time/Most of the time/A good bit of the time/Some of the time/A little of the time/None of the time.</p> <p>The questions above are taken from one study and it should be noted that a wide variety of alternative instruments are available (Jones 1991; Juniper et al. 1992; Marks et al. 1992; Hyland et al. 1991).</p>
Rationale	<p>This longer questionnaire has the advantage of extending both the range and detail of the topics covered, beyond that collected with the short consultation-based index (15A). Many questionnaires of this type are in sections, allowing separate analysis of sub-scores. For instance the sub-sections from the example given are general health, emotional health, asthma symptoms and asthma, and life style. As well as providing individual scores for comparison with other asthmatics, analysis of the scores from the general or emotional health sub-sections would facilitate comparisons of patient assessed outcomes across different conditions.</p>

Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register.
Potential uses	Such a tool could be used both as a cross-sectional measure to screen for morbidity or longitudinally to measure the impact of treatment. It is perhaps less likely, because of the resource implications of data collection, that this indicator would be used routinely in the management of individual cases of asthma. More appropriate use may be in the development of norms, for example at health authority level, from annual surveys. Such norms could then be used to guide the development of standards for local audit (eg within a GP practice); and as a basis for effectiveness comparisons between individual GPs or practices. The validity of such comparisons will be affected by factors including the numbers of cases within the groups being compared, the response rate obtained and the presence of confounding factors.
Potential users	Clinicians, commissioners.
Possible confounders	Interpretation of this indicator may be aided if it, and its associated norms, are broken down by BTS treatment step - acting as a proxy for disease severity. It is also possible that symptomatic patient assessment may vary with age and sex.
Data sources	The data would be collected through postal questionnaires (taking about 10-15 mins per person) which could either be given out during consultation on other matters not related to asthma or sent to known asthma sufferers as part of an annual review. High response rates from trials of these batteries of questions are evidence that patients are willing to provide such information (Juniper et al. 1992).
Data quality	No particular points.
Comments	<p>The focus of the example indicator on the 'last month' represents a sensible compromise between the need for reliability and the limitations of respondents' memories. The indicator could be biased by opportunistic data collection as patients may present with asthma related problems. Better data would come from periodic reviews. As an alternative, stable patients might be specifically targeted for questioning - thus avoiding any patients with a current acute exacerbation of their symptoms. This would however entail the reliable identification of stable patients.</p> <p>A longer questionnaire may have an advantage over a shorter one in terms of the greater opportunity to design an instrument which has both discriminatory power as well as responsiveness to change. Indeed, one stated aim of the Hutchinson et al's questionnaire is that it should be able to measure the impact of an intervention over time, as well as health status at a point in time. Such measures require testing to ensure sensitivity and responsiveness to change. While the validity of this instrument has been reported, we have noted earlier that there are many other instruments designed to provide similar information.</p>

Further work

Further studies on the Hutchinson et al. (1995) questionnaire are currently underway using this indicator in a routine setting (McColl et al. 1995). Once this piloting is complete, the results should be compared with similar alternative measures. Work will also need to be done on interpretation.

Conclusion & priority

High priority should be given to conducting surveys based on validated questionnaires such as this. These would probably be specially commissioned surveys and not part of routine data collection.

F - To be further developed because specification is incomplete.

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Candidate indicator 15C

Title	Patient-assessed impact measure: computer-based
Intervention aim	Reduce/avoid risk of asthma; assure return to function after acute attack; reduce impact of asthma on general well-being.
Characteristics	Specificity: Condition-specific Perspective: Patient Time-frame: Cross-sectional or longitudinal Outcome relationship: Direct.
Indicator definition	For an individual asthma sufferer, the measure is defined by <i>the patient's response to a battery of questions surrounding asthma symptoms, management and quality of life</i> . An example is the Asthma Health Status for ambulatory care questionnaire (Steen et al. 1994). The indicator, for a given population of patients with asthma, would be compiled from individual scores to give aggregated values for the group of patients as a whole.
Rationale	Such questions would be part of a computer based intelligent system in which the questioning focuses on issues determined by the patient's responses to earlier questions. The advantages of this method over the previous indicators are that, whilst it would still elicit information in the areas highlighted as important by the Working Group, it also allows for detailed questioning relating to issues of importance to the individual.
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register.
Potential uses	Formal monitoring of these symptoms, with reference to normative data, may be valuable in highlighting the need for alteration in the management of individual cases of asthma - eg appropriateness of medication and organisation of self-care. Aggregated data for this variable could be used for norms, as above; standards for use in local audit (eg within a GP practice); and as a basis for effectiveness comparisons between individual GPs or practices.
Potential users	Clinicians, commissioners.
Possible confounders	Interpretation of this indicator may be aided if it, and its associated norms, are broken down by BTS treatment step - acting as a proxy for disease severity. It is also possible that symptomatic patient assessment may vary with age and sex.
Data sources	The data would be captured through a computer in the surgery using touch screen or other data entry methods currently being developed. Another option would be optical mark read forms (similar to the those used in the UK National Lottery) which would speed up the data entry and not limit patient use.

Data quality	No particular points.
Comments	<p>The same considerations apply as described in the first paragraph of 'comment' for Candidate 15B.</p> <p>Methods of assessment and data collection in asthma management using intelligent computer questioning are currently being developed and piloted such as the South Wales - Shared Care Asthma Project (Edwards et al. 1996) and should be considered as potential standard models of data collection.</p>
Further work	Further research into development and validation of such methods and techniques.
Conclusions & priority	This indicator collection method is novel and should have a medium priority, pending further research and development.
References	<p>F - To be further developed because specification is incomplete.</p> <p>Steen, N., Hutchinson, A., McColl, E., Eccles, M. P., Hewison, J., Meadows, K. A., Blades, S.M., and Fowler, P. (1994). Development of a symptom based outcome measure for asthma. <i>British Medicine Journal</i>, 309, 1065-1068.</p> <p>Edwards, P., Jones, S., Shale, D., and Thursz, M. (1996). <i>Shared care: a model for clinical management</i>. Radcliffe Medical Press, Oxford.</p>

Candidate indicator 16

Title	Patient satisfaction with asthma care
Intervention aim	Reduce or avoid acute attacks; assure return to function after acute attack; reduce impact of asthma on general well-being.
Characteristics	Specificity: Condition-specific Perspective: Patient Time-frame: Cross-sectional Outcome relationship: Direct.
Indicator definition	<p>For a specified population of asthma patients, the indicator is defined as the <i>mean satisfaction score of responses to the following questions.</i></p> <p><i>How satisfied are you with the information and care received from health care professionals (doctors and nurses) in the following areas? (National Asthma Campaign 1996):</i></p> <p><i>Concerns about having an attack</i> <i>Symptoms eg. cough, wheeze, shortness of breath</i> <i>Difficulty in taking part in activities eg sport</i> <i>Taking medication</i> <i>Unpredictable nature of attacks</i> <i>Not feeling in control</i> <i>Restrictions on daily life</i></p> <p>Each area to be assessed as one of the following:</p> <p>Very satisfied/fairly satisfied/not very satisfied/dissatisfied/don't know.</p>
Rationale	Although patient satisfaction is itself a desirable outcome, evidence has also accumulated which suggests that care which is less satisfactory to the patient is also less effective. Poor compliance, delays in seeking care and poor understanding and retention of medical information are frequently the result of patient dissatisfaction. It has also been shown that patients' reported levels of satisfaction can reflect doctors' technical competence as judged by independent, professional assessors (Dimatteo and Hays 1980).
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register, or asthma as specified on a hospital record - in-patient diagnosis.
Potential uses	Management of local clinical practice, and provider-based comparisons.
Potential users	Commissioners, provider management, clinicians, consumers and the public.

Possible confounders Assessment of patient satisfaction may be affected by the extent to which the patient knows the health care professionals in question. Some control for frequency of attendances within a GP setting may be advisable. Health status and mood at the time of questioning may affect satisfaction with treatment and care.

Data sources The question could be appended to a postal survey at, for example, an annual review of symptoms. Alternatively it could be used as either an assessment or evaluative tool after a set number of consultations following the initial diagnosis of asthma.

Data quality The indicator question is adapted from a question used in a survey of members by the National Asthma Campaign (1996). The validity, completeness and range of responses of data collected within that survey is unknown. Clearly, full testing of the psychometric properties of the indicator would be desirable.

Comments Alternative generic patient satisfaction questionnaires also exist, mainly developed in the US. They therefore may need some adaptation to British circumstances. There is also some criticism that many satisfaction questionnaires have been developed but only few have been tested for reliability and validity. Further developmental work is likely to be of benefit in this area.

Examples (which could be used as a whole or in part.)

Patient Satisfaction Scale (Wilkin et al. 1992)

Example questions:

“I don’t think I would recommend this doctor to a friend.”

“During the examination the doctor hardly ever tells me what he or she is doing.”

Responses: five point Likert scale ranging from “strongly agree” to “strongly disagree”.

This satisfaction questionnaire is not visit-specific and therefore completion of the questionnaire does not need to be directly after consultations. Use of postal surveys would be possible.

Consumer satisfaction survey and users manual - Group Health Association of America Washington DC, GHAA. - has ‘visit-specific’ questionnaires developed from the RAND MOS.

Further work More work is required to enable this indicator to be interpreted. Scales should be validated, collection methods designed and the relationship between satisfaction and health care provision established.

Conclusion & priority

Patient satisfaction is an important outcome. It is likely that a range of measures of satisfaction will be appropriate in different circumstances. For example, patient satisfaction may be the focus of a quality improvement initiative. If comparisons are to be made between sites or settings then a standardised measure of satisfaction will be needed using the same wording.

F - To be further developed because specification is incomplete.

References

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Candidate indicator 17

Title	Awareness of asthma management
Intervention aim	Reduce or avoid acute attacks; reduce impact of asthma on general well-being.
Characteristics	<p>Specificity: Condition-specific</p> <p>Perspective: Patient</p> <p>Time-frame: Cross-sectional</p> <p>Outcome relationship: Proxy outcome for appropriate self-management.</p>
Indicator definition	<p>For an individual asthma sufferer or carer (in the case of a child), the measure is defined by <i>the response to the following question:</i></p> <p><i>Do you have a self-management plan that you know how to use?</i></p> <p>The indicator is defined for a given GP, or group of GPs, and patient age band as the distribution of scores including response rate.</p>
Rationale	<p>It is acknowledged that certain factors trigger asthma attacks. If possible the avoidance of such factors should be part of the self-management plan of asthma patients. Understanding and awareness among individuals of the particular risks which personally affect them is therefore an essential part of their health education and partnership with their clinician. However, some trigger factors may be less easily avoided than others and, therefore, the use of medication is an equally important part of asthma management. A good understanding of what type of medication (ie preventers or relievers as described by the National Asthma Campaign) to take, and when, is also vital. Achieving this level of understanding among asthma patients is considered a role of primary health care staff. Studies of links between knowledge and self management skills have yielded mixed results (Hilton et al. 1986; Wilson et al. 1993).</p>
Asthma definition	Asthma as diagnosed by GP (Read code (5 character) H33) and recorded in the patients' notes or on an asthma register.
Potential uses	Management of local clinical practice, clinical audit, provider based comparisons.
Potential users	Clinicians, commissioners
Possible confounders	No specific ones identified.
Data sources	The question could be asked opportunistically when an asthma patient attends the practice for a non-asthma related consultation. Alternatively the question could be appended to a postal questionnaire survey of symptoms, eg as part of an annual review.

Data quality	The completeness of the numerator data would rely on the method employed eg within a questionnaire or during consultation. The relatively simple question should mean that reasonably accurate and complete data are obtainable. The quality of denominator data will rely on the completeness and accuracy of the asthma register within practices.
Comments	No specific points.
Further work	Mode of collection and usefulness of results need to be explored.
Conclusion & priority	F - To be further developed because specification is incomplete.
References	<p>Hilton, S., Anderson, H. R., Sibbald, B., and Freeling, P. (1986) Controlled evaluation of the effects of patient education on asthma morbidity in general practice <i>Lancet</i>, 8471, 26-29.</p> <p>Wilson, S. R., Scamagas, P., German, D. F., Hughes, G. W., Lulla, S., Coss, S., Chardon, L., Thomas, R.G., Starr-Schneidkraut, N., Stancavage, F.B., and Arsham, G.M. (1993). A controlled trial of two forms of self-management education for adults with asthma. <i>Journal of the American Medical Association</i>, 94, 564-576.</p>

6. RECOMMENDATIONS

To be implemented generally on a routine basis.

6.1 It is **recommended** that the following indicators be implemented generally on a routine basis:

- 1: hospital admission rate for asthma per general population**
- 12: age-specific mortality rate**
- 13: years of life lost.**

6.2 The data for **hospital admission rates** are already collected and their analysis is straight-forward. Data can be used to compare admission rates across health authority populations and between general practice populations to help plan where asthma initiatives might be focused. Trends within similar geographical areas over time could be used to monitor the success of policies to reduce hospitalised morbidity or to assess the impact of environmental changes.

6.3 Asthma deaths make headline news and may be a marker of service failure since two-thirds are potentially preventable. It makes sense to present information in a standard manner and the two recommended indicators are well established public health measures. The data are available on ONS and other databases and can be analysed by health authorities or provider catchment areas at relatively little cost. These indicators may be useful in identifying 'blackspots' that justify further local investigation as well as successes where improved care results in fewer deaths.

To be implemented where local circumstances allow

6.4 It is **recommended** that the following indicators be implemented where local circumstances allow:

- 3: emergency re-admission rate per population of in-patients discharged with asthma**
(to be collected and compiled on a routine basis)
- 4: general practice consultation rate per general population**
(to be collected and compiled on a routine basis)
- 7: BTS treatment step profile**
(to be collected and compiled on a routine basis)
- 15A: consultation-based patient-assessed impact measure**
(to be collected and compiled on a routine basis)
- 9: compliance with BTS guidelines for acute asthma care**
(compiled by periodic survey).

- 6.5** The **emergency re-admission rate** can be compiled now in those places using a unique identifier. The advent of the new NHS number should facilitate the linking of hospital episodes to identify emergency re-admissions in all geographical areas. This indicator can be used as a pointer to possible adverse outcomes of preceding health care.
- 6.6** **GP consultation rates** for asthma provide an assessment, although somewhat imperfect, of the burden of mild to moderate asthmatic disease in the population. With practice-based computing it is now relatively easy to collect the basic data. It is also becoming increasingly possible to aggregate data from different practices and to compare them.
- 6.7** The **BTS treatment step profile** is an indicator of the use made of the service and of the severity/casemix of asthma patients. Essential to its derivation are GP-based computerised prescribing datasets and associated algorithms for analyses. With these in place collation of the basic data and their compilation into indicators, will be relatively simple.
- 6.8** Simple **patient-generated data** could be derived from questions being asked at every routine asthma contact. It would be feasible to collect the data required for the recommended indicator for all asthma patients as part of their regular review required by the Chronic Disease Management Programme. The information could be collated by practice, pooled across practices, and used as an audit tool to provide a direct measure of the impact that asthma has on patients in primary care.
- 6.9** The **BTS direct guidelines for acute asthma** can provide seven process measures and one direct outcome measure. The data can be collected now and used for the audit of asthma care standards. However, before more than local use is made of the information it will be necessary to:
- pool the requisite data on computer systems
 - obtain a greater understanding of interpretation of the information for comparative purposes.

To be implemented once IT is developed

- 6.10** It is **recommended** that the following indicators be considered for implementation after further developments in information systems:
- 6: accident and emergency attendance rate for asthma related problems per population of people with asthma**
(to be collected and compiled on a routine basis)
 - 10: current lung function as percentage of individuals' best lung function** (compiled by periodic survey)
 - 11: loss of best lung function over time** (compiled by periodic survey).

6.11 Attendances at A&E departments may sometimes result from inadequate primary care or a poor perception by patients of primary care. A&E attenders are often patients who have 'fallen out' of the system. This indicator requires that a diagnosis is made and recorded on a computer. While information requirements are moving in this direction the feasibility of reliably collecting details in the busy circumstances of A&E departments remains untested. If implementation of such systems proves feasible, the data would be available on a routine basis.

6.12 Peak flow measurements are now widely available. The measure of **lung function expressed as percentage of best lung function** for that individual is independent of asthma severity and thus information aggregated for this indicator would be a measure of how effective a general practice is in providing asthma care. As a direct and objective measure it has obvious appeal but the difficulties of organising data collection probably limit its use to periodic surveys.

6.13 In asthma, lung function declines in severely affected patients but the relationships to severity of underlying disease and effectiveness of treatment are not well understood. With enhanced computer systems it will be possible to collect **peak flow data longitudinally** and to see changes in performance. However, further work is required to ascertain whether changing PEF over time is a measure of the adequacy of health care delivery or not.

To be further developed

6.14 It is **recommended** that the indicators described in paragraphs 6.15 and 6.16 need further work either in identifying their link with effectiveness or in their technical design.

6.15 If the results of further work show them to be useful, the following indicators should be collected and compiled on a routine basis:

- 2: emergency admission rate per population of people with asthma**
- 5: general practice consultations before diagnosis of asthma is first made**
- 14: case-fatality rate within a defined period of hospital admission.**

6.16 If the results of further work show them to be useful, the following indicators should be compiled by periodic survey:

- 8: incidence of progression to BTS treatment step 3 and greater**
- 15B: questionnaire-based patient-assessed impact measure**
- 15C: computer-based patient-assessed impact measure**
- 16: patient satisfaction with asthma care**
- 17: awareness of asthma management.**

6.17 Increasing **emergency admission rates** in people with asthma may reflect an adverse outcome of antecedent care. Although a numerator is reasonably easy to calculate from hospital episode data, there may be considerable technical difficulties in:

- obtaining comparable numerator data where alternative provision to emergency in-patient care exists such as open access clinics
- identifying appropriate denominators, ie people already known to have asthma
- interpreting the information obtained.

6.18 The identification of the **number of GP consultations for respiratory symptoms before a diagnosis is made** is an attempt to measure delay in diagnosis and thus would be an indicator of clinical awareness. It would be acceptable to use this indicator as an audit and educational tool but comparisons between practices will be difficult to interpret if only because there are differences between geographical areas in the propensity of people to use GP services generally. Further work is required to refine the measurement and methods of recording.

6.19 Mortality from asthma during or soon after an admission is uncommon. Any comparative information may be difficult to interpret. The majority of deaths occur outside hospital unassociated with an admission. The main value of this indicator would be to monitor long term trends in a large population, such as the whole of England, although local monitoring of the such deaths as 'sentinel events' is to be encouraged. The cost of compiling the data for this indicator must be considered against the benefits it might provide.

6.20 The basic data for the indicator on **progression to treatment step 3** is the same as that for the BTS step profile (see paragraph 6.7) but the indicator for the former needs to be compiled from data obtained longitudinally at annual reviews. Further work is required to develop the indicator for routine use and it may prove useful in understanding the progression of the natural history and treatment of asthma.

6.21 Although detailed **health status and quality of life** questionnaires are already available there is a need, if results are to be compared, to decide which one should be selected and how and when it should be administered. It will be expensive to survey all patients in a practice even once a year. Logistical problems of data collection need to be addressed before widespread use can be recommended.

6.22 A computer-based outcome assessment could overcome some of the practical data collection problems by using a patient-completed computer instrument with a touchscreen or other similar 'patient friendly' approach. However, it is not known how many asthma patients would be willing or able to work correctly with the computer interface. Further work is to be strongly encouraged in this area.

6.23 Patient satisfaction has been little studied in asthma. Simple questions could be very useful in assessing the service provided. However, detailed studies are required to:

- define the most appropriate questions
- identify when and how to ask them
- relate results to service delivery.

Once this work has been completed it should be possible to define a suitable indicator more fully.

6.24 Similar comments apply to studies of **patient awareness of asthma management**. It is well known that asthma deaths sometimes occur in people who have failed to realise their asthma was bad and other patient outcomes may be affected if patients do not understand how to manage their condition. Instruments for assessing patients' awareness of their asthma need to be validated and their relationship to improving function tested.

Conclusions

6.25 As described in the indicator specifications, indicators collected routinely may be used to highlight:

- differences over time
- variations between providers
- differences between groups of patients.

6.26 The main use of such indicators is to make broad comparisons to identify significant differences or anomalies that require further detailed examination. Small differences in routine indicators may be attributable to a wide range of factors many of which will probably not reflect differences in health outcomes.

6.27 Extra information may be obtained by reviewing a number of indicators in combination rather than relying on an indicator singly. For example, the number of respiratory consultations in primary care before the diagnosis of asthma is first made will identify practices at the two extremes: those with very few consultations before a diagnosis for asthma and those with very many consultations before the diagnosis of asthma. In isolation it is impossible to tell from this indicator whether a GP who diagnoses asthma early is a 'good' GP with astute powers of diagnosis or a 'less good' GP who over-diagnoses asthma. However, taken along with other indicators, such as patient admission rates to hospital, BTS step profile and accident and emergency attendance rates, it may give a clearer picture of the profile of care being offered by a practice.

APPENDIX A: WORKSHOP HELD IN JANUARY 1995

KEY FACTORS INVOLVED IN CHOICE OF TOPICS

* **Burden of illness including:**

- incidence and/or prevalence of the condition, its severity and likely course if managed suboptimally
- impact of the condition on quality of life and well-being
- resources required to manage the condition.

* **Ability to influence outcome:**

- evidence that there are interventions which will change the natural history of the condition for the better.

* **Variation in practice/outcome:**

- evidence of variation in practice (especially when services are under pressure)
- evidence of differences between providers in achieved outcomes.

* **Feasibility of defining and collecting data to monitor standards:**

- ideally measures should be collected as part of routine care.

* **Ability to interpret standards and their achievement in that:**

- clear and identifiable connections between practice and outcomes should be possible.

* **Likely impact and health benefit of using the standards.**

CLINICAL TOPICS RECOMMENDED TO STUDY

Disease based:

- * Asthma
- * Diabetes mellitus
- * Ischaemic heart disease or myocardial infarction
- * Hypertension and stroke
- * Colorectal cancer
- * Prostatic cancer or prostatic hypertrophy

- * Ovarian cancer
- * Lung cancer
- * Breast cancer
- * Mental illness or schizophrenia or depression or deliberate self harm
- * Cataract
- * Fractured neck of femur
- * Arthritis or rheumatoid arthritis or osteoarthritis
- * Epilepsy
- * Skin disease or psoriasis
- * Anaemia
- * Chronic renal failure.

Symptom based:

- * Backache
- * Pain management
- * Palliative care
- * Mobility
- * Incontinence
- * Pressure sores
- * Leg ulcers
- * Children with communication disorders
- * Irritable bowel syndrome.

Procedure based:

- * Total hip replacement
- * Hysterectomy.

Other:

- * Pregnancy or teenage pregnancy or neonatal care
- * Accidents or accidents in children or teenage accidents
- * Care of the elderly
- * Dental health
- * Severe learning disorders.

APPENDIX B: ASTHMA WORKING GROUP

Chairman and members:

Physicians	:	Michael Pearson, Liverpool (Chairman) Martyn Partridge, Whipps Cross, London
Paediatrician	:	John Warner, Southampton
GPs	:	David Bellamy, Bournemouth Kevin Jones, Newcastle
Nurse	:	Greta Barnes, Stratford-on-Avon
Psychologist	:	Michael Hyland, Plymouth
Researchers	:	Ross Anderson, St. George's, London Christine Bucknall, Glasgow
CEOs	:	Jeff James, Gloucester Rosie Knights, Warrington
DoH	:	Ann Dawson
National Asthma Campaign	:	Melinda Letts

Academic support and secretariat:

Michael Goldacre, Alastair Mason and John Fletcher, University of Oxford
James Coles, Robert Cleary and Moyra Amess, CASPE Research, London
Anthony Hopkins, Royal College of Physicians, London
Alison Eastwood, NHS Centre for Reviews and Dissemination, University of York
Paul Dixon, UK Clearing House on Health Outcomes, Nuffield Institute of Health, University of Leeds
Andy Partridge, CHOU, Department of Health

APPENDIX C: WORK COMMISSIONED FROM NHS CENTRE FOR REVIEWS AND DISSEMINATION

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Organisation of asthma care: what difference does it make? A systematic review of the literature

Alison J Eastwood, Trevor A Sheldon

Abstract

Objectives – To evaluate the effectiveness of different forms of organisation (delivery) of asthma care.

Methods – A systematic review of the published evidence of effectiveness organisational methods of asthma management. Searches on computerised databases including Medline, CINAHL, and HELMIS, and relevant citations and letters to experts were used to identify relevant studies

Results – 27 studies were identified that evaluated different organisational methods of delivery across both primary and secondary sectors, such as shared care, general practice asthma clinics, out-patient programmes, in-patient admissions policies, and the use of specialists. Only one third of the studies used a randomised controlled trial and many had small sample sizes. No conclusive evidence was found to favour any particular organisational form, although limited evidence would suggest that specialist care is better than general care and that shared care can be as effective as hospital led care.

Conclusions – There is little good published research evaluating different ways of organising the delivery of asthma care. There is need for good quality research on organisational methods of delivery of asthma care that could be used to inform policy makers, in particular examining whether patients treated by healthcare professionals with expertise and interest in asthma will experience better outcomes.

Introduction

Asthma is a common chronic condition that affects both children and adults, that calls on the skills of various healthcare professionals and services in both the primary and secondary care sectors. The quality of asthma care varies and there is evidence of poor treatment in both hospitals¹ and general practice.² The education of junior doctors in the United Kingdom is still lacking,³ and general practitioners, pharmacists, paediatric nurses, and nurses in community asthma clinics have deficiencies in knowledge.^{4,5} For example, inadequate training in metered dose inhaler techniques was found in a significant proportion of healthcare providers dealing with asthmatic patients.

Consensus based national clinical practice guidelines for the management of asthma have been developed by professional organisations,^{7,9} and revised guidelines are soon to be published. Although the guidelines were supported by reviews of the published literature no distinction is made between evidence and consensus based statements, and they have not been subject to rigorous evaluation. There is little evidence to suggest that the guidelines have improved standards of care. Studies have shown that asthma management diverges from that recommended in guidelines,^{10,11} even in a specialist respiratory unit.¹² Keeley emphasises the need to ensure the comprehensive implementation of the current knowledge about asthma management in general practice.¹³

Little attention has been paid to how care should be delivered and by whom, the organisational aspects of the delivery of care and the modes of delivery of service as opposed to the treatments themselves. For example, how should asthma management be structured? Within primary care should treatment be given through general practitioner consultations, nurse consultations, or an asthma clinic? Should patient review be formalised or opportunistic? There are also issues of which personnel should provide treatment. Do specialists provide more elective treatment than generalists? Should trained asthma nurses or community nurses be involved in the management of asthma?

In the past few years there has been organisational change within the provision of health care. For example, in the United Kingdom the most recent “general practice contract health promotion package” includes fixed payments for chronic disease management programmes for asthma and diabetes, as an incentive to care for chronic illness in primary care.¹⁴ This had led to a large increase in the number of practice nurses, who may be involved in the care of asthmatic patients, and is part of a general shift towards primary care in the purchase and provision of care.¹⁵ The assumption is that shared care will have an impact on quality, over and above that obtained from specific treatments.¹⁶

These changes have been made on the assumption that these forms of organisation, for example, shared care and practice nurses, are beneficial. The aim of this paper is to explore the knowledge base by reporting the results of a systematic review of the research on the effectiveness of different forms of organisation of asthma care.

Methods

To identify studies, the Medline database was searched from 1976 to the first quarter of 1995. The CINAHL, HELMIS, Manchester Primary and Secondary Care Interface, Health Planning and Administration, and DHSS databases were also searched, with the keyword "asthma". Relevant citations from identified articles were retrieved. A letter was sent to members of the national asthma guide-lines working party,⁹ to solicit their assistance in identifying articles.

Studies were included that evaluated organisational methods of asthma management, and were written in English. No study design limitations were imposed due to the small volume of research literature in this area. Data were extracted on to structured abstract sheets.

Studies are categorised into the following broad settings: emergency; in-patient; out-patient; community; general practice; and integrated or shared care. Within settings, when appropriate, studies are grouped according to the healthcare professional involved in the intervention: general practitioner, nurse, school doctor, community nurse, school nurse, and respiratory and general physicians. Many issues will be relevant across more than one setting or professional group.

Studies are graded by the reliability of their results according to study design, the randomised controlled trial being considered the most reliable source of evidence.¹⁷

Results

Twenty seven studies were identified, only nine of which were randomised controlled trials. The other designs were non-randomised controlled trials (four studies), and observational series (14 studies), mainly before-after studies, audit, and descriptive reports. Table 1 shows detailed summaries of the individual studies.

SHARED CARE (ONE STUDY)

The GRASSIC study used a randomised incomplete block design to assess the effectiveness of shared care between out-patient specialist and general practitioner. The authors suggest that shared care is as effective as conventional out-patient care and cheaper from the perspective of hospitals, general practice fundholders, and patients. The total cost for shared care was £101 / patient / year, compared with £141 for conventional care (1991/92 prices).¹⁹ A survey of a random sample of general practitioners involved in the GRASSIC study showed that general practitioners were enthusiastic about the principles of shared care for asthma and reported good communication with hospital consultants.²⁰ Without successful communication, the effectiveness of the scheme might be compromised.

ASTHMA CLINICS IN GENERAL PRACTICE (FOUR STUDIES)

There are no randomised controlled trials evaluating asthma clinics in general practice. Of the four studies identified two evaluated clinics run by general practitioners and two by nurses. A matched controlled before-after comparison of children attending a mini-clinic run by the general practitioner and those receiving conventional asthma care through general practice consultations found no difference in morbidity measures, except for a decrease in all cause school absences. In another uncontrolled study the introduction of an asthma clinic resulted in patients being more easily identified, but overall clinical improvement among asthma patients was not obvious.²²

Two uncontrolled before-after studies of different groups of patients in the same nurse run asthma clinic reported significant, although not always sustained, improvement in morbidity for patients.^{23 24} The authors also suggest that a clinic run by a nurse provides a setting where patients who feel unable to talk to their general practitioner can get more information about asthma.

One problem with asthma clinics is the time commitment required by healthcare professionals. This was highlighted as an issue in both clinics run by general practices, where the clinic was unable to cope with the number of patients,²² and also in clinics run by a nurse, where it was thought that the duration of the consultation in the trial may not be sustainable under normal circumstances.²³

ASTHMA CONSULTATIONS IN GENERAL PRACTICE (THREE STUDIES)

Three studies considered aspects of asthma care delivered through conventional general practice consultations. A randomised controlled trial evaluated the use of an audit facilitator to influence the outcomes of children with asthmatic symptoms. The children were targeted for clinical review by either their general practitioner or practice nurse. The trial found that the facilitator favourably influenced the diagnosis and treatment of childhood asthma, but had an inconclusive impact on clinical outcome.²⁵ It also reported a shift in costs from hospital to primary care.

Uncontrolled before-after studies of two audits²⁶ and the implementation of a consensus management plan²⁷ reported conflicting results on the likely impact of initiatives to improve the quality of care in general practice and are unreliable.

COMMUNITY BASED PROVISION (SIX STUDIES)

The six studies identified, all aimed at children with asthma, evaluated different interventions with a variety of healthcare professionals: community nurses, general practitioners, school nurses, school doctors, and community health workers.²⁸⁻³³

Three studies evaluated interventions involving community nurses, two of which were randomised controlled trials,^{28 29} and one of which was a before-after study.³⁰ In general the randomised controlled trials reported improvements in parents' or teachers' knowledge about asthma (and consequently their ability to discriminate the severity of attacks) but no reduction in outcomes such as school absenteeism or exclusion from

games lessons due to asthma.²⁸⁻²⁹ One of the trials was stratified by ethnic group (European and Polynesian), and suggested that interventions need to be culturally relevant.²⁹ This was also reinforced by the before-after study which evaluated a community outreach programme and highlighted the need to deal with the specific requirements of different ethnic groups.³⁰

The other three studies all involved different healthcare professionals. One randomised controlled trial evaluated a primary school intervention, in which school nurses were trained to educate teachers and check children's inhaler technique, and general practitioners were asked to follow guidelines.³¹ This led to an increase in teachers feeling able to supervise asthmatic children and children being allowed to keep inhalers with them at school, but no change in morbidity measures. A before-after study evaluated a community based asthma campaign led by school doctors which also reinforced the benefit of educating teachers.³² Butz et al. provide a description of the use of community health workers to provide and obtain limited information from low income families with asthmatic children.³³

OUT-PATIENT PROVISION (SIX STUDIES)

Six studies were identified in total,³⁴⁻³⁹ two of which incorporated links with the community or primary care.³⁴⁻³⁵ All of the interventions evaluated required the presence of a specialist nurse, and physicians were involved in three.³⁴⁻³⁵

Two randomised controlled trials considered evaluations in an out-patient setting with links to the community or primary care. Children living in the inner city, assessed in an out-patient clinic by a paediatric respirologist, and having subsequent home visits by a nurse had better outcomes than those receiving standard treatment by a primary care physician (although the study groups were not comparable at baseline).³⁴ Another randomised controlled trial found that patients referred to an asthma clinic in a paediatric out-patient department, run by a nurse who provided education, information, and reminders for primary care review, tended to improve their asthma control.

Four studies, all based in North America, considered interventions based solely within out-patient departments.³⁶⁻³⁹ In the only randomised controlled trial, an intensive treatment and educational programme run from a special clinic was evaluated.³⁷ Patients received treatment from one physician and a full time nurse practitioner and were encouraged to contact staff at the clinic at any time. The intervention resulted in a reduction both in hospital admission and day use compared with a routine out-patient clinic. It was also concluded that nurse practitioners may well be as effective as physicians in educating non-compliant adult asthmatic patients. Two non-randomised controlled trials compared routine standard care with educational interventions run by nurses. These aimed at improving standards of care in poorly controlled non compliant children³⁸ and self management skills in asthmatic children and their parents.³⁹ Both studies reported an improvement in outcomes and a savings in costs in the intervention compared with the control group, although both studies were small and the impact of potential confounders was not considered.

IN-PATIENT PROVISION (FOUR STUDIES)

Three of the four studies⁴⁰⁻⁴³ with in-patient settings compared the treatment given by specialist and generalist physicians. A prospective study of patients allocated to specialist or generalist care on the basis of day of admission (pseudorandomisation), found that those patients admitted to general medical units with a specialist respiratory physician were significantly more likely to be prescribed oral steroids, have objective measurements of lung function, and have their inhaler technique assessed than those admitted to units without a specialist.⁴⁰ The short term follow up reported significantly fewer symptoms and readmissions for asthmatic patients allocated to specialist care. The apparent advantage of respiratory physicians compared with non-respiratory physicians was also reported in two audits providing evidence of limited strength.^{41 42}

The use of a hospital self admission scheme for severely asthmatic patients is reported by Crompton et al.⁴³ This is a retrospective description of a scheme which has been in use for 15 years. The scheme is reported to give confidence to both patients and general practitioners.

EMERGENCY PROVISION (THREE STUDIES)

Three studies were identified which evaluated interventions in an emergency department.⁴⁴⁻⁴⁶

A randomised controlled trial of an education programme based in an emergency department evaluated the impact of having a healthcare professional who also has asthma to provide information, based on the hypothesis that interpersonal similarity will improve communication as well as the provision of education.⁴⁴ The study suggests that the role of information was modified by the means of delivery, with a significant improvement when educational information was provided by an asthmatic nurse compared with a non-asthmatic nurse. Unfortunately the follow-up reported for this study was only short term (two weeks), although the trial had a final observation period of six months.

Neither of the other two trials identified were randomised controlled trials and so the results must be interpreted with caution. A non-randomised single blind observational design was used to evaluate a short verbal presentation to residents on emergency department rotation in terms of acute and discharge treatments.⁴⁵ This study found that the intervention was associated with an improvement in prescribing, but was only partially effective in optimising discharge treatment. The replacement of senior house officers (SHOs) with registrars for decisions on admissions, and the education of SHOs were evaluated in a before-after study.⁴⁶ Both interventions were associated with improvements in the admission policy after compared with before implementation.

Discussion

There has been little research on differing methods of organising or delivering asthma care.

The GRASSIC study provided evidence that shared care may be marginally more cost effective than conventional out-patient care. However, more research is required to identify which types of patients are suitable for shared care,²⁰ and to examine whether this effect is confined to enthusiastic general practitioners or could be generalised. Asthma clinics may facilitate communication between professionals and patients, and those run by asthma nurses may provide more time for patients to increase their knowledge and confidence. However, there is little evidence to suggest that such clinics can lead to a long term sustained improvement in patient morbidity. Community based programmes may prompt more appropriate use of health care by hard to reach asthmatic patients, if tailored to the needs of the target group (for example, making programmes culturally relevant to specific ethnic groups).⁴⁷ Most interventions which aimed to provide more education and information to patients or parents did seem to succeed in improving knowledge and confidence, but not necessarily morbidity.

Research is needed to look at dissemination and implementation of specific programmes as well as their content.⁴⁸ For example, effective communication between different groups of professionals and also between professionals and patients may be central to the effective implementation of care.^{35 49-51}

The issue of who delivers asthma care seems to influence outcomes and may be independent of where care is delivered. It is possible that, in any setting, patients may benefit more when treated by healthcare professionals with expertise and interest in asthma. However, research on this question has been limited, despite its importance for the organisation of care across all settings. Greenhalgh, in her review of shared care for diabetes, concluded that: “structured care by general practitioners with an interest in diabetes and supported by an enthusiastic and committed specialist liaison team produces comparable levels of care to that provided in hospital, but that unstructured care by disinterested and unsupported general practitioners is ineffective and wasteful of resources.”⁵²

Insufficient education of healthcare professionals in the treatment of asthma may explain in part why specialist care may yield better outcomes for in-patient care than that provided by general physicians. However, a comparison of two groups of specialists (consultant physicians with an interest in chest diseases and paediatricians who manage children with asthma) found variation between and within groups in their opinions on the appropriate management of asthma.⁵³ Further good quality research is required to assess the impact of levels of expertise and interest on the quality of asthma care.

Top 10 research and development priorities for the NHS on asthma management.⁵⁵

- Delineation of predictors of response to the treatment of wheezing illness in children
- Evaluation of interventions based on individual patients or households to prevent the development of asthma, reduce its severity or improve its prognosis
- Synthesising and evaluating outcome measures for asthma in adults and children
- Review of gaps in evidence for current guidelines on asthma management, followed by primary research to address these
- Evaluation of risks, benefits, and costs of long-term use of treatment for asthma
- Social and psychological influences on use of asthma services leading to the development and evaluation of strategies to address these
- Identification and management of patients at risk from severe attacks of asthma
- Evaluation of methods of communication between health professionals (including asthma nurses) and patients, teachers, and carers
- Evaluation of models of delivery of care for asthma management in different settings
- Investigation of beliefs and behaviour of patients with asthma

The evidence available is not only limited by the quantity but also the quality of the research. Few studies used randomised controlled trials; in general the studies were simple before-after uncontrolled studies (both retrospective and, less often, prospective), or non-randomised comparative studies. These do not usually adjust for confounding factors in their analyses, which can lead to biased estimates. For example, several studies had non-comparable groups, differing by factors likely to influence outcome such as differing age and sex. It is thus impossible to attribute differences in outcome to the intervention. Poorly controlled studies are likely to give biased estimates because of the often large spontaneous changes in health status.

Many of the studies have too small a sample size. Further, it is difficult to judge whether statistically significant differences are actually clinically significant. In general, patients studied may not be representative and are likely to be more compliant and enthusiastic, and so the reported effect of any intervention may be more pronounced.

It is particularly difficult to evaluate organisational issues; location, structure, personnel, treatment, etc. all play a part but it is difficult to disentangle the impact of each one. Trials are usually designed to evaluate a specific intervention in terms of the treatment given. The organisational component is often ad hoc or lacking.

The results of this review largely confirm a United States report which stated that: “there has been virtually no systematic research examining the relationship between organisational forms in the health care system and asthma outcomes”⁵⁴

An expert advisory group was recently set up to identify priorities for the National Health Service research and development programme on asthma management.⁵⁵ The evaluation of models of delivery of care for asthma management in different settings, is one of the top 10 priorities identified (see box).

Insufficient attention has been given to packages of care, settings of care, and healthcare professional’s skills, which this review suggests might be important. Further, there is little evidence to support the organisational changes which are currently taking place, reflecting the trend from secondary to primary care. Randomised controlled trials of sufficient size with economic analysis are required to provide this evidence. It is vital to identify the specific aspects of organisation and delivery of care. For example, to evaluate the impact of professional interests, trials could be stratified according to whether the professional had an interest in asthma. It is necessary to be certain exactly which aspects of organisation the research is considering, and to undertake research which isolates these individual effects and the interactions between them.

In most studies resource implications are not considered. It is important to assess both the patient related and healthcare related costs of any intervention, not only in terms of costs to the health services involved, but also any shifting of costs to other sectors which may occur as a result of the intervention.

Table 1: Studies reporting on organisational aspects of the delivery of asthma care

**Integrated care:
Drummond et al
(1994)¹⁸**

1. Study, population, setting, study design, and size

Asthmatic patients attending UK out-patient clinic. Pragmatic randomised incomplete block design, I = 363 patients, C = 438 patients.

2. Intervention

Evaluation of integrated asthma care: I: Questionnaire sent to patient (prompting GP consultation) and GP. Documentation returned to specialist, patient's records are updated. Copy returned to the GP along with any recommendation for changes in management. C: Regular out-patient care. Questionnaire sent before each visit.

3. Outcomes measured, follow up

Use of medication; GP consultations and hospital admissions; restrictions on normal activity; psychological aspects; patient satisfaction; and costs. 12 months follow up.

4. Results

No significant differences between groups for most outcomes. I: significantly more likely to be in control of their asthma all the time and less likely to be very satisfied with the medical care they received. C: were more likely to perceive both advantages and disadvantages of integrated care. Integrated care estimated to save the hospital £3.06, the GP (fundholder) £2.41, and the patient £39.52 per patient per year (1991 prices). The evidence suggests that integrated care is a cost effective management option in comparison with conventional out-patient care, for patients, GPs, and hospital consultants.

5. Comments

A well designed study. No details are reported of those patients who declined to take part or who were allocated to conventional care as their asthma was deemed too severe.

**General practice -
Asthma clinics:
Usherwood et al
(1988)²¹**

1. Study population, setting, study design, and size

Asthmatic children in two group practices in Scotland. Non-randomised controlled study. I = C = 31 patients (24 males).

2. Intervention

Asthma mini-clinic for children: I: GP chest clinic after school hours. 2-12 weekly intervals as necessary. C: Children from neighbouring practice receiving conventional GP care, matched to I by age and sex.

3. Outcomes measured, follow up

Medication, school absence, consultations, parental reported symptoms. 12 months follow up.

4. Results

There was no notable difference between children in both groups preintervention. Postintervention there was no difference, except a decrease in school absence, fewer GP consultations, home visits, and out of hours visits for group I. Frequent follow up brought little benefit and has been discontinued.

5. Comments

No comparison of absolute consulting patterns between the two practices. School absence could be due to non-asthma causes, or GP visits for group C (I group clinic was after school hours).

Martys (1992)²²

1. Study population, setting, study design, and size

Asthmatic patients in a Derbyshire practice. Pre and postclinic audit. 161 patients preclinic 238 patients postclinic.

2. Intervention

GP run asthma clinic: first consultation emphasises patient education, PEFR measured at each visit, diary card issued. Subsequent visits at 6 monthly intervals or more frequently if necessary.

3. Outcomes measured, follow up

Asthma in computer problem list, PEFR, smoking, review in previous years, asthma medication. 1 year postclinic audit. Attitude and morbidity questionnaire. 12 months follow up.

4. Results

Preclinic asthma prevalence of 4%, postclinic of 6%. Significantly more patients had the term asthma in their problem list, PEFR measurements, and their smoking history recorded. Asthmatic patients are more easily identified, overall clinical improvement among patients is more difficult to detect.

5. Comments

Only 38% of postclinic patients had a review in the past year. The clinic should ensure two visits per year. It was not able to cope with the volume of patients. No demographic comparisons of the before and after groups are made.

Charlton et al (1992)²³

1. Study population, setting, study design, and size

GP patients using inhaled steroids or sodium cromoglycate in Norfolk. Before-after study. 105 patients.

2. Intervention

Nurse run asthma clinic: 45 minute appointment taking history, checking technique, education, self management plans. 15 minute follow up appointment after one week. Check ups at least every 8 weeks.

3. Outcomes measured, follow up

Attitude and morbidity questionnaire. 12 months follow up.

4. Results

Significant reduction in morbidity and fall in number of days lost from work or school, but not in number of patients taking time off. Significant reduction in stigma score and confidence in self care. But no difference in confidence in doctor. Weak association between morbidity and stigma.

5. Comments

Age and sex distribution of respondents differed from all asthmatic patients identified in the clinic (no statistical analysis was reported). Attenders may be a biased group.

Charlton et al (1991)²⁴

1. Study population, setting, study design, and size

GP patients using prophylactic treatment, in Norfolk. Before-after study. 115 patients (31 went for only 1 or 2 appointments).

2. Intervention

Nurse run asthma clinic: 45 minute appointment taking history, checking technique, education, self management plans. 15 minute follow up appointment after one week. Check ups at least every 8 weeks.

3. Outcomes measured, follow up

Patient morbidity (drugs, nebulisations, absence, and GP consultations). 12 months follow up, pre and postinitial visit.

4. Results

Significant decrease in GP asthma consultations after introduction of clinic, but not sustained in 2 and 6 months. Significant decrease in total number of oral steroid courses. For all morbidity criteria, there was a drop in the first 6 months with rebound in the next. Practice and patient care organisation was improved.

5. Comments

The same clinic is studied for a different population in Charlton et al (1992).²³ Patient numbers in some of the subgroup comparisons were very small. No comparison made between attenders and non-attenders.

**General practice –
Asthma consultations:
Bryce et al (1995)²⁵**

1. Study population, setting, study design, and size

Children with symptoms suggestive of asthma, in a sample of 12 Scottish general practices. Randomised controlled trial (stratified by age and asthma treatment). I = 1585 patients, C = 1563 patients.

2. Intervention

Audit facilitator in general practice. Information/equipment for opportunistic review of asthmatic children. I: Case records marked with asthma chart, protocol, GP letter requesting patient review, and guidelines. Each practice received education materials, inhaler devices, portable nebulisers. C: Unmarked records, but same GPs, thus heightened asthma awareness.

3. Outcomes measured, follow up

Asthma consultations, diagnosis, and assessment, prescriptions (respiratory drugs), hospital attendances, health service costs. 12 months follow up.

4. Results

Significant increase in consultations, new and reaffirmed diagnosis of asthma in year 2, oral bronchodilator and inhaled cromoglycate. Increased use of assessment stamps, prescription rates for peak flow meters, steroids, and inhaled bronchodilators. Decreased rate of consultation for respiratory diseases (non-asthma) and prescriptions for theophylline, oral bronchodilators, antibiotics, cough linctus. Diagnosis and treatment of childhood asthma in general practice were favourably influenced by an audit facilitator. Changes in general practice care lead to increased primary care costs and may decrease hospital costs.

5. Comments

Some of the data presented implies differences in groups at baseline. Calculations of the period effect use data from the C group only. Analysis is with absolute numbers of consultations/ hospital days, rather than number of patients with consultations/ hospital days.

Barritt et al (1991)²⁶

1. Study population, setting, study design, and size

Asthmatic patients in a Shropshire training practice. Repeat audit 1984 and 1987. 126 (1984); 192 (1987); 85 patients (both years).

2. Intervention

Minimal asthma care through GP consultations in surgery hours (aims: diagnosis, home peak flow meters and inhaled bronchodilators with nebulisers, bronchodilator education and prophylactics, regular follow up).

3. Outcomes measured, follow up

Structured questionnaire, PEFr, inhaler technique. Intervention implemented after audit. 3 year follow up.

4. Results

Improvements in all objectives for good care, except knowledge about bronchodilator duration. Increase in oral and inhaled prophylactic steroids. 40% of patients with high disability scores defaulted from/or were resistant to starting prophylactic treatment. No significant differences in disability scores for the 85 patients present in both audits.

5. Comments

Comparisons between groups are difficult (they are not matched nor are they independent). No statistical tests were carried out for some of the findings.

Modell et al (1983) ²⁷

1. Study population, setting, study design, and size

Asthmatic patients in a London group practice (8 GPs, 13000 patients). Before-after case study.

2. Intervention

Consensus asthma management plan drawn up by GPs, emphasising drug treatment, discussion, education, self management. Plan implemented on spontaneous asthma consultation.

3. Outcomes measured, follow up

Peak flow, disability and symptoms, attitudes and knowledge of asthma. 1 year (20% drop out).

4. Results

Little change in patients' satisfaction and knowledge. Just under half the patients were dissatisfied with their understanding of asthma and GPs' explanations. Severity reduction most pronounced in children. A few patients remained severely affected, most has not been appropriately assessed or adequately treated.

5. Comments

Children's response may be influenced by parents, but difficult to estimate in which direction. Difficult to judge representativeness. Raises GP-patient communication needs.

**Community:
Carswell et al (1989)** ²⁸

1. Study population, setting, study design, and size

Families of asthmatic children in Avon (1 urban, 1 suburban practice). Randomised controlled trial. I = C = 43 families.

2. Intervention

Home visiting community nurse specially trained in asthma. I: discussion of asthma (risks, treatment, preventing/curtailing attacks). Judgement as to visits required. C: no details of control group given.

3. Outcomes measured, follow up

PEFR, asthma symptoms, theoretical knowledge score (TKS) from structured questionnaires. 6 months follow up.

4. Results

Significant improvement in PEFR for I cf. C at all assessments except baseline. Correlation between number of visits and change in TKS over 6 months. No difference in absence from work or school. Direct cost of nurse estimated at £4.30 per visit. Nurses improved the ability to discriminate severity of attack and management. Possible placebo effect of the nurse.

5. Comments

No randomisation details or comparison of groups. Asthma severity not given. 41% missing data for some PEFR measurements. No long term follow up to see if improvements were maintained.

Mitchell et al (1986)²⁹

1. Study population, setting, study design, and size

European and Polynesian asthmatic children discharged from paediatric medical wards, New Zealand. RCT stratified by ethnicity I: 94 European, 84 Polynesian C: 106 European, 84 Polynesian.

2. Interventions

Asthma education by community child health nurses in the home. I: 6 monthly home visits by nurse (explain asthma, provoking factors, drugs, stimuli avoidance, drug compliance, encourage follow up and GP rather than emergency department). C: No details given.

3. Outcomes measured, follow up

Drugs, school absence, hospital readmissions, use of hospital for primary care, ability to manage attacks at home. 18 months follow up (12 postintervention).

4. Results

European children significantly socioeconomically advantaged, taking more medications than Polynesians. European I children taking significantly more drugs, had more readmissions, and used the hospital service for primary care more often than C. This was not associated with a reduction in admission to hospital or absenteeism. No difference between Polynesian I and C groups for any of the outcome measures during either time frame. Low response for Polynesian parents.

5. Comments

Low response rate for 2nd questionnaire in Polynesian families. No comparison between C and I groups undertaken. No objective measures of severity or baseline measures used between groups.

Greineder et al (1995)³⁰

1. Study population, setting, study design, and size

Children with asthma, being treated in an urban HMO centre in Boston, USA. Before-after study, n = 53.

2. Intervention

Asthma outreach: one to one orientation with nurse (management, medication, triggers, inhalers, peak flow meters), individualised treatment programme, regular contact.

3. Outcomes measured, follow up

Emergency visits and hospital admissions. 6-24 months follow up. 38% enrolled > 1 year.

4. Results

Correlation between admission to hospital and black ethnicity. Significant decrease in hospital admissions and emergency visits. Net savings estimated at \$76200 (1993 prices). Enrolled patients experienced a significant reduction in use of emergency ward and hospital admissions, resulting in reduced cost of care.

5. Comments

Small sample size (especially those with at least one year follow up). Design not rigorous, but RCT currently ongoing. Highlights need to deal with special requirements of different ethnic groups.

Hill et al (1991)³¹

1. Study population, setting, study design, and size

Nottingham primary school children with absence in the previous year, taking no treatment or β_2 agonists only. Randomised controlled trial. I: 49 schools, 228 children C: 52 schools, 223 children.

2. Intervention

Simple intervention programme in primary schools. I: Parents asked to take their child to the GP. GPs asked to follow guidelines and fill in a questionnaire. School nurses trained to educate teachers and check technique. C: Filled in outcomes questionnaire.

3. Outcomes measured, follow up

School absence, missed games and swimming lessons, school policy towards asthma management. 12 months follow up.

4. Results

No significant changes in participation in school activities or morbidity measures. Significant difference in children keeping inhalers in school and using inhalers before games between I and C groups. Teachers in I schools were more likely to feel prepared to supervise asthmatic children. Teacher education was successful in increasing teachers' knowledge and confidence. The intervention may be more effective in areas where the prevalence of diagnosed asthma is lower.

5. Comments

Randomisation by school, no comparison of schools preintervention. Loss to follow up 34% (drop out was similar in both groups and respondents and non-respondents did not differ significantly).

Colver (1984)³²

1. Study population, setting, study design, and size

Asthmatic school children in disadvantaged area of Newcastle-upon-Tyne. Before-after study 120 children (data on 81).

2. Intervention

Community based asthma campaign, led by school doctors. Children identified are given school doctor consultation to explain asthma and provide information, letter sent to family GP.

3. Outcomes measured, follow up

Symptoms, absence, attitudes of school nurses and doctors, parents, teachers. Home visit 12 months after school consultation.

4. Results

Many children not identified during GP consultation or routine medical checks. At follow up, 77% of families thought symptoms had improved, 96% found the school doctor consultation helpful. Teachers were more likely to let children stay in school and keep their inhalers.

5. Comments

Differences between follow up and non-follow up not reported. Descriptive study, no statistical analysis reported.

Butz et al (1994)³³

1. Study population, setting, study design, and size

Asthmatic children from 42 schools in 2 Afro-American inner city areas, USA. Descriptive study (part of larger RCT). 140 children.

2. Intervention

Use of CHW with low income families. Obtained information, provided basic asthma education, facilitated access to medical care. Children received programme both with and without school based education programme.

3. Outcomes measured, follow up

Medication use, emergency room visits, housing conditions. 5 months intervention period (number of CHW visits not stated).

4. Results

3 CHWs dropped for inadequate performance. All children who visited emergency rooms were current medication users. Most families has carpeted floors, forced air heat, and >1 smoker. Use of plastic covers for bedding was low. CHWs are effective in obtaining information from families in inner city communities. Limitations of their use include lack of skills to assess medication use and misuse, lack of familiarity with abnormal physical findings.

5. Comments

No comparison was made of baseline severity of asthma, nor was insurance status of families reported. Authors conclude that CHW can provide valuable service, but no conclusive evidence to support this.

Out-patient: Hughes et al (1991)³⁴

1. Study population, setting, study design, and size

Children admitted to Izaak Walton Killam Children's Hospital, Canada with a diagnosis of asthma. Randomised controlled trial. I: 47 patients (44 at end) C: 48 patients (45 at end).

2. Intervention

Home and ambulatory asthma management programme. I: Individual programme by paediatric respirologist. Inhaler technique, in home management of acute exacerbations. Education pamphlet, at least two visits, environmental checklist. C: Treatment by primary care physician, attendance at clinic for assessments at specified intervals.

3. Outcomes measured, follow up

Symptoms, medication, PEFr, physician visits, school absence, metered aerosol technique, hospital admission, asthma knowledge. 1 years intervention, 1 year postintervention.

4. Results

Significantly more primary care physician visits by C during follow up. Flow rates significantly lower in C, but differences disappeared after 1 year. School absenteeism fell for both groups. I showed better inhaler technique. Significantly fewer I families wanted more asthma information at the end of the study, more felt that their child took responsibility for asthma management. Programmes must be sustained to be beneficial. Data suggest that costs to the health insurance system of C patients were more than I patients.

5. Comments

64% response rate, 6% drop out. The I group had higher asthma knowledge all the way through the study, including prestudy.

Charlton et al (1994)³⁵

1. Study population, setting, study design, and size

Admissions for asthma or attenders at a paediatric out-patient department, Winchester, England. Randomised controlled trial (by age, sex, prophylaxis). I: 48 patients, C: 43 patients.

2. Intervention

Nurse run asthma clinic. I: Clinic in DGH paediatric department. Information on asthma and self management over and above standard information. Reminders for asthma review in primary care. C: Standard information, no additional education or reminders.

3. Outcomes measured, follow up

Asthma symptoms, peak flow and morbidity questionnaire. 12 month follow up.

4. Results

Significant differences between I and C groups for days of activity restriction and percentage of time spent with poor lung function. Significantly more excellent and less inappropriate patient/ parent responses to acute attack in I group. I group patients more likely to make a correct response than C. The nurse run asthma clinic showed a tendency to modify symptoms and peak flow. Highlights the need for coordination between hospital, patient, and primary healthcare team.

5. Comments

The number of in-patients and out-patients is not given, this could impact on differences in severity. Initial comparisons between groups showed differences. Although no tests were reported.

Mayo et al (1990)³⁷

1. Study population, setting, study design, and size

Adult asthmatic patients admitted to Bellevue Hospital Center, New York. Randomised controlled trial, with non-random crossover. I = 47 patients, C = 57 patients, crossover = 19 patients.

2. Intervention

Intensive out-patient programme: I: Education through repeated contacts, no written or audiovisual materials. Patients encouraged to participate in decisions, initiate self treatment, or seek early emergency room treatment. Medical regimens designed to encourage compliance. C: Routine clinic details not given.

3. Outcomes measured, follow up

Readmission, hospital day rates, treatment, patient knowledge. 8 months follow up. 3 years pre and postenrolment. 8 month comparison two years apart.

4. Results

No patient showed satisfactory MDI technique, asthma knowledge and treatment options were vague. Hospital use less in I, and readmission and hospital day rate fell. Reductions were found for patients in the crossover group. Readmission rate constant, suggesting sustained benefit of clinic. Costs estimated at \$1500 per patient for 8 months, compared with \$4000 for routine care. Physician accessibility/ accountability was important. Nurse practitioners may be as effective as physicians in reducing readmission rates among difficult adult asthmatics.

5. Comments

Exclusion of potentially non-compliant patients may lead to overestimation of the impact of the intervention. Inclusion criteria are not consistently reported and it is unclear why randomisation was unequal. Useful discussion about the need for an individualised approach, and to combine the role of educator and medical provider.

Alexander et al (1988)³⁸

1. Study population, setting, study design, and size

Asthmatic children with no consistent source for asthma management, Memphis, USA. Non-randomised controlled trial. I = 11, C = 10 children.

2. Intervention

Clinical nurse specialist for poorly controlled, non-compliant asthmatic children. I: Clinical nurse specialist provides information, education, and point of contact for patient. C: Received primary continuity care through the general paediatric clinic.

3. Outcomes measured, follow up

Emergency room visits pre and postclinical nurse specialist intervention 12 months follow up pre and postenrolment.

4. Results

C had no change and I experienced a significant reduction in the number of emergency room visits for asthma. I has significantly fewer emergency room visits than C. Neither group showed any difference in hospital admissions or the number of days in hospital. Reduction in emergency room visits represented \$3300 (1985) savings in uncompensated care, the cost of the clinical nurse specialist is a fraction of this. Further research into programmes such as this is indicated.

5. Comments

Small study size. Possible confounders not examined. The population were all Medicaid recipients and thus represent a specialised population.

Fireman et al (1981)³⁹

1. Study population, setting, study design, and size

Asthmatic children at allergists or allergy clinic, Pittsburgh, USA. Non-randomised controlled trial, age matched patients allocated sequentially. I = C = 13 patients.

2. Intervention

Nurse educator teaching self management skill to asthmatic children and their parents. I: Individual education sessions, two group sessions, and telephone access. Telephone monitoring every 2-3 months and completion of diary. C: Received standard physician care.

3. Outcomes measured, follow up

Symptoms, medications, school attendance, emergency room visits, hospitalisations, costs, family attitudes and knowledge. Average duration 13 months (range 8 to 16). Spirometry and medication. 6-12 month follow up.

4. Results

Self management training by a nurse educator led to improvements in comprehension of and compliance with asthma management, resulting in increased asthma medications, earlier initiation of therapy, fewer hospitalisations, emergency room visits, and asthma attacks, less school absenteeism, and lower hospital costs. Savings to society would be much greater if potential indirect costs for the family were considered, also perceived benefits, positive feeling and attitude of families.

5. Comments

Not a rigorous study, with little detail given. Small sample size, too small for subgroup analysis reported. All families were self motivated to seek care and kept appointments regularly.

Dzyngel et al (1994)³⁶

1. Study population, setting, study design, and size

Adult out-patient referrals, Toronto Hospital, Canada. Audit: 342 patients; 127 for 6-12 month comparison.

2. Intervention

Ambulatory care asthma programme incorporating physician assessment and treatment and individualised patient education sessions by a full time nurse educator.

3. Outcomes measured, follow up

Spirometry and medication. 6-12 months follow up.

4. Results

Increased use of inhaled anti-inflammatory drugs and decreased theophylline. Significant reduction in asthma exacerbations requiring hospital/emergency room care or systemic steroids while reducing the prevalence and severity of airflow limitations.

5. Comments

36% drop out for follow up appointment. Issues of patient recall, biases of self reporting. Selective population. No control group (considered unethical).

In-patient: Bucknall et al (1988)⁴⁰

1. Study population, setting, study design, and size

Acute asthma admissions to four general medical units in Glasgow Royal Infirmary. Prospective survey. Patients allocated by admission date. R = 64 patients, G = 86 patients.

2. Intervention

Patient management, supervision, and outcome on general medical units with and without a specialist respiratory interest. R: patients admitted to general medical units with specialist respiratory physician. G: patients admitted to general medical units without specialist.

3. Outcomes measured, follow up

Medication, morning tightness, readmissions, sleep disturbance, wheeze, clinic review. Home interview 2 weeks after discharge. Hospital case notes 2 months after home interview.

4. Results

R more likely than G to be treated with oral steroids, have PEFR/spirometry measured, have inhaler technique assessed when in hospital. R had higher proportion of increased inhaled treatment, fewer with no review planned at discharge. Significantly fewer R patients with sleep disturbance, morning tightness, and wheeze. 20% of G were readmitted for asthma within one year compared with 2% in R. Differences in asthma management between units with and without a specialist respiratory interest affect outcome. Poor management practices cause preventable morbidity.

5. Comments

Patients may have self selected by presenting at hospital at a specific time.

Pearson et al (1995)⁴¹

1. Study population, setting, study design, and size

Adult acute severe asthma admissions. Audit (non-random sample of UK hospital records). 766 patients: R 426, G 340, 36 hospitals: 12 teaching, 24 DGH.

2. Intervention

Audit of the standard of asthma management. Hospitals selected on asthma audit co-ordinator, geography, mixture of teaching and DGHs. R: Patients admitted by respiratory physicians G: Patients admitted by general physician or geriatrician.

3. Outcomes measured, follow up

Assessment of patient, initial treatment, monitoring, discharge process, follow up arrangements. (90% of physicians approached agreed to be co-ordinators).

4. Results

More R than G patients were taking steroids on admission. 8% of patients received no steroids in first 24 hours, significantly more were G patients. 8% of patients had written management plans on discharge, 24% had no planned out-patient appointment. 60% of patients were seen in clinic in < 2 months. Hospital management of a significant minority of patients deviates from recommended standards, some deviations are potentially serious. Respiratory physicians provide significantly better care than non-respiratory.

5. Comments

Hospitals selected may provide better care than overall, as co-ordinators were physicians with an interest in asthma. Conclusion about variation in care based on non-comparable groups.

Bell et al (1991)⁴²

1. Study population, setting, study design, and size

Acute asthma admissions to an English DGH. Random sample of records. T = 34, G = 42 patients.

2. Intervention

Asthma care audit by chest and general physicians. T: treatment by thoracic physician G: treatment by general physician (group determined by admission).

3. Outcomes measured, follow up

Readmission, mortality, acute asthma assessment and management. No follow up.

4. Results

T had more measures of severity, the greatest difference in serum potassium concentration recorded, significantly more likely to get emergency treatment with steroids < one hour of arrival. 64% of G were not referred for out-patient follow up. More readmissions for patients in G.

5. Comments

Patients may self select by presenting at a specific time (the main focus of the study is audit).

Crompton et al (1987)⁴³

1. Study population, setting, study design, and size

Asthma patients attending the respiratory unit at an Edinburgh hospital. Retrospective description. 195 patients.

2. Intervention

Hospital self admission scheme for patients with severe asthma to reduce asthma mortality, by decreasing the time taken for patients to be admitted to hospital.

3. Outcomes measured, follow up

Number of admissions, time of admission, mortality. 15 years since scheme inception.

4. Results

110 patients left the list, 6 re-enrolled. 873 admissions (1/3 of the time patients allowed home without formal admission). Comparing 1st and last 3 years: shift to out of hours admission, decrease in attack duration before admission. 3 deaths in hospital, 6 outside. No disadvantages to scheme found, lives almost certainly saved. Service has no cost, gives confidence to patients and GPs.

5. Comments

Descriptive study, no clear evaluation of effectiveness (considered unethical to do a RCT). Work follows from other 2 papers on first 7 and 10 years of service.

Emergency: Maiman et al (1979)⁴⁴

1. Study population, setting, study design, and size

Adult asthmatic patients admitted to emergency department, Baltimore, USA. RCT (3x2)x2x2 sequential intervention introduction. 245 patients.

2. Intervention

Interpersonal similarity (nurse intervention by identified; unidentified asthmatic; non-asthmatic); positive written appeal (booklet; no booklet). Stage 1 intervention, Stage 2 interview, Stage 3 follow up nurse reinforcement by telephone.

3. Outcomes measured, follow up

Visits to emergency department. 2 weeks in each intervention arm before the next treatment. Only short term results reported in this paper.

4. Results

Significant asthmatic nurse effect (identified or unidentified). No effect found for the book, nurse-book interaction, or interview. From initial interview to telephone follow up, there was a significant nurse effect for the asthmatic nurse intervention compared with the non-asthmatic. Interpersonal similarity should be taken into account, role of information seems to be modified by its source.

5. Comments

The study methodology is not very clearly explained, and intervention group numbers are not reported. Follow up is very short term (2 weeks) for each intervention, this would not necessarily be long enough to determine behaviour.

Joe et al (1992)⁴⁵

1. Study population, setting, study design, and size

Emergency department residents and adult asthmatic patients, Tennessee USA. Non-randomised, single blind observational study A: 8 residents, 82 patients B: 8 residents, 139 patients C: 8 residents, 129 patients.

2. Intervention

A: Short verbal presentation to residents on emergency department rotation, literature summary and protocols. B: A, plus long term anti-inflammatory treatment at discharge. C: control group, no intervention. (Residents prescribing patterns were covertly collected).

3. Outcomes measured, follow up

Acute and discharge treatment, length of stay. From entry into emergency department until discharge.

4. Results

Emergency department β agonist treatment similar for all 3 groups, low theophylline use more pronounced in A and B. Nebulisation, steroids greater in A and B than C. At discharge, A had more tapering prednisone than C and B, more use of β agonists than B. Inhaled steroids had more use in B than C. Theophylline lower in A and B compared with C. No difference in length of stay between groups. Intervention is effective in improving acute management prescribing patterns, but partially effective in optimising discharge treatment.

5. Comments

Severity of asthma on presentation and physician characteristics are not reported, and could differ between groups. The text of the results does not concur with the tables for the prescribing patterns (both acute and discharge). Some conclusions do not follow from the results.

Connett et al (1993)⁴⁶

1. Study population, setting, study design, and size

Acute asthmatic children presenting at hospital in Brighton. Before-after study. I. 197 children, 158 seen by registrar, 39 seen by SHO. II. 687 children.

2. Intervention

I. Replacement of SHOs with registrar for admission decision. II. SHO training with home treatment package for acute asthmatic children. I. Assessment by registrar/SHO (80%/ 20%) v SHO preintervention. II. Assessment by SHO with education v SHO before education.

3. Outcomes measured, follow up

Admissions and readmissions (I and II), symptom, daytime cough and wheeze, activity, medications (II). I. 1 weeks; II. 2 week follow up. Some patients sent diary cards.

4. Results

I. 34 (15)% of children seen by registrar or SHO were sent home, 9(3)% of whom reattended in <1 week, 2(3)% were admitted. More children sent home compared with previously. II. 44% of children seen by educated SHOs were sent home, 5% of whom reattended in < 1 week, 2% subsequently admitted. Referrals were similar to previous years, but fewer admissions. More children sent home in study compared with previously.

5. Comments

Not a rigorous study, no comparison of groups, or measure of asthma severity. Not randomised. Impact of previous admissions may reflect on current admissions (only 45% of those admitted and 61% of those not admitted returned the diary cards).

Key to abbreviations

I = intervention group; C = control group; RCT = randomised controlled trial; CHW = community health worker; DGH = district general hospital; SHO = senior house officer; HMO = health maintenance organisation; MDI = metered dose inhaler; PEFr = peak expiratory flow rate.

Conclusions

There is a lack of good quality research evaluating organisational aspects of the delivery of asthma care. No conclusive evidence has been identified to favour any particular organisational form, although limited evidence would suggest that specialist care is associated with better outcomes than care provided by non-specialists. Also, shared care under certain circumstances can be as effective as hospital led care in the treatment of adults with asthma. Further research, with long term follow up, is required to provide reliable evidence to inform policy. Of particular interest is the question of who delivers asthma care, to find whether patients treated by healthcare professionals with expertise and interest in asthma, independent of setting, will experience better outcomes.

Attention should move away from looking solely at individual treatments to looking at complete packages of treatment and their component parts. Carefully designed and well thought out randomised controlled trials are needed to identify the specific aspects of organisation to inform policy makers. As noted in the case of shared care for diabetes, changes in the delivery of care are being implemented before they have been fully evaluated.⁵⁶ There is a need for thorough evaluation of such programmes (with long term follow up) before widespread implementation.

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APPENDIX D: GUIDANCE NOTES FOR INDICATOR SPECIFICATIONS

Title	A short title to identify the indicator
Intervention aim	<p>Distinguishes the level of intervention for which the indicator is primarily developed. It is assumed that, for a given condition, an ideal set of indicators would be reasonably balanced across the spectrum of health intervention stages. For asthma these stages are:</p> <ul style="list-style-type: none">- reduce or avoid risk of asthma- detect asthma early- reduce or avoid acute attacks- reduce risk of death- assure return to function after an acute attack- reduce impact of asthma on general well-being.
Characteristics	<p>Classifies the indicator on four dimensions:</p> <ul style="list-style-type: none">- Specificity: <i>condition-specific or generic</i>- Perspective: <i>population, clinical or patient</i>- Time-frame: <i>cross-sectional measure or longitudinal</i> assessment of change- Outcome relationship: whether it is a <i>direct</i> measure of outcome or a <i>indirect</i> measure of structure or process, used as a proxy for outcome.
Indicator definition	<p>In addition to a definition of the variable of interest, the description should specify:</p> <ul style="list-style-type: none">- how the variable is to be aggregated across cases eg definitions of both a numerator and a denominator- whether the indicator is to be reported with respect to a set of denominators eg mortality broken down by age and sex- if appropriate, how longitudinal change in the variable is to be represented eg over what time interval; whether absolute difference or proportional change.
Rationale	<p>A brief statement of the reasons and objectives behind the indicator, both in terms of the issues it addresses and its selection from a range of potential alternatives.</p>
Asthma definition	<p>Indicates definition of asthma employed in indicator in question. The definition used will be determined both by the indicators' rationale and by the available data sources. The definition will consist of one of the following, or some combination thereof:</p> <ol style="list-style-type: none">Asthma as diagnosed by GP (Read code (5 character) H33) and recorded on an asthma register.Asthma as diagnosed by GP with a response to bronchodilators of a least 60 litres/minute improvement in Peak Expiratory Flow (PEF) (or expressed as a percentage).

- iii) Asthma as defined by those who are prescribed inhaled drugs. (Read codes: cromoglycate c71% - c72%; beta agonists c1%; inhaled steroids c61% -c64z).
- iv) Asthma as specified on a hospital record - In-patient diagnosis (ICD-9 493 or ICD-10 J45-J46)
- v) Asthma as a primary cause on death certificate (ICD-9 493 or ICD-10 J45-J46).

Potential uses

The following classification has been used:

- local clinical practice:
- local audit
- provider based comparisons
- population based comparisons
- assessment of regional/national trends or progress towards targets.

It is recognised that a given indicator may serve several purposes. Indicators that are valuable for the management of individual patients are likely to have practical advantages with respect to data collection in a clinical setting, however in order for such indicators to be useful for other purposes, a method of aggregation across cases must be specified for the variable of interest.

Potential users

The following classification has been used:

- clinicians
- provider management
- commissioners
- national/regional policy makers
- consumers/public.

Possible confounders

This section has attempted to identify the population risk factors likely to influence the outcome indicator, and therefore useful in its interpretation. Where such factors are well defined and have a clear or potential association with the outcome of interest, they may be used to specify denominators to be included in the indicator definition itself.

Data sources

Where possible, identifies existing sources of data for deriving the indicator (eg chronic disease registers, hospital discharge data sets) and indicates the degree to which complete coverage of the population of interest would be obtained. Where data are not widely available from existing systems, suggestions for new methods of data collection, capable of wide implementation over a (say) five year time scale, have been made. Data collection proposals have made reference to relevant developments in NHS information systems (eg the NHS number).

Data quality	While the theoretical capabilities of existing and proposed information systems are outlined above, the actual or expected limitations of those systems in terms of their completeness and accuracy are noted here.
Comments	General comments regarding the definition, validity and practicality.
Further work	Suggestions about the additional research and development work required to complete the indicator's specification to a level appropriate for large scale piloting.
Conclusions & priority	A statement indicating the Working Group's assessment of the priority for implementation amongst the asthma indicator set.
References	Appropriate references used in the construction of the indicators.

APPENDIX E: WORK COMMISSIONED FROM UK CLEARING HOUSE FOR INFORMATION ON HEALTH OUTCOMES

Reprint of a document published by the UK Clearing House:

'Measuring the health care outcomes of adult asthmatics: an annotated bibliography'

SECTION 1

REVIEWS OF SEVERAL INSTRUMENTS

There are a number of reviews of questionnaires for measuring asthma outcomes. The most extensive is Hutchinson et al (1995) which summarises the properties of the measures available and provides an introduction to methods of outcome measurement (see Appendix 1). A supplement of the American Journal of Critical Care Medicine is essential reading for anyone planning to measure asthma outcomes as it comprises papers from a workshop devoted to measuring outcomes in asthma, organised by the National Institutes of Health (1994, 149: S1-S43).

Bailey WC, Wilson SR, Weiss KB, Windsor RA and Wolle JM (1994) Measures for use in clinical research: overview of the NIH workshop, American Journal of Respiratory and Critical Care Medicine, 149: S1-S8.

AIM: To provide an overview of the United States' National Institutes for Health (NIH) workshop entitled "Workshop on Outcome Measures for Research Studies".

COMMENTARY: Provides background and an overview of a workshop which covered the following types of measures: physiologic, clinical symptoms, functional status, role performance and quality of life, treatment regimen and side effect measures, patient/family medication use, patient management behaviour and health care utilisation. Papers on each of these themes are given followed by a discussant section. Conclusions and recommendations of areas for further research are given. The workshop papers are presented as a supplement to the journal and are essential reading for those studying this topic.

Bauman LJ (1994) NIH workshop on asthma outcome measures: discussant section, American Journal of Respiratory and Critical Care Medicine, 149: S40-S43.

AIM: To suggest definitions of terms relating to outcome measurement for asthma

COMMENTARY: Provides a conceptual framework for describing outcome measurement and quality of life assessment in relation to asthma, as a contribution to the American National Institute for Health's workshop on asthma outcome measurement. Aims to clarify the definitions involved in order to help researchers decide what to measure. Gives a set of recommendations for outcomes research into asthma.

Enright PL, Lebowitz MD and Cockcroft DW (1994) Physiologic measures: pulmonary function tests, asthma outcome, *American Journal of Respiratory and Critical Care Medicine*, 149: S9-S18.

AIM: To review the various pulmonary function tests available for measuring the effectiveness of asthma interventions in a research setting.

COMMENTARY: Provides a review of the physiologic measures (of variable airways obstruction) which can be used to measure the severity of asthma. The advantages, disadvantages and appropriate settings for baseline spirometry, reversibility of obstruction, airway responsiveness, ambulatory monitoring and other pulmonary function tests are summarised. It is noted that a "gold standard" for the measurement of asthma severity does not exist, but these measures contribute additional information useful for measuring asthma outcome within clinical trial settings.

Hutchinson A, McColl E, Meadows K, Riccalton C and Fowler P (1995) A health status measures guide for asthma and diabetes, Newcastle: University of Newcastle upon Tyne, Centre for Health Services Research, University of Hull, Department of Public Health Medicine.

INSTRUMENTS: Asthma Quality of Life Questionnaire, Asthma Symptoms Checklist, Attitudes to Asthma, Baseline and Transition Dyspnoea Indexes, Chronic Respiratory Disease Questionnaire, Health Related Quality of Life in Asthma, IUATLD Bronchial Symptoms Questionnaire, Living with Asthma, MRC Respiratory Symptoms Questionnaire, Newman Taylor Asthma Questionnaire, St George's Respiratory Questionnaire

AIM: To review condition specific measures for asthma and diabetes to measure health status in ambulatory care settings.

COMMENTARY: Valuable review of instruments used for measuring health status in asthma and diabetes. Provides an overview of measuring health, essential information on each measure (length, original purpose, psychometric testing, method of administration and contact name). Includes original references for all measures, but not copies of measures themselves.

Hyland ME (1992) Quality of life assessment in respiratory disease: an examination of the content and validity of four questionnaires, *Pharmacoeconomics*, 2 (1): 43-53.

INSTRUMENTS: Chronic Respiratory Disease Questionnaire, St George's Respiratory Questionnaire, Living with Asthma Questionnaire, Asthma Quality of Life Questionnaire

AIM: To review the content and validity of 4 quality of life measures for asthma sufferers.

COMMENTARY: Useful summary of the content and method of validation of 4 key measures used in assessing the quality of life in asthmatics. Highlights the differences between the measures and the way they were developed. Provides a brief description of different methods of validating measures. Does not contain copies of any of the measures.

James M, Richards JR and Hemstreet MP (1994) Measures of life quality, role performance and functional status in asthma research, *American Journal of Respiratory and Critical Care Medicine*, 149:S31-S39.

AIM: To provide a review of generic and disease specific measures for assessing quality of life in asthma research.

COMMENTARY: Useful review of generic and disease specific measures which have been used for assessing functional status and quality of life in asthma research, provides a distinction between role performance, functional status and quality of life. Presents clear conclusions and recommendations on what types of measures should be used in research studies. Also discusses the use of QALYs in assessing outcomes.

Jones PW (1993) Measurement of health related quality of life in asthma and chronic obstructive airways disease. In Walker SR and Rosser RM (eds) *Quality of life assessment: key issues in the 1990s*, Lancaster: Kluwer: 301-320.

INSTRUMENTS: Quality of Well Being Scale (QWB), Sickness Impact Profile (SIP), Chronic Respiratory Questionnaire (CRQ), St George's Respiratory Questionnaire (SGRQ), Living with Asthma Questionnaire (LWAQ)

COMMENTARY: Reviews a number of general and disease specific questionnaires that can be used to measure health related quality of life in asthma and chronic obstructive airways disease. Provides basic information on the natural history of the disease, therapeutic aims of treatment and a useful summary of general requirements for measurement in this disease area. The review is selective rather than comprehensive. Information on the validation of each of the measures is given together with conclusions for their use.

Williams SJ (1989) Chronic respiratory illness and disability: a critical review of the psychosocial literature, *Social Science and Medicine*, 28 (8): 791-803.

COMMENTARY: Useful review of the literature focusing on psychosocial issues relating to chronic obstructive airways disease (COAD). Highlights some of the problems relating to methodology and measurement within psychosocial research including quality of life and disability measures.

SECTION 2

This section provides the core references to the major English language questionnaires developed to measure asthma outcomes.

TESTING AND DEVELOPMENT OF INSTRUMENTS INTENDED FOR USE IN ASTHMA

AMBULATORY CARE PROJECT MEASURES

The Newcastle based Ambulatory Care Project produced both a review of measures, and recommendations for core measurements of outcomes in primary care. These recommendations include sets of items from the Living with Asthma Questionnaire, the SF-36 and the Hospital Anxiety and Depression Scale.

Hutchinson A, McColl E, Meadows K, Riccalton C and Fowler P (1995) A health status measures guide for asthma and diabetes, Newcastle: University of Newcastle upon Tyne, Centre for Health Services Research, University of Hull, Department of Public Health Medicine.

INSTRUMENTS: Asthma Quality of Life Questionnaire, Asthma Symptoms Checklist, Attitudes to Asthma, Baseline and Transition Dyspnoea Indexes, Chronic Respiratory Disease Questionnaire, Health Related Quality of Life in Asthma, IUATLD Bronchial Symptoms Questionnaire, Living with Asthma, MRC Respiratory Symptoms Questionnaire, Newman Taylor Asthma Questionnaire, St George's Respiratory Questionnaire

AIM: To review condition specific measures for asthma and diabetes to measure health status in ambulatory care settings.

COMMENTARY: Valuable review of instruments used for measuring health status in asthma and diabetes. Provides an overview of measuring health, essential information on each measure (length, original purpose, psychometric testing, method of administration and contact name). Includes original references for all measures, but not copies of measures themselves.

McColl E, Steen IN, Meadows KA, Hutchinson A, Eccles MP et al (1995) Developing outcome measures for ambulatory care: an application to asthma and diabetes, *Social Science and Medicine*, 41 (10): 1339-1348.

AIM: To describe the theory and practice underlying the development of outcome measures for asthma and diabetes in ambulatory care settings.

COMMENTARY: Provides a step by step guide to the process of the development of the ambulatory care outcome measures for asthma and diabetes. Includes clear guidance on key components of outcome measures. The ambulatory care outcome measures have been developed from existing quality of life measures and the selection and testing of these is described. Information on the psychometric properties of the component measures is given. Should be read in conjunction with other papers on this work.

Steen N, Hutchinson A, McColl E, Eccles MP, Hewison J et al (1994) Development of a symptom based outcome measure for asthma, *British Medical Journal*, 309 (6901): 1065-1068.

INSTRUMENTS: Ambulatory Care Project Measures

AIM: To describe the development of two symptom based measures for outcome assessment within ambulatory care settings.

COMMENTARY: Describes the development and psychometric testing of two 5-item scales to measure asthma symptoms which have been proposed as outcome measures for adult asthmatics in ambulatory care settings. Information on the contents of the questionnaires is given, but not copies themselves. Suggests that the measures are more responsive to change than a generic outcome measure. Further testing is to be carried out, on the clinical utility of the scales and whether they can be used for individual patient management.

ASTHMA BOTHER PROFILE

This 17-item questionnaire both records symptoms and psychosocial impacts; and is distinctive for separately asking how bothersome each is.

Hyland ME, Ley A, Fisher DW and Woodward V (1995) Measurement of psychological distress in asthma and asthma management programmes, *British Journal of Clinical Psychology*, 34: 601-611.

INSTRUMENTS: Asthma Bother Profile

AIM: To describe the preliminary development of a questionnaire and its use in an asthma management clinic.

COMMENTARY: Paper describing the preliminary development of the 15-item Asthma Bother Profile. The questionnaire has been designed to aid clinical diagnosis or as an outcome measure for use in studies investigating the efficacy of psychological interventions in asthma. It focuses on psychological symptoms which affect or "bother" asthmatics. Tests described showed the questionnaire to be valid and reliable in an asthma management clinic setting. However tests for responsiveness were not described. This should be explored before recommendation for use as an outcome measure. A copy of the actual questionnaire is not included (however the items are listed).

ASTHMA QUALITY OF LIFE QUESTIONNAIRE (Juniper et al)

This 32-item questionnaire includes items on exposure to precipitating factors as well as reports of symptoms and psychosocial impacts.

Juniper EF, Guyatt GH, Epstein RS, Ferrie PI, Jaesche R et al (1992) Evaluation of impairment of health related quality of life in asthma: development of a questionnaire for use in clinical trials, *Thorax*, 47: 76-83.

INSTRUMENTS: Asthma Quality of Life Questionnaire (AQLQ)

AIM: To describe the development of a questionnaire to measure quality of life in asthma clinical trials.

COMMENTARY: This is the original paper describing the development of the Asthma Quality of Life Questionnaire, a 32-item questionnaire taking a maximum of 15 minutes to complete. Although content validity was established no other tests for validity and reliability are described. Further information is needed on the psychometric properties of the questionnaire before it can be shown to be appropriate for assessing quality of life of asthmatics in clinical trials. A copy of the questionnaire is included. This should not be confused with the questionnaire of a similar name by Marks et al.

Note: This has been referred to elsewhere as the Health Related Quality of Life in Asthma Questionnaire.

ASTHMA QUALITY OF LIFE QUESTIONNAIRE (Marks et al)

In its final form this is a 20-item questionnaire covering both symptoms and psychosocial items.

Hyland ME (1992) Quality of life assessment in respiratory disease: an examination of the content and validity of four questionnaires, *Pharmacoeconomics*, 2(1): 43-53. See page 116

Marks GB, Dunn SM and Woolcock AJ (1992) A scale for the measurement of quality of life in adults with asthma, *Journal of Clinical Epidemiology*, 45 (5): 461-472.

INSTRUMENTS: Asthma Quality of Life Questionnaire (AQL)

AIM: To describe the development and testing of a scale to measure quality of life in adult asthmatics.

COMMENTARY: The final 20-item questionnaire was tested on large sample sizes in both out-patient and community settings. It proved to be valid and reliable at measuring quality of life in these samples, but needs further testing before recommendation as an outcome measure. A copy of the questionnaire is included in the appendix.

Note: This questionnaire should not be confused with the questionnaire of the same name by Juniper et al.

Marks GB, Dunn SM and Woolcock AJ (1993) An evaluation of an asthma quality of life questionnaire as a measure of change in adults with asthma, *Journal of Clinical Epidemiology*, 46 (10) : 1103 - 1111.

INSTRUMENTS: Asthma Quality of Life Questionnaire (AQL)

AIM: To describe the development of the AQL and test its validity and responsiveness as a measure of change in quality of life.

COMMENTARY: Building on an earlier paper outlining the development, and psychometric testing of the 20-item Asthma Quality of Life Questionnaire, longitudinal validity and responsiveness of the questionnaire is explored. The results show it to be responsive to change. Further testing should be carried out before using it as an outcome measure in clinical trials of asthma interventions. The questionnaire should not be confused with the Asthma Quality of Life Questionnaire by Juniper et al. Copy of the questionnaire is not included. Should be read in conjunction with other papers.

ASTHMA SYMPTOM CHECKLIST

This 36-item questionnaire was developed by Kinsman et al to explore both the symptomatology and psychosocial impact of asthma attacks.

Hyland ME, Kenyon CAP, Taylor M and Morice AH (1993) Steroid prescribing for asthmatics: relationship with Asthma Symptom Checklist and Living with Asthma Questionnaire, *British Journal of Clinical Psychology*, 32: 505-511.

INSTRUMENTS: Asthma Symptom Checklist (ASC), Living with Asthma Questionnaire (LWAQ)

AIM: To assess the psychological consequences of asthma and show the relationship between them and the steroids prescribed by physicians.

COMMENTARY: Useful paper for highlighting the difference between two questionnaires commonly used for assessing quality of life in asthma sufferers (the Asthma Symptom Checklist (ASC) and the Living with Asthma Questionnaire (LWAQ)). The ASC measures experience during attacks and the LWAQ measures experience between attacks. Indicates that the independence of ASC subscales needs to be examined. Suggests that physicians' prescribing rates are not influenced by reported problems between asthma attacks - but this may be different in a primary care setting - and that panic/fear is an important dimension affecting asthma management.

Kinsman RA, Luparello T, O'Banion K and Spector S (1973) Multidimensional analysis of the subjective symptomatology of asthma, *Psychosomatic Medicine*, 35 (3): 250-267.

INSTRUMENTS: Asthma Symptom Checklist

AIM: To describe the development of the Asthma Symptom Checklist.

COMMENTARY: Original paper on the development of the Asthma Symptom Checklist, a 36-item measure of the subjective symptoms experienced by asthma sufferers. The checklist was derived from interviews with severe asthma sufferers and tested on 100 adults in an out-patient clinic. Psychometric tests performed on the items in the checklist are described. Information given on its reliability and validity is difficult to interpret because of unconventional tests used. Cannot be recommended as an outcome measure until its responsiveness is demonstrated.

ATTITUDES AND BELIEFS ABOUT ASTHMA

This 31-item questionnaire covers psychosocial impacts, attitudes to the condition and attitudes to medical care. Though relatively old, it remains one of the few questionnaires whose topic coverage is relevant to the measurement of outcomes of asthma related health education.

Sibbald B, Collier J and D'Souza M (1986) Questionnaire assessment of patients attitudes and beliefs about asthma, *Family Practice*, 3 (1): 37-41.

INSTRUMENTS: Attitudes and Beliefs about Asthma Questionnaire

AIM: To develop and test a questionnaire to measure patients beliefs and attitudes to asthma.

COMMENTARY: The development and testing of a 40-item questionnaire to assess patients attitudes to their asthma is described on a small sample size (45), but validity and reliability is not adequately shown. After modifications from a visual analogue to a Likert scale it was shown to be acceptable to most patients, again on a small sample size (20). A copy of the questionnaire is given in the appendix.

Note: This questionnaire has been referred to elsewhere as the Attitudes to Asthma Questionnaire

Sibbald B, White P, Pharoah C, Freeling P and Anderson HR (1988) Relationship between psychosocial factors and asthma morbidity, *Family Practice*, 5 (1): 12-17.

INSTRUMENTS: Attitudes and Beliefs about Asthma Questionnaire

AIM: To describe psychosocial attributes of asthma patients and relate these to morbidity.

COMMENTARY: Describes a survey which used the Attitudes to Asthma Questionnaire to determine the psychosocial impact on a patients life and the effect this has on morbidity. Provides useful information on psychosocial morbidity related to asthma.

Note: This questionnaire has been referred to elsewhere as the Attitudes to Asthma Questionnaire

BASELINE DYSPNOEA INDEX

This 3-item index uses Likert scaling to record the extent of impairment as well as the type of task and effort that precipitates dyspnoea

Mahler DA, Weinberg DH, Wells CK and Feinstein AR (1984) The measurement of dyspnoea: contents, interobserver agreement and physiologic correlates of two new clinical indexes, *Chest*, 85 (6): 751-757.

INSTRUMENTS: Baseline Dyspnoea Index, Transition Dyspnoea Index

AIM: To develop indexes which measure dyspnoea (breathlessness) and include functional impairment and magnitude of effort components.

COMMENTARY: Original paper describing the development and testing of the Baseline and Transition Dyspnoea Indexes - observer rating scales to providing details of 3 categories relating to dyspnoea (functional impairment, magnitude of task and magnitude of impairment). The two indexes allow comparison of changes in dyspnoea. General validity and reliability is explored.

Mahler DA, Rosiello RA, Harver A, Lentine T, McGovern IF et al (1987) Comparison of clinical dyspnoea ratings and psychophysical measurements of respiratory sensation in obstructive airways disease, *American Review of Respiratory Diseases*, 135: 1229-1233.

INSTRUMENTS: Medical Research Council Scale (MRC), Oxygen Cost Diagram, Baseline and Transition Dyspnoea Indexes, psychophysical tests

AIM: To investigate whether clinical and psychophysical testing provides different information about dyspnoea (breathlessness).

COMMENTARY: The study showed that clinical dyspnoea ratings such as the MRC Scale, the Oxygen Cost Diagram and the Baseline Dyspnoea Index correlate with lung function tests but are independent of perception of breathing loads and as such show different results from psychophysical tests. The authors suggest that clinical methods are more appropriate for evaluating the impact of dyspnoea on a patient's daily activities. The study was carried out on a relatively small sample size (24 with obstructive airways disease - including 3 asthmatics, 12 controls). Examples of scales used are given.

Mahler DA and Harver A (1992) A factor analysis of dyspnoea ratings, respiratory muscle strength, and lung function in patients with chronic obstructive pulmonary disease, *American Review of Respiratory Diseases*, 145: 467-470

INSTRUMENTS: Medical Research Council Scale (MRC), Oxygen Cost Diagram, Baseline Dyspnoea Index (BDI)

AIM: To demonstrate that clinical ratings of breathlessness and physiologic function comprise separate dimensions underlying the pathophysiology of patients with chronic respiratory disease. To demonstrate that measurements of dyspnoea should be undertaken routinely as a measure of outcome in this group of patients.

COMMENTARY: Factor analysis was used to illustrate that the dyspnoea ratings, maximal respiratory pressures and lung function are independent factors that characterise or describe the health status of patients suffering from chronic obstructive pulmonary disease (COPD). Suggests that clinical evaluations of COPD patients should include routine measurement of dyspnoea and respiratory muscle strength in addition to spirometry.

INTERNATIONAL UNION AGAINST TUBERCULOSIS ASTHMA QUESTIONNAIRE

These references describe the development and testing of a questionnaire for use in surveys to measure the distribution and prevalence of asthma. This work builds on the more general IUATLD of assessing the prevalence of all respiratory disorders.

Abramson MJ, Hensley MJ, Saunders NA and Wodarczyk JH (1991) Evaluation of a new asthma questionnaire, *Journal of Asthma*, 28 (2): 129-139.

INSTRUMENTS: IUATLD Bronchial Symptoms Questionnaire

AIM: To test the validity of the IUATLD questionnaire.

COMMENTARY: The tests reported show the IUATLD bronchial symptoms questionnaire to be a valid measure for use in epidemiological surveys of asthma. However the paper should be read in conjunction with other papers on the instrument's development to gain a full picture of its psychometric properties. A copy of the questionnaire is included in the appendix.

Burney P and Chinn S (1987) Developing a new questionnaire for measuring the prevalence and distribution of asthma, *Chest*, 91 (6) (Supplement): 79S-83S.

INSTRUMENTS: Bronchial Symptoms Questionnaire of the International Union Against Tuberculosis and Lung Disease (IUATLD)

AIM: To describe the development and initial testing of the Bronchial Symptoms Questionnaire of the International Union Against Tuberculosis and Lung Disease (IUATLD).

COMMENTARY: Describes the development of the questionnaire and gives background to the methods used in its psychometric testing. Conclusions on the validity and reliability of the questionnaire are not reached. Needs to be read in conjunction with other papers on the testing of the questionnaire.

LIVING WITH ASTHMA

The 68-item Living with Asthma is one of the longer British instruments for measuring asthma outcomes in research.

Grampian Asthma Study of Integrated Care (GRASSIC) (1994) Integrated care for asthma: a clinical, social and economic evaluation, *British Medical Journal*, 308 (6929): 559-564.

INSTRUMENTS: Hospital Anxiety and Depression Scale, Living with Asthma Scale

AIM: To evaluate integrated care for asthma in clinical, social and economic terms.

COMMENTARY: A pragmatic randomised trial to evaluate integrated care for asthma in clinical, social and economic terms in Scotland is described. The trial used a range of outcome measures; bronchodilators, steroid use, hospital admission rates, restrictions on normal activity and psychological aspects of health (measured using the anxiety part of the HAD and some questions from the LWAQ). The methodology of the trial and the use of the outcome measures are well documented. However the actual questions used and how they were selected are not described. The paper clearly illustrates how a range of measures (clinical, generic and condition specific) can be used in an evaluation study.

Hyland ME, Finnis S and Irvine SH (1991) A scale for assessing quality of life in adult asthma sufferers, *Journal of Psychosomatic Research*, 35 (1): 99-110.

INSTRUMENTS: Living with Asthma Questionnaire

AIM: To develop and test a scale suitable for measuring quality of life in adult asthmatic patients, to evaluate the effectiveness of treatment management programmes.

COMMENTARY: Original paper on the development of the 68-item Living with Asthma Questionnaire. Provides information on how the questionnaire was constructed after interviews with focus groups of asthma sufferers and was subsequently refined after testing the questionnaire on sample groups of asthmatics. Tests showed the scale to be reliable, but it was acknowledged that this could be due to the highly motivated group who completed the questionnaire. Contains copy of the scale. Should be read in conjunction with other papers.

Hyland ME (1991) The Living with Asthma Questionnaire, *Respiratory Medicine*, 85 (Supplement B): 13-16.

INSTRUMENTS: Living with Asthma Questionnaire (LWAQ)

AIM: To describe the development and validation of the Living with Asthma Questionnaire.

COMMENTARY: Important paper on the development and validation of the Living with Asthma Questionnaire. Adequate validity and reliability is reported. Should be read in conjunction with other papers on the development of the questionnaire. Notes that the questionnaire contains 68 items and has 11 domains. A copy of the scale is not included. Suggests the scale is useful as a screening device and as an outcome measure in clinical trials - but may need to be shortened for this purpose.

Hyland ME (1992) Quality of life assessment in respiratory disease: an examination of the content and validity of four questionnaires, *Pharmacoeconomics*, 2 (1): 43-53.
See page 116

Hyland ME, Kenyon CAP, Taylor M and Morice AH (1993) Steroid prescribing for asthmatics: relationship with Asthma Symptom Checklist and Living with Asthma Questionnaire, *British Journal of Clinical Psychology*, 32: 505-511.
See page 121

Jones PW (1993) Measurement of health related quality of life in asthma and chronic obstructive airways disease. In Walker SR and Rosser RM (eds) *Quality of life assessment: key issues in the 1990s*, Lancaster: Kluwer: 301-320.
See page 117

NATIONAL HEART AND LUNG INSTITUTE ASTHMA QUESTIONNAIRE

This is a short (9-item) questionnaire on respiratory symptoms, originally intended for survey work.

Venables KM, Farrer N, Sharp L, Graneek BJ and Newman Taylor AJ (1993) Respiratory symptoms questionnaire for asthma epidemiology: validity and reproducibility, *Thorax*, 48: 214-219.

INSTRUMENTS: National Heart and Lung Institute Asthma Questionnaire

AIM: To describe the development and testing of a questionnaire to measure respiratory symptoms, primarily designed for epidemiological survey work.

COMMENTARY: Development and testing of the 9-item National Heart and Lung Institute Asthma Questionnaire showed it to be valid and reliable over the short term for use in epidemiological surveys. The authors note that it compares with similar questionnaires for other respiratory conditions. A copy of the questionnaire is not included.

Note: This questionnaire has been referred to as the Newman Taylor Questionnaire elsewhere.

QUESTIONNAIRES CONCENTRATING ON SELF-REPORTS OF RESPIRATORY SYMPTOMS

These references provide an overview of this area and discuss the relative significance of different symptoms.

McGavin CR, Artvinli M, Naoe H and McHardy GJR (1978) Dyspnoea, disability and distance walked: comparison of estimates of exercise performance in respiratory disease, *British Medical Journal*, 2 (6132): 241-243.

INSTRUMENTS: Distance walked in 12 minutes

AIM: To correlate exercise tolerance (assessed by a walking test) with basic respiratory function values and a subjective assessment of exercise performance by the patient.

COMMENTARY: Useful paper showing the value of a simple walking test to assess disability and patients' response to treatment of respiratory disorders.

O'Connor GT and Weiss ST (1994) Clinical and symptom measures, *American Journal of Respiratory and Critical Care Medicine*, 149: S21-S28.

INSTRUMENTS: Medical Research Council Questionnaire, American Thoracic Society-Division of Lung Disease (ATS-DLD) Questionnaire, International Union Against Tuberculosis and Lung Disease (IUATLD) Bronchial Symptoms Questionnaire, Asthma Foundation of Tasmania Questionnaire, University of Sydney Questionnaire, Denver Asthma Symptom Checklist, University of Alabama at Birmingham Comprehensive Asthma Program Scales, St George's Hospital Questionnaire, American Institute for Research Adult Asthma Questionnaire, University of Cincinnati Disease Severity Score and Airway Reactivity Questionnaire, Usherwood Questionnaire, American Institute for Research "Wee Wheezers" Questionnaire.

AIM: To review a range of asthma symptom questionnaires as outcome measures in research applications, focusing on their validity and reliability.

COMMENTARY: Useful review article of a range of symptom questionnaires for adult and child asthmatics. Provides overview of questionnaire and summarises the psychometric properties of each questionnaire, but does not include copies. Clear conclusions and recommendations on the use of certain measures for a range of research purposes.

Steen N, Hutchinson A, McColl E, Eccles MP, Hewison J et al (1994) Development of a symptom based outcome measure for asthma, *British Medical Journal*, 309 (6961): 1065-1068.

See page 119

SHORT UN-NAMED INSTRUMENTS FOR ROUTINE MONITORING

These articles describe very short (less than 5-item) combined checklists and questionnaires for routine monitoring in primary care.

Jones KP (1991) Correlates of asthma morbidity in general practice, *Thorax*, 46: 318-319.

INSTRUMENTS: Morbidity index

AIM: To describe the development of a morbidity index.

COMMENTARY: Very brief abstract on the development of a short morbidity index for identifying asthmatic patients. No information is given on the testing and validation of the index. Needs to be read in conjunction with other articles.

Jones KP, Bain DIG, Middleton M, Mullee MA (1992) Correlates of asthma morbidity in primary care, *British Medical Journal*, 304: 361-364.

INSTRUMENTS: Morbidity index

AIM: To derive a simple morbidity index for screening asthmatic patients in primary care settings .

COMMENTARY: Describes the development of a simple 3-item morbidity index, but provides no evidence of its reliability or responsiveness. Should be read in conjunction with other papers.

Jones KP, Charlton IH, Middleton M, Preece WJ and Hill AP (1992) Targeting asthma care in general practice using a morbidity index, *British Medical Journal*, 304: 1353-1356.

INSTRUMENTS: Morbidity index

AIM: To evaluate a morbidity index as a postal surveillance tool in identifying previously diagnosed asthmatics in need of extra education or management.

COMMENTARY: Describes a study to evaluate the use of a short, simple morbidity index as a surveillance tool for asthmatics in general practice. A good response rate to the survey was achieved. The morbidity index was a more useful tool than questions on patient perceptions of their illness in identifying patients in need of further management or education. Suggests that questions regarding perceptions of asthma or drugs taken would not have identified the patients. Notes that further validation of the morbidity approach is in progress.

Keeley D (1993) How to achieve better outcome in treatment of asthma in general practice, *British Medical Journal*, 307 (6914): 1261-1263.

INSTRUMENTS: Morbidity index

AIM: To show that use of simple questions can be used to provide outcome data on a routine basis in general practice.

COMMENTARY: Argues that simple questions can be used to measure outcome in asthmatic patients in general practice. Outlines 3 simple questions that could be used but provides no evidence as to how these were derived or their validity, reliability or usefulness as an outcome measure. Needs to be read in conjunction with other papers.

TRANSITION DYSPNOEA INDEX

This 3-item index uses Likert scaling to record the extent of impairment as well as the type of task and effort that precipitates dyspnoea.

Mahler DA, Weinberg DH, Wells CK and Feinstein AR (1984) The measurement of dyspnoea: contents, interobserver agreement and physiologic correlates of two new clinical indexes, *Chest*, 85 (6): 751-757.

See page 123

Mahler DA, Rosiello RA, Harver A, Lentine T, McGovern JF et al (1987) Comparison of clinical dyspnoea ratings and psychophysical measurements of respiratory sensation in obstructive airways disease, *American Review of Respiratory Diseases*, 135: 1229-1233.

See page 123

Mahler DA and Harver A (1992) A factor analysis of dyspnoea ratings, respiratory muscle strength, and lung function in patients with chronic obstructive pulmonary disease, *American Review of Respiratory Diseases*, 145: 467-470.

See page 123

SECTION 3

GENERAL RESPIRATORY QUESTIONNAIRES AND OTHER MEASUREMENTS THAT HAVE BEEN APPLIED TO ASTHMA

This section provides the core references on a range of general respiratory questionnaires which have been used in asthma applications.

CHRONIC RESPIRATORY DISEASE QUESTIONNAIRE

This is a Canadian questionnaire developed by Guyaff et al in the mid 1970s. Although it has only 19 items, some of these contain long lists of response options and the interview based version may take at least 15 minutes to administer.

Guyatt GH, Berman LB, Townsend M, Pugsley SO and Chambers LW (1987) A measure of quality of life for clinical trials in chronic lung disease, *Thorax*, 42: 773-778.

INSTRUMENTS: Chronic Respiratory Disease Questionnaire (CRDQ)

AIM: To describe the development and testing of the Chronic Respiratory Disease Questionnaire (CRDQ).

COMMENTARY: Core paper on the development and validation of the Chronic Respiratory Disease Questionnaire. Results of the study showed that the questionnaire was valid, reliable and was able to detect change in four dimensions. Further testing should be continued in clinical trials. The four dimensions covered by the questionnaire are dyspnoea, fatigue, emotional function and patient's feelings of control over the disease. A copy of the questionnaire is included.

Guyatt GH, Townsend M, Berman LB and Pugsley SO (1987) Quality of life in patients with chronic airflow limitation, *British Journal of Diseases of the Chest* 81: 45-54.

INSTRUMENTS: Chronic Respiratory Disease Questionnaire (CRDQ)

AIM: To describe the rationale, development and testing of a questionnaire to measure the impact of chronic airflow limitation on quality of life (Chronic Respiratory Disease Questionnaire) for use in clinical trials.

COMMENTARY: Whilst the development, administration and results obtained from the 19-item questionnaire are described in detail, little information is given on the testing of the questionnaire for reliability and validity. Its psychometric properties cannot be ascertained from reading this article. The full questionnaire (108 questions) may be too long for many applications. Must be read in conjunction with other articles. A copy of the questionnaire is included.

Hyland ME (1992) Quality of life assessment in respiratory disease: an examination of the content and validity of four questionnaires, *Pharmacoeconomics*, 2(1): 43-53.
See page 116

Jones PW (1993) Measurement of health related quality of life in asthma and chronic obstructive airways disease. In Walker SR and Rosser RM eds) *Quality of life assessment: key issues in the 1990s*, Lancaster: Kluwer: 301-320.
See page 117

INTERNATIONAL UNION AGAINST TUBERCULOSIS RESPIRATORY QUESTIONNAIRE

There are several versions of this questionnaire; all are very short, even the longest has only 14 items. It is intended for general survey work to provide estimates of distribution and prevalence. A version that is more specific to asthma is under development.

Burney P and Chinn S (1987) Developing a new questionnaire for measuring the prevalence and distribution of asthma, *Chest*, 91 (6) (Supplement): 79S-83S.

INSTRUMENTS: Bronchial Symptoms Questionnaire of the International Union Against Tuberculosis and Lung Disease (IUATLD)

AIM: To describe the development and initial testing of the Bronchial Symptoms Questionnaire of the International Union Against Tuberculosis and Lung Disease (IUATLO).

COMMENTARY: Describes the development of the questionnaire and gives background to the methods used in its psychometric testing. Conclusions on the validity and reliability of the questionnaire are not reached. Needs to be read in conjunction with other papers on the testing of the questionnaire.

Burney PGJ, Laitinen LA, Perdrizet S, Huckauf H, Tattersfield AE et al (1989) Validity and repeatability of the IUATLD, Bronchial Symptoms Questionnaire: an international comparison, *European Respiratory Journal*, 2: 940-945.

INSTRUMENTS: IUATLD (1984) Bronchial Symptoms Questionnaire

AIM: To determine the validity and repeatability of translated versions of the IUATLD questionnaire.

COMMENTARY: The original development and testing of the questionnaire is described elsewhere. This study describes the testing of translated versions of the questionnaire (French, Finnish and German) against an English sample. Discussion of any issues or problems involved in translation was very limited. The sample sizes used in each country were small (20) and different methods of recruitment and background of subjects were used, making comparisons difficult. Initial results were encouraging but further testing is required before any conclusions on validity and use of the questionnaires can be made.

MEDICAL RESEARCH COUNCIL RESPIRATORY SYMPTOMS QUESTIONNAIRE

The original development and testing of the MRC questionnaire is described. This 48 item questionnaire was initially intended to assist in the detection of chronic bronchitis. Subsequently, the questionnaire and selected extracts have been used for epidemiological purposes.

Fairburn AS, Wood CH and Fletcher CM (1959) Variability in answers to a questionnaire on respiratory symptoms, British Journal of Preventative and Social Medicine, 13: 175-193.

INSTRUMENTS: Medical Research Council Respiratory Symptoms Questionnaire (MRC Questionnaire)

AIM: To compare the results different observers achieved when administering the Respiratory Symptoms Questionnaire with the aim of improving the questionnaire and interview technique for future surveys.

COMMENTARY: Describes briefly the development of the Medical Research Council (MRC) Respiratory Symptoms questionnaire, an instrument originally designed for assessing prevalence of bronchitis in epidemiological survey work. The questionnaire is now widely used and is often used as a gold standard. Little information is given on the psychometric testing properties of the questionnaire. A copy of the instrument is included in an appendix.

Samet JM (1978) A historical and epidemiological perspective on respiratory symptoms questionnaires, American Journal of Epidemiology, 108 (6): 435-446.

INSTRUMENTS: Medical Research Council Respiratory Symptoms Questionnaire (MRC Questionnaire)

AIM: To review the evidence on the validity and reliability of the Medical Research Council Respiratory Symptoms Questionnaire.

COMMENTARY: Provides a comprehensive review of the reliability and validity of the MRC questionnaire, itself developed for epidemiological not clinical use. Includes useful information on the psychometric testing of questionnaires and possible sources of bias. Concludes that questions relating to phlegm have proved to be valid, but other symptom questions have not been validated adequately. Notes that there is a large literature base on the questionnaire and as such any new respiratory symptoms questionnaires should be calibrated against it (in an epidemiological not clinical context).

OXYGEN COST DIAGRAM

This single item instrument asks respondents to note the least energetic item that induces breathlessness. Its development and intended uses are described.

McGavin CR, Artvinli M, Naoe H and McHardy GJR (1978) Dyspnoea, disability and distance walked: comparison of estimates of exercise performance in respiratory disease, *British Medical Journal*, 2 (6132): 241-243.

See page 126

Viramontes JL and O'Brien B (1994)

Relationship between symptoms and health-related quality of life in chronic lung disease, *Journal of General Internal Medicine*, 9: 46-48.

INSTRUMENTS: SF-36

AIM: To determine whether a generic quality of life measure (SF-36) is suitable for use as a general health status measure amongst chronic lung disease patients.

COMMENTARY: Brief paper on the suitability of the SF-36 as a measure of health status amongst adults with chronic lung disease, including asthma. SF-36 scores for 54 adult asthmatic patients were compared with scores assessed using an Oxygen Cost Diagram and classifications of symptoms measured by the UK Medical Research Council guidelines. Results showed an association between disease severity and SF-36 domains of physical functioning, physical role, energy and health perception, but not emotional role, social functioning, pain and mental health domains. The authors conclude that the SF-36 is valid for use in this patient group, but the results do not fully support this conclusion in all domains of the SF-36. In addition, the results are presented for chronic lung conditions as a whole of which only half of these were asthmatic; there is no indication of the results for asthmatics alone.

PULMONARY FUNCTION MEASUREMENTS, INCLUDING SPIROMETRY

This is a very selective list from a large field. Discussions of the most recent approach to pulmonary function measurement - the issuing of portable peak flow meters to patients on prescription - are also given.

Enright PL, Lebowitz MD and Cockcroft DW (1994) Physiologic measures: pulmonary function tests, asthma outcome, *American Journal of Respiratory and Critical Care Medicine*, 149: S9-S18.

AIM: To review the various pulmonary function tests available for measuring the effectiveness of asthma interventions in a research setting.

COMMENTARY: Provides a review of the physiologic measures (of variable airways obstruction) which can be used to measure the severity of asthma. The advantages, disadvantages and appropriate settings for baseline spirometry, reversibility of obstruction, airway responsiveness, ambulatory monitoring and other pulmonary function tests are summarised.

Grampian Asthma Study of Integrated Care (GRASSIC) (1994) Integrated care for asthma clinical, social and economic evaluation, *British Medical Journal*, 308 (6929): 559-564.

INSTRUMENTS: Hospital Anxiety and Depression Scale, Living with Asthma Scale

AIM: To evaluate integrated care for asthma in clinical, social and economic terms.

COMMENTARY: A pragmatic randomised trial to evaluate integrated care for asthma in clinical, social and economic terms in Scotland is described. The trial used a range of outcome measures, bronchodilators, steroid use, hospital admission rates, restrictions on normal activity and psychological aspects of health (measured using the anxiety part of the HAD and some questions from the LWAQ). The methodology of the trial and the use of the outcome measures are well documented. However the actual questions used and how they were selected are not described. The paper clearly illustrates how a range of measures (clinical, generic and condition specific) can be used in an evaluation study.

Grampian Asthma Study of Integrated Care (GRASSIC) (1994) Effectiveness of routine self monitoring of peak flow in patients with asthma, *British Medical Journal*, 308 (6929): 564-567.

AIM: To evaluate the effectiveness of self monitoring of peak flow for asthma out-patients.

COMMENTARY: Randomised study to evaluate the effectiveness of prescribing Peak Flow Monitors on a routine basis for asthma out-patients. A range of outcome measures were used (use of bronchodilators and steroids, general practice consultations, hospital admissions, restrictions on activity and psychological aspects). The study showed that routine prescribing of peak flow meters was unlikely to improve morbidity or mortality in the majority of asthma patients and illustrates the use of a range of outcome measures. Should be read in conjunction with other papers from this study.

Kendrick AH, Higgs CMB, Whitfield MJ and Laszlo G (1993) Accuracy of perception of severity of asthma: patients treated in general practice, *British Medical Journal*, 307 (6901): 422-424.

AIM: To determine the frequency of poor perception of severity of asthma in general practice.

COMMENTARY: The study measured a random sample of adult asthma patients' perception of the severity of their asthma by correlating visual analogue scores and peak expiratory flow. Results of the study suggest that 60% of patients were unable to assess the severity of their asthma correctly. A careful objective assessment of lung function should be made in the management of asthma patients.

ST GEORGE'S RESPIRATORY QUESTIONNAIRE

A widely used 76-item questionnaire that is most applicable to patients with Chronic Obstructive Airways Disease (COAD) or asthma.

Hyland ME (1992) Quality of life assessment in respiratory disease: an examination of the content and validity of four questionnaires, *Pharmacoeconomics*, 2

(1): 43-53.

See page 116

Jones PW, Quirk FH and Baveystock CM (1991) The St George's Respiratory Questionnaire, *Respiratory Medicine*, 85 (Supplement B): 25-31.

INSTRUMENTS: The St George's Respiratory Questionnaire (SGRQ)

AIM: To describe the background, rationale and analysis of the development of the St George's Respiratory Questionnaire.

COMMENTARY: This is the original paper on the development of the (now widely used) St George's Respiratory Questionnaire (SGRQ). The questionnaire was developed to provide a measure of quality of life in patients suffering from airways disease (including asthma), which would allow direct comparisons between patients, populations and therapies and be applicable to patients with mild or severe forms of disease. It is relatively long, with 76 items, divided into 3 sections. No indication of the length of time taken to complete the questionnaire is given. Although weights for the items included in the questionnaire were obtained from a wide range of patients suffering from airways disease, it is not clear how these were obtained. Evidence on validity and reliability is shown. A copy of the questionnaire is not included.

Jones PW, Quirk FH, Baveystock CM and Littlejohns P (1992) A self-complete measure of health status for chronic airflow limitation: the St George's Respiratory Questionnaire, *American Review of Respiratory Diseases*, 145: 1321-1327.

INSTRUMENTS: St George's Respiratory Questionnaire (SGRQ)

AIM: To describe the validation of the St George's Respiratory Questionnaire.

COMMENTARY: Important paper on the validation of the St George's Respiratory questionnaire. The authors conclude the the questionnaire is valid, reliable and sensitive to change for adult patients (over 20 years old) with chronic airways obstruction. Should be read in conjunction with papers on the development of the questionnaire. Does not include copy of the questionnaire.

Jones PW (1993) Measurement of health related quality of life in asthma and chronic obstructive airways disease. In Walker SR and Rosser RM (eds) *Quality of life assessment: key issues in the 1990s*, Lancaster: Kluwer: 301-320.

See page 117

SECTION 4

GENERAL PURPOSE HEALTH STATUS QUESTIONNAIRES

USED IN

RESPIRATORY DISEASE APPLICATIONS

Most of the “generic” health status questionnaires have been used in relation to respiratory diseases. The references in this section refer to the use of these instruments in respiratory applications, not to their many other reported uses. Key references to the development and properties of these instruments are also included. Some are also listed in the reviews in section one.

HOSPITAL ANXIETY AND DEPRESSION SCALE

The HAD is a 14-item scale developed in 1983. It is a widely used scale, in a range of applications. The original paper and an example of its use with asthmatics are cited below.

Grampian Asthma Study of Integrated Care (GRASSIC) (1994) Integrated care for asthma: a clinical, social and economic evaluation, British Medical Journal, 308 (6929): 559-564.

See page 125

Zigmond AS and Snaith RP (1983) The Hospital Anxiety and Depression Scale, Acta Psychiastica Scandinavica, 67: 361-370.

INSTRUMENTS: Hospital Anxiety and Depression Scale (HAD)

AIM: To describe the development of the Hospital Anxiety and Depression Scale (HAD).

COMMENTARY: Original paper on the development and testing of the Hospital Anxiety and Depression Scale. The measure is short (comprising 2 subscales with 7 items each) and was shown to be valid but there was less evidence about its reliability and responsiveness. The measure was designed to detect psychiatric problems in non psychiatric settings and has subsequently been used in a number of areas and settings, including asthma.

QUALITY OF WELL BEING SCALE

The QWB is a 38-item questionnaire that was developed in the early 1970s predominately for the purpose of generating quality of life values for use in QALY calculations and other policy related research.

Jones PW (1993) Measurement of health related quality of life in asthma and chronic obstructive airways disease. In Walker SR and Rosser RM (eds) Quality of life assessment: key issues in the 1990s, Lancaster: Kluwer: 301-320.

See page 117

Kaplan RM, Anderson JP and Ganiats TG The Quality of Well Being Scale: rationale for a single quality of life index. In Walker SR and Rosser RM (eds) (1993) Quality of life assessment: key issues in the 1990s, Lancaster: Kluwer: 65-94.

INSTRUMENTS: Quality of Well Being Scale (QWB)

COMMENTARY: Provides good background information on the Quality of Well Being Scale and the model on which it was developed (general health policy model). The scale is a combined index of mortality and morbidity which the authors advocate can be used to quantify health outcomes and allow comparisons between treatments and conditions which can be used in policy making and cost utility analysis. A number of possible examples of its use are given, but no information is provided on its reliability and validity. Must be read in conjunction with other articles to obtain details of its psychometric properties.

SHORT FORM 36 (SF-36)

The SF-36 is a 36-item questionnaire covering 8 dimensions of psychosocial impact and perceived general health. General and asthma specific references are given.

Bousquet J, Knani J, Dhivert H, Richard A, Chicoye A et al (1994) Quality of life in asthma: internal consistency and validity of the SF-36 questionnaire, American Journal of Respiratory and Critical Care Medicine, 149: 371-375.

INSTRUMENTS: SF-36 (French version)

AIM: To ascertain the internal consistency and validity of the SF-36 with a population of adult asthmatics.

COMMENTARY: The study aimed to illustrate whether a generic health status measure, the SF-36 (French) version, could be used to assess quality of life in adult asthmatics. The study showed that the measure correlated with other severity of illness measures and was valid and reliable within a French out-patient clinic setting. The authors recommended that the SF-36 could be used to compare asthmatic and normal subjects in an epidemiological study, and to compare quality of life in asthma and other chronic lung disorders. If further work is carried out on the responsiveness of the measure, it could, in the future, also be used in clinical trials to assess the efficacy of a therapeutic intervention.

Dixon P, Heaton J, Long AF and Warburton A (1994) Reviewing and applying the SF-36, Outcomes Briefing, 4: 3-25.

INSTRUMENTS: Short Form 36 (SF-36)

COMMENTARY: Provides an independent review of the SF-36. Includes background material on its development, evidence on its validity, reliability and responsiveness and a comprehensive bibliography on its use to date. Questions whether the SF-36 can be a true generic measure. Concludes that more evidence is needed on its validity, responsiveness and reliability before use in a wide range of settings.

Viramontes JL and O'Brien B (1994) Relationship between symptoms and health-related quality of life in chronic lung disease, *Journal of General Internal Medicine*, 9: 46-48.

See page 132

Ware JE, Snow KK, Kosinski M and Gandek B (1993) SF-36 Health Survey: manual and interpretation guide, Boston, Ma: New England Medical Center, The Health Institute.

INSTRUMENTS: Short Form 36 (SF-36)

AIM: Manual on the SF-36.

COMMENTARY: Essential manual on the background, development, testing, administration and applications of the SF-36. Originally developed as a general measure of health status, the SF-36 has been used in a wide range of applications. Provides copy of the questionnaire, norms, scoring information and references. Should be read in conjunction with other articles to provide full information on its reliability and validity in various applications.

SICKNESS IMPACT PROFILE (SIP) AND FUNCTIONAL LIMITATIONS PROFILE (FLP)

The SIP is one of the longest health status questionnaires. It has 136 items under 12 subheadings, and generates one score for general health and separate scores for physical and psychosocial health. The FLP is a modified version of the SIP for use in the UK.

Bergner M, Bobbitt MA, Kressel S, Pollard WE, Gibson BS et al (1976) The Sickness Impact Profile: conceptual formulation and methodology for the development of a health status measure, *International Journal of Health Services*, 6 (3): 393-415.

INSTRUMENTS: Sickness Impact Profile (SIP)

AIM: To describe the background, development and testing of the Sickness Impact Profile.

COMMENTARY: Describes in detail the development and background of the Sickness Impact Profile (SIP). The interviewer administered questionnaire is long and exists in two forms a 146-item and a 235-item. It is shown to be valid and although not reported in this paper it is also reliable in measuring health status. It has subsequently been used in a wide range of applications which should be investigated before using for a specific application.

Patrick DL and Peach H (eds) (1989) *Disablement in the community* Oxford:Oxford University Press.

INSTRUMENTS: Functional Limitations Profile (FLP)

AIM: To present issues relating to the measurement of disability and handicap and describe the development of 2 questionnaires, the Functional Limitations Profile and the Lambeth Disability Screening Questionnaire.

COMMENTARY: Provides good background on the measurement of impairment, disability and handicap in community settings. Contains information on the development and testing of the Lambeth Disability Screening Questionnaire and the Functional Limitations Profile (FLP) - the English version of the Sickness Impact Profile (a widely used measure of health status in research applications). The FLP is a 136-item questionnaire, divided into 12 domains (ambulation, body care and movement, mobility, household management, recreation and past-time, social interaction, emotion, alertness, sleep and rest, eating, communication, work). Copies of the questionnaires are included together with administration and scoring information

SECTION 5:

MEASURES OF ASTHMA SEVERITY

Outcomes work should include some measurement of severity, at the very least as a basis for case mix controls. The companion review *Measuring the health care of adult asthmatics*, (Dixon et al, 1996) discusses this issue in more detail. The references given below highlight the problems and instruments used to record severity. Many of the references listed in the following section on symptomatology are also relevant here.

Bailey WC, Higgins DM, Richards BM and Richards JM (1992) Asthma severity: a factor analytic investigation, *The American Journal of Medicine*, 93 (3): 263-269.

AIM: To develop and test a series of scaled questions to assess asthma severity, which can be incorporated into questionnaires and other measures

COMMENTARY: Highlights the problems involved in assessing the severity of asthma symptoms by developing and testing questions which could be included in future studies. Data was collected by interviewing patients attending an out-patient clinic for asthma treatment and their physicians and reviewing clinic records. The results obtained from the patients correlated positively with physicians' judgements. Factor analysis of the results showed that there were three components to asthma severity: symptom intensity, airflow impairment and management intensity. It recommended that questions on these areas should be included in future research studies and would provide a simple method of measuring asthma severity.

British Thoracic Society, Royal College of Physicians of London, Research Unit, Kings Fund Centre, National Asthma Campaign (1990) Guidelines for the management of asthma in adults: I chronic persistent asthma, *British Medical Journal*, 301 (6753): 651-653.

AIM: To provide guidelines for the management of asthmatic patients.

COMMENTARY: Provides important guidance on the management of chronic persistent asthma.

British Thoracic Society, Royal College of Physicians of London, Research Unit, Kings Fund Centre, National Asthma Campaign (1990) Guidelines for the management of asthma in adults: II acute severe asthma, *British Medical Journal*, 301 (6755):797-800.

AIM: To provide guidelines for the management of asthmatic patients.

COMMENTARY: Provides important guidance on the management of acute severe asthma in the patient's home and in hospital.

British Thoracic Society, British Paediatric Association, Royal College of Physicians, Research Unit, Kings Fund Centre, National Asthma Campaign et al (1993) Guidelines for the management of asthma: a summary, *British Medical Journal*, 306 (6880):776-653.

AIM: To provide guidelines for the management of asthmatic patients.

COMMENTARY: Important background paper, summarising guidelines (in a chart form) on the management of care for asthmatics in a range of situations. Includes: management of chronic asthma in adults, management of chronic asthma in children, acute severe asthma in adults and children, acute severe asthma in adults in general practice, asthma in accident and emergency departments.

Aas SCORE

The Aas score is a measure of asthma symptom severity.

Aas K (1981) Heterogeneity of bronchial asthma, *Allergy*, 36: 3-14.

COMMENTARY: Useful review on the symptoms of different types of asthma and different stages of the disease.

SECTION 6

ASTHMA SYMPTOMATOLOGY AND ASSOCIATIONS BETWEEN SYMPTOMS HEALTH STATUS AND PSYCHOSOCIAL IMPACTS

This varied set of references includes material on the early stages of questionnaire development, research into the symptomatology of asthma and several different types of secondary analysis and review. There are two ways in which they support the development of outcomes measurement. Firstly, they provide insights into the topics that patients and care professionals regard as the most important outcomes of asthma care. Secondly, by reporting the relations between the different types of symptoms and impacts, they facilitate decisions on the use of proxy measurements and the construction of balanced data sets.

Bailey WC, Higgins DM, Richards BM and Richards JM (1992) Asthma severity: a factor analytic investigation, *The American Journal of Medicine*, 93 (3): 263-269.

See page 138

Bousquet J, Knani J, Dhivert H, Richard A, Chicoye A et al (1994) Quality of life in asthma: internal consistency and validity of the SF-36 questionnaire, *American Journal of Respiratory and Critical Care Medicine*, 149: 371-375.

See page 136

Burrows B, Niden AH, Barclay WR and Kasik JE (1965) Chronic Obstructive Lung Disease: II relationship of clinical and physiologic findings of the severity of airways obstruction, *American Review of Respiratory Disease*, 91: 665-678.

AIM: To determine which physiologic measures most closely parallel the severity of airways obstructive disease.

COMMENTARY: Demonstrates that Forced Expiratory Flow (FEF) corresponds with the severity of dyspnoea and the physicians' assessment of the severity of the disease.

Grampian Asthma Study of Integrated Care (GRASSIC) (1994) Integrated care for asthma: a clinical, social and economic evaluation, *British Medical Journal*, 308 (6929): 559-564.

See page 125

Grampian Asthma Study of Integrated Care (GRASSIC) (1994) Effectiveness of routine self monitoring of peak flow in patients with asthma, *British Medical Journal*, 308 (6929): 564-567.

See page 133

Hyland ME (1991) The Living with Asthma Questionnaire, *Respiratory Medicine*, 85 (Supplement B): 13-16.

See page 125

Hyland ME, Kenyon CAP, Taylor M and Morice AH (1993) Steroid prescribing for asthmatics: relationship with Asthma Symptom Checklist and Living with Asthma Questionnaire, *British Journal of Clinical Psychology*, 32: 505-511.

See page 121

Hyland ME, Bott J, Singh S and Kenyon CAP (1994) Domains, constructs and the development of the breathing problems questionnaire, *Quality of Life Research*, 3: 245-256.

INSTRUMENTS: Breathing Problems Questionnaire

AIM: To describe the development and testing of the validity of the breathing problems questionnaire

COMMENTARY: Describes the development and testing of the Breathing Problems Questionnaire, which was shown to be valid in a research setting. Provides useful information on the validity testing of quality of life measures for use in clinical trials. Shows items included in questionnaire but not a copy of the questionnaire itself.

Jones KP, Bain DIG, Middleton M, Mullee MA (1992) Correlates of asthma morbidity in primary care, *British Medical Journal*, 304 (6823): 361-364.

See page 128

Jones PW (1993) Measurement of health related quality of life In asthma and chronic obstructive airways disease In Walker SR and Rosser RM (eds) *Quality of life assessment: key issues in the 1990s*. Lancaster: Kluwer: 301-320.

See page 117

Juniper EF, Guyatt GH, Epstein RS, Ferrie PI, Jaesche R et al (1992) Evaluation of impairment of health related quality of life in asthma: development of a questionnaire for use in clinical trials, *Thorax*, 47: 76-83.

See page 120

Kendrick AH, Higgs CMB, Whitfield MJ and Laszlo G (1993) Accuracy of perception of severity of asthma: patients treated in general practice, *British Medical Journal*, 307 (6901): 422-424.

AIM: To determine the frequency of poor perception of severity of asthma in general practice.

COMMENTARY: The study measured a random sample of adult asthma patients' perception of the severity of their asthma by correlating visual analogue scores and peak expiratory flow. Results of the study suggest that 60% of patients were unable to assess the severity of their asthma correctly. A careful objective assessment of lung function should be made in the management of asthma patients.

Kinsman RA, Luparello T, O'Banion K and Spector S (1973) Multidimensional analysis of the subjective symptomatology of asthma, *Psychosomatic Medicine*, 35 (3): 250-267.

See page 122

Leiner GC, Abramowitz S, Lewis WA and Small MJ (1965) Dyspnoea and pulmonary function tests, *American Review of Respiratory Disease*, 92: 822-823.

INSTRUMENTS: Dyspnoea tests, Forced Vital Capacity (FVC), Forced Expiratory Volume (FEV)

AIM: To determine whether simple dyspnoea tests such as climbing stairs provide the same information as lung function tests such as Forced Expiratory Volume (FEV).

COMMENTARY: Brief paper which described a study to compare patients' subjective views (based on their opinion of their shortness of breath after climbing a flight of stairs) against lung function tests (FEV) and Forced Vital Capacity (FVC). Results showed that there was no correlation between patients' views and results of the lung function tests, implying that patients' subjective views are not reliable indicators of their pulmonary status. However no test of climbing stairs was carried out.

Mahler DA, Rosiello RA, Harver A, Lentine T, McGovern JF et al (1987) Comparison of clinical dyspnoea ratings and psychophysical measurements of respiratory sensation in obstructive airways disease, *American Review of Respiratory Diseases*, 135: 1229-1233.

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Mahler DA and Harver A (1992) A factor analysis of dyspnoea ratings, respiratory muscle strength, and lung function in patients with chronic obstructive pulmonary disease, *American Review of Respiratory Diseases*, 145: 467-470.

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Marks GB, Dunn SM and Woolcock AJ (1992) A scale for the measurement of quality of life in adults with asthma, *Journal of Clinical Epidemiology*, 45 (5): 461-472.

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Marks GB, Dunn SM and Woolcock AJ (1993) An evaluation of an asthma quality of life questionnaire as a measure of change in adults with asthma, *Journal of Clinical Epidemiology*, 46 (10): 1103-1111.

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McGavin CR, Artvinli M, Naoe H and McHardy GJR (1978) Dyspnoea, disability and distance walked: comparison of estimates of exercise performance in respiratory disease, *British Medical Journal*, 2 (6132): 241-243.

See page 126

Sibbald D, White P, Pharoah C, Freeling P and Anderson HR (1988) Relationship between psychosocial factors and asthma morbidity, *Family Practice*, 5 (1): 12-17.

See page 122

Snadden D and Belle Brown J (1992) The experience of asthma, *Social Science and Medicine*, 34 (12): 1351-1361.

AIM: To explore the concept of stigma in asthma and the illness experienced by a sample of asthma patients.

COMMENTARY: Interesting qualitative study to determine the effects of asthma on patients' lives and patients' feelings and experience of their asthma. Two symptoms experienced proved to be fear and fatigue.

Steen N, Hutchinson A, McColl E, Eccles MP, Hewison J et al (1994) Development of a symptom based outcome measure for asthma, *British Medical Journal*, 309 (6961): 1065-1068.

See page 119

Viramontes JL and O'Brien B (1994) Relationship between symptoms and health-related quality of life in chronic lung disease, *Journal of General Internal Medicine*, 9: 46-48.

See page 132

Williams SJ and Bury MR (1989) Impairment, disability and handicap in chronic respiratory illness, *Social Science and Medicine*, 29 (5): 609-616.

INSTRUMENTS: Forced Expiratory Volume (FEV), Oxygen Cost Diagram, General Health Questionnaire (GHQ-12), Functional Limitations Profile (FLP)

AIM: To assess impairment, disability and handicap in patients suffering from chronic respiratory illness.

COMMENTARY: Study uses a range of measures to highlight the social problems experienced by patients suffering from chronic respiratory illnesses, including asthma. Suggests that social consequences of illness should be taken into account when planning future services.

Williams SJ (1989) Chronic respiratory illness and disability: a critical review of the psychosocial literature, *Social Science and Medicine*, 28 (8): 791-803.

See page 117

Woolcock AJ and Read J (1965) Involvement in bronchial asthma not reflected in forced expiratory volume, *Lancet*, 2: 1323-1325.

AIM: To describe a study which illustrates how some patients receive an improvement in their breathing after a course of steroids which is not shown by improvements in Forced Expiratory Volume.

COMMENTARY: Description of a study of a small group (7) of patients whose breathing improved after taking steroids, but this was not matched by an improvement in Forced Expiratory Volume (FEV). Indicates that lung volume should be measured in addition to FEV

SECTION 7

METHODOLOGICAL BACKGROUND

This set of references contains works cited as the methodological basis for instruments such as the Attitudes to Asthma Questionnaire. It also includes some more general works on the methodology of questionnaire development and testing.

Becker OH, Haefner DP, Kasl SV, Kirscht JP, Maiman LA et al (1977)

Selected psychosocial models and correlates of individual health behaviours, *Medical Care*, 15 (5) (Supplement): 27-46.

COMMENTARY: Describes and summarises models of different health behaviours. The authors suggests that these can be used as a framework for further research on patient related aspects of health maintenance and disease control. In subsequent research, the models have provided methodological background to questionnaire development, including the development of asthma questionnaires.

Hyland ME (1992) Quality of life assessment in respiratory disease: an examination of the content and validity of four questionnaires, *Pharmacoeconomics*, 2 (1): 43-53.

See page 116

McDowell I and Newell C (1987) *Measuring health: a guide to rating scales and questionnaires*, New York: Oxford University Press.

COMMENTARY: Invaluable guide to measuring health and the wealth of scales available. Contains details of scales in the following areas: functional disability and handicap, psychological well being, social health, quality of life, pain measurements and general health measurements. Excerpts or full copies of the scales are presented together with a brief review of the evidence of their reliability and validity.

Walker SR and Rosser RM (eds) (1993) *Quality of life assessment: key issues in the 1990s*, Lancaster: Kluwer.

INSTRUMENTS: Quality of Well Being Scale (QWB), Sickness Impact Profile (SIP), Nottingham Health Profile (NHP), McMaster Health Index Questionnaire (MHI), Rosser Index, Index of Health Related Quality of Life, 15D, Euroqol, WhoQol.

COMMENTARY: Provides a good introduction to the topic of quality of life assessment and its use in measuring outcomes. In addition to focusing on concepts involved in the measurement of quality of life, it includes sections on key instruments, the measurement of quality of life in major disease areas and puts forwards a number of viewpoints and perspectives on quality of life assessment. Copies of a number of questionnaires are included in an appendix.

Wilkin D, Hallam L and Doggett MA (1992) *Measures of need and outcome for primary health care*, Oxford: Oxford University Press.

COMMENTARY: Invaluable guide to different methods of measuring outcome within primary health care settings. Provides copies or excerpts of scales in the following areas: functioning, mental illness and mental health, social support, multi-dimensional measures, disease specific measures and patient satisfaction.

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