Understanding asthma:
A study to evaluate the impact of an educational computer program on children's knowledge and self-management skills.

By

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PUBLICATIONS BASED ON THIS THESIS

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ABSTRACT

Childhood asthma is an extensive problem and is particularly pronounced in the UK. Asthma can restrict activities, cause school absence and can be the source of considerable stress in both children and their parents. Mortality is rare and preventable, although poor perception of symptoms and delay in seeking medical attention are strong risk factors for a fatal asthma attack. Self- management actively involves the child in their own healthcare and entails monitoring symptoms and responding accordingly and has been linked to better outcomes. This can be facilitated by health education.

The aims of this project were to develop an educational computer program to promote self-management skills in children and young people with asthma, to evaluate its effectiveness in a clinical sample and to validate measures of asthma knowledge and locus of control.

The Asthma Files uses a 'secret agent' theme to encourage users to investigate information about asthma. The program was piloted with 28 children aged 7-16 over a one year period and revised in accordance with both qualitative and quantitative data obtained.

To evaluate the computer program, 101 children aged between 7 and 14 years were recruited from three hospital asthma out- patient clinics to participate in a randomised, controlled trial. They were interviewed using asthma knowledge and asthma- specific locus of control measures developed and validated for the purposes of the study. All children were given an information booklet one month later and, in addition, 50 children used the computer program.

Baseline knowledge levels were low. At one- month follow- up (n=99), children in the computer group had significantly greater increases than those in the control group ($p<0.001$), along with an rise in internal locus of control ($p<0.01$). There was no evidence of changes in objective lung function measures, hospitalisations or oral steroid use between the groups at this time. However, at six months follow-up (n=90), children in the computer group were significantly less likely to have required oral steroids or school absence than the control group ($p<0.05$). The program was popular with the children across the age range and received positive feedback on both content and mode of delivery. Responding to comments provided by the children in the RCT, some minor amendments were made to the program, which is now available for public use.

The Asthma Files computer program was successful in increasing knowledge and promoting internal locus of control. More research is needed to evaluated how this might translate into longer term improvements in self- management.

DECLARATION

No portion of work referred to in this thesis has been submitted in support of an application for another degree or qualification in the University of Nottingham or any other institute of learning. All work in the thesis was completed by myself, except where mentioned in the relevant sections.

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For

Rose McPherson

&

Ann Prosser

CHAPTER 1: INTRODUCTION AND OVERVIEW OF ASTHMA

1.1 Introduction

This thesis examines the challenge of managing asthma in childhood. It seeks to explore some of the cognitive underpinning of health- related behaviour when managing chronic illness. Although asthma affects people of all ages, the thesis concentrates mainly on childhood asthma. This overview chapter will address the prevalence and burden of asthma, as well as outline common treatments and management of the illness.

The following chapter, Chapter Two, presents a review of the literature surrounding cognition and asthma education, focussing on 'self-management'. The use of multimedia and its potential for education is also examined.

In Chapter Three, the conceptual development of 'locus of control' is described and literature reviewed, addressing how much control children feel they have over health behaviour and managing illness. The rationale behind illness- specific locus of control scales is also outlined, developed further in Chapter Four, which describes a study seeking to establish the validity and reliability of a locus of control scale developed specifically for children with asthma.

Chapter Five describes the validation of an asthma knowledge questionnaire in the study population, using school children to distinguish between high and low levels of asthma knowledge. Reliability of the scale is also investigated.

Chapter Six details a randomised, controlled trial which examines the impact of a multimedia program on the knowledge levels, sense of control and self-management of children receiving hospital outpatient care for their asthma.

Chapter Seven provides a summary and discussion of the findings in the thesis.

1.2 Definition and diagnosis

"Asthma is a chronic inflammatory disorder of the ***airways*** *in which many cells play a role.... In susceptible individuals this inflammation causes recurrent episodes of wheezing,* ***breathlessness,*** *chest tightness and cough, particularly at night* ***and/ or****in the* ***early*** *morning. These symptoms are usually associated with widespread but variable airflow limitation that is at least partly reversible either spontaneously or with treatment".*

(International Consensus Report on the Diagnosis and Management of Asthma, 1992; p605)

There is no single test that can confirm a diagnosis of asthma; symptoms are the primary indicators that the patient is suffering from the respiratory disorder. The most common presenting symptom in a very young child is wheeze, although this can have a number of causes without it necessarily warranting a diagnosis of 'asthma'. For example, a child (usually under three years) could have 'viral associated wheeze', wheezing due to irritants in their surroundings or a single episode of wheeze connected with a specific environmental event (Silverman and Wilson, 1997). The label 'asthma' needs careful consideration, given its association with long- term care and, possibly, related stigma (Kanabar, 2000). However, although approximately 20% of these early wheezers do go on to develop asthma, wheezing generally abates during the first years of life, enabling a clearer diagnosis in later childhood. In addition to wheezing, asthma is characterised by dyspnoea (breathlessness), chest tightness, cough and hyper-reactivity of the airways (Gates, 2001). Bronchoconstriction, inflammation and secretion of mucus impedes airflow which leads to reduced lung function. Changes in the airway associated with asthma can be seen in Figure 1.1.

Figure 1.1- Normal airway (a) and airway experiencing bronchospasm and mucus secretion (b). (Reproduced with permission from BMJ Publishing Group).

Lung function tests such as Peak Expiratory Flow (PEF, 'peak flow') or Forced Expiratory Volume in the first second (FEV_1) can aid the diagnosis. As symptoms worsen, the airways get narrower thus making exhalation more difficult, which in turn results in a lower reading on the peak flow meter or spirometer. A PEF or FEV_1 reading, then, provides an objective assessment of lung function. In people with asthma, lung function characteristically varies over the course of a day (termed 'diurnal variation'), often being worse first thing in the morning and at night. Measuring lung function before and after taking medication designed to diminish obstruction in the airways to improve airflow- a 'reversibility' test- is sometimes used as a more stringent diagnosis for asthma; a threshold of 15% change in lung function is often used to indicate an asthma diagnosis (Levy *et al.*, 1997). However, very young children may be unable to perform the appropriate manoeuvres and, in older children, lung function may not necessarily be altered at the time of testing. Whilst reversibility of that magnitude confirms suspected asthma, lesser changes do not preclude an asthma diagnosis (British Thoracic Society and Scottish Intercollegiate Guidelines Network [BTS & SIGN], 2003). The pattern of asthma symptoms remain the primary guide for a diagnosis of asthma.

Chronic asthma can be defined in different ways although a simple definition is "...asthma requiring maintenance treatments" (Gates, 2001; p976). To generalise, a person with asthma categorised as 'mild' may experience infrequent attacks which respond well to initial medication and have very little disturbance of their daily activities. Children with 'moderate' asthma would typically experience symptoms regularly and have a marked exacerbation (an 'asthma attack') a couple of times a month. 'Severe' asthma produces symptoms which restrict the child's daily living activities, disturb sleep and cause extended school absence. There may also be growth retardation (Kanabar, 2000).

1.3 Burden of asthma

1.3.1 Prevalence & cost

Approximately 5.1 million people in the UK are currently receiving treatment for asthma, of which 1.4 million are children aged 2-15 years (National Asthma Campaign [NAG], 2001), making it the most common long- term childhood condition in this country (NAC, 2002). In an international survey, the UK had the highest prevalence of asthma in children aged 13-14 years out of all 56 countries contributing data (Asher *et al.*, 1998). Studies have used different methods to track changes in asthma prevalence, but it is now widely accepted that the prevalence of asthma has greatly increased in the past 20-30 years, which has been particularly pronounced in children and adolescents (Magnus and Jaakkola, 1997; Kanabar, 2000; Department of Health, 2000; NAC, 2001; Helms, 2001; BTS & SIGN, 2003; Jørgensen *et al.*, 2003).

There are also considerable financial costs associated with chronic asthma - it has been estimated that the cost of childhood asthma to the National Health Service in the UK is approximately £254 million, half of which comes from the quarter of children who have an asthma attack (NAC, 2002). Hospitalisation is often required for children experiencing severe exacerbation of symptoms, placing further strain on secondary healthcare: 14% of all admissions to hospital for childhood illnesses are for respiratory conditions (NAC, 2002).

1.3.2 Quality of life

In a recent nationwide study conducted in the USA, children experiencing limitations in their daily activities were more likely to have asthma than any other chronic illness (Newacheck and Halfon, 2000). The study conducted analysis on responses relating to over 62 000 children which were obtained as part of the 'National Health Interview Survey (NHIS)', a continuing survey of health status in the non- institutionalised US population with a 90% response rate. The survey identified 939 children with activity limitations due to asthma and 3119 children with limitations due to other chronic conditions. The survey categorised children as having activity limitations if they were unable to participate in age- appropriate activities i.e. playing, going to school etc., because of their chronic illness. The extent of the limitations due to asthma varied from being unable to take part in their main activity (0.2% of all children), to being able to take part in activities but having to limit the amount or type (0.5% of all children), to being able to take part in main activities but with limitations in other areas, such as after- school sport (0.7% of all children). In addition to school absences and limitations caused by common childhood ailments, children with disabling asthma experienced limitations in daily activities totalling almost three weeks every year and missed approximately 10 school days, demonstrating the significant additional burden of asthma. Figure 1.2 demonstrates the percentages of children with asthma unable to take part in major activity, unable to attend school and those who were hospitalised, when compared with children experiencing limitations with other chronic illnesses. The authors conclude that "...disability due to asthma has a greater impact on the child, the educational system and the health care system than disability due to other causes" (p291).

The data were obtained through parental report and did not verify the clinical diagnosis, hence there may be the potential for bias. However in the UK, a survey by the National Asthma Campaign found similar figures: three-quarters of children reported missing school due to their asthma in the previous year (NAC, 1999); furthermore, in a different UK survey, 64% of children with asthma reported that it affected their activities, necessitating an average of 13 days school absence per pupil per year (Gleeson, 1995).

Nocturnal symptoms can affect the quality of life for both child and parents and it is not uncommon for at least one parent to remain at home for fear of the child becoming unwell whilst they are working, which may have financial implications (Lenney, 1997). Parents of children with asthma frequently experience a great deal of stress and anxiety due to their child's illness; fears over their child's health and risk of death may lead them to restrict both their own and their child's lives (Tieffenberg *et al.,* 2000)

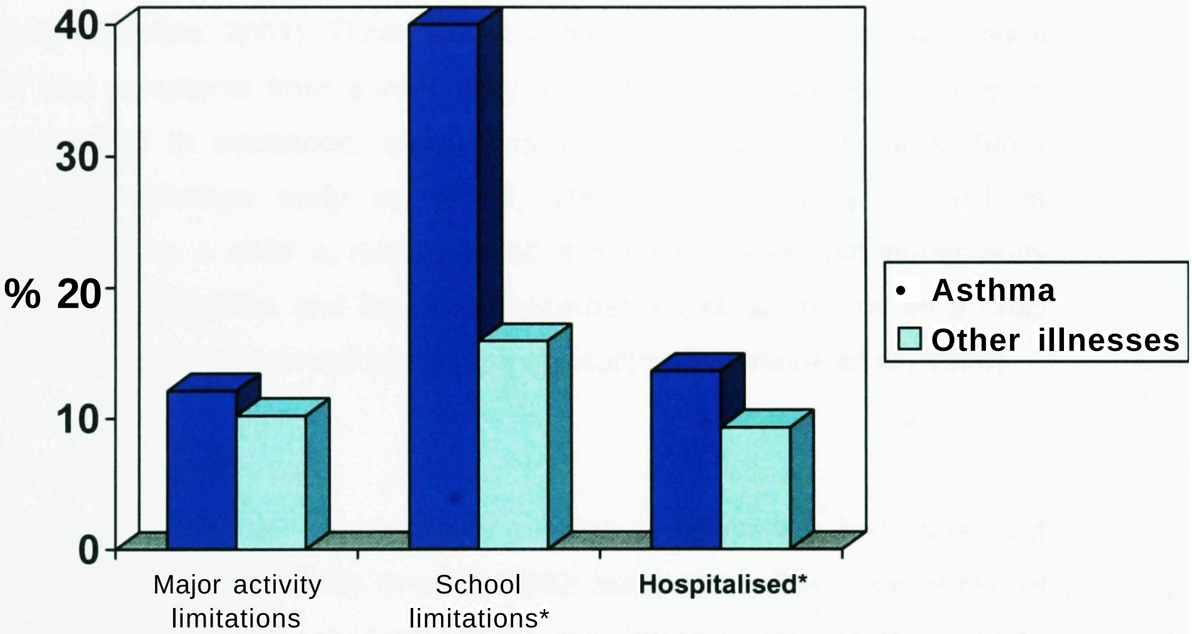


Figure 1.2- Effects of disability due to asthma and other chronic conditions among US children (*significantly different p<0.01). Data taken from Newacheck and Halfon, 2000.

L3.3 Prognosis

As previously stated, a large proportion of very young children experience wheezing, although this generally appears to resolve during the first few years of life, so that 60-70% of babies who wheezed in the first 6 months of life are symptom free at 6 years (Martinez *et al.,* 1995; Sherriff *et al.,* 2002). The characteristics of children who go on to develop further asthma symptoms during childhood and into adolescence are not entirely clear, although a family history of allergic conditions has been identified as a risk factor (Jenkins *et al.,* 1994; BTS & SIGN, 2003). Teenagers with asthma are particularly vulnerable: they have less contact with services and generally display poor levels of compliance, resulting in a higher mortality rate than any other age group in the child population (Kanabar, 2000; Jørgensen *et al,* 2003).

A significant proportion of people, especially males, appear to 'grow out' of their asthma symptoms (Jenkins *et al.,* 1994), although approximately 60% of children with a diagnosis of asthma still suffer symptoms 25 years after their diagnosis (Helms, 2001). Those whose asthma persists into adulthood have often had symptoms from a very early age and typically demonstrate poor lung function in adulthood, suggesting that their airways have suffered permanent damage early on (NAC, 2002). The severity of asthma experienced as a child is related to adult asthma: those with persistently impaired lung function and frequent exacerbations of symptoms as a child are more likely to remain symptomatic into adulthood (Jenkins *et al.,* 1994).

1.3.4 Mortality

Death in children and young people relating to asthma is both rare and preventable (British Thoracic Society, 1982; Male *et al,* 2000; Jørgensen *et al,* 2003). Despite this, children still die from asthma exacerbations, often before they reach hospital (BTS & SIGN, 2003). However, it is not only children with very severe asthma who are at risk of a life- threatening attack, although those with severe asthma or the form of asthma with which symptoms develop rapidly without warning (termed 'brittle asthma') are certainly the most vulnerable (BTS & SIGN, 2003). Jørgensen and colleagues retrospectively identified 108 deaths in children aged 1-19 years between 1973 and 1994 in a Danish population. None of the children in the sample died during their first asthma attack and all had been diagnosed with asthma for several years (excluding 1 - 4 year age group). In the 5-14 year age group, a life- threatening attack had been previously experienced by about a third of patients and non- adherence was a characteristic in a third of overall cases (using information provided in the medical notes). Almost half of the children in this age group had demonstrated gradual deterioration over the previous month, but probably the most pertinent finding of all concerned delays in seeking medical attention: fifty percent of attacks lasted longer than three hours without the patient or their parent seeking help from a GP or hospital. Previous work has found that delays such as these are often a result of incorrect perception by children of the severity of symptoms (Male *et al,* 2000). This avoidable nature of fatal asthma attacks was also echoed in the BTS & SIGN guidelines for the management of asthma: this identified previous near fatal attacks and non- adherence as factors contributing to fatal asthma episodes in the UK (BTS & SIGN, 2003). Although the report delineates behavioural and psychological features associated with asthma mortality, any factors affecting compliance or contact with services will contribute to poorer outcomes. More detailed discussion of factors affecting asthma outcomes can be found in Chapter Two.

1.4 Causes of asthma

Why increasing numbers of people are being diagnosed with asthma is unclear; the advancement of knowledge about the disease and changes in diagnostic categories may well have led to people being diagnosed more frequently but this alone cannot account for such a rise. (Magnus and Jaakkola, 1997). Women who smoke during their pregnancy are more likely to have children who wheeze (Martinez *et al.,* 1995; Sherriff *et al,* 2002) but researchers have also suggested that modern living may have contributed to the increase. Energy efficiency in the home has led to houses becoming well insulated with less ventilation than houses of previous decades, thereby trapping more dust, which has been shown to trigger asthma in some people (see section below on 'Triggers'). Similarly, increases in soft furnishings and carpets also play a role due to their proclivity to harbour dust-mites.

The 'hygiene hypothesis' has also received support from some quarters. The proponents hold that children in industrialised nations are more likely to develop asthma now because they have less exposure in childhood to viruses and infections, due to the widespread use of immunisations, smaller families, improved hygiene and accessible medical care. Previously, it is argued, fighting these infections would have 'neutralised' or 'switched off allergic responses, which are now expressed as illnesses such as asthma and eczema (Kanabar, 2000; BTS & SIGN, 2003). Research has produced some findings to support this theory, with evidence that larger family size, lower hygiene levels and pet ownership may potentially 'protect' against the development of allergic illness (Strachan, 2000; Sherriff *et al,* 2002), but there are many elements of this theory still to explain.

1.5 Atopy and triggers

Asthma, along with eczema and hay fever are diseases of the immune system (Sherriff *et al,* 2002) and those suffering from them are usually termed 'atopic'. Atopy is the predisposition to hypersensitivity when in contact with certain stimuli (Helms, 2001) due to inappropriate levels of IgE- a class of immunoglobulin associated with allergic inflammation. In people with asthma, airways become inflamed and constrict, causing obstruction to airflow, leading to asthma symptoms (Gates, 2001). The stimuli or allergens which initiate this physiological sequence are termed 'triggers'.

Triggers can often be identified by observing changes in asthma symptoms when in close proximity to a suspected allergen or irritant. There are a number of triggers that have emerged as commonly causing exacerbation of asthma symptoms, which include house dust mite, animal dander, viral infections, cigarette smoke, physical exercise, mould spores, cold weather and states of high emotion. However, not all have the same mechanism. Hypersensitivity caused by allergens such house dust mite and animal dander is mediated through raised levels of IgE whereas others, such as cold weather and exercise, are thought to act on the airways directly although their exact mechanism is as yet unknown (NAG, 2000). For some of the allergens, a confirmatory 'skin- prick' test can be performed, which involves exposing the child to a small amount of the allergen through the skin and noting the reaction. A raised, red patch with a diameter of 3mm or more indicates a positive reaction to the allergen (Berger, 2002) although it is not wholely conclusive that the person's asthma symptoms will be exacerbated if the allergen enters through the airways. Conversely, if there is no response to the skin prick test, the person's airways may still be hyperreactive to the allergen.

A person with asthma may be affected by one trigger but completely unaffected by others. People may also have very specific triggers, for example, certain food or particular household cleaners. Some believe stress to exacerbate asthma symptoms although this is controversial. Rietveld *et al.* report inducing breathlessness in adolescents with asthma by getting them to play a frustrating game with a cash reward. Despite experiencing significant breathlessness, they found no evidence of airway obstruction (Rietveld *et al,* 1999). It will become clear in more detailed discussions of self- management in later chapters that identifying and avoiding triggers are central to good respiratory health.

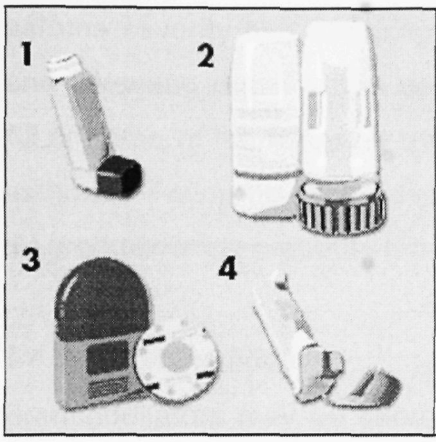
1.6 Treatment

The aims of asthma treatment are to:

- minimise or abolish symptoms
- maximise lung function
- avoid exacerbations
- minimise use of medication and side- effects of medication

(Kanabar, 2000; Gates, 2001; BTS & SIGN, 2003)

Treatments for asthma are generally prescribed in inhaler form, to enable the medication to enter the airways as quickly as possible. There are many types of inhalers, including the well known aerosol inhaler, called a metered dose inhaler (MDI), those which are breath- actuated, as well as dry powdered inhalers (See Figure 1.3 for examples of inhalers used in the treatment of asthma).



1. Metered Dose Inhaler (MDI)
2. Dry powder inhaler
3. Diskhaler
4. Breath actuated inhaler

Figure 1.3- Inhalers used to treat asthma.

Some children experience difficulties using a MDI on its own, since it requires fine co-ordination to release the dose and inhale at the same time. To overcome this problem, a large volume spacer can be used in conjunction with an MDI (see Figure 1.4). Once a dose has been released from the inhaler device into the chamber of the spacer, the velocity of the particles is reduced, more of the propellant disappears and the particles can be inhaled more deeply into the lungs (Kanabar, 2000). The medication can also be inhaled with several breaths, which is helpful in children who may find a single deep inspiration problematic. When experiencing acute asthma, delivering bronchodilator medication this way is optimal (Gates *et al.,* 2003).

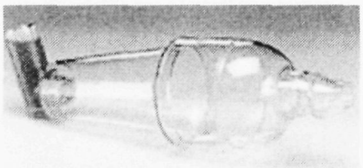


Figure 1.4- Spacer with metered dose inhaler (MDI)

Children should be prescribed their preferred inhaler and have their inhaler technique assessed regularly, as poor manoeuvres are a common source of under- treatment (Kanabar, 2000; Child *et al.*,2002).

In the UK, the British Thoracic Society have published a 'stepwise' approach to managing asthma, which practitioners are encouraged to follow. This involves starting the child on whichever step is appropriate to their present asthma severity and 'stepping up' treatment to afford greater asthma control and 'stepping down' when good control has been reached and maintained. All or some of the following treatments may be utilised in the management of asthma. Following the overview of asthma treatments, Figure 1.5 diagrammatically presents this 'stepwise' approach to asthma management.

1.6.1 Bronchodilators

Bronchodilators may be short- acting or long- acting and are taken through an inhaler device, although rarely they may be taken as tablets or syrup. The short- acting bronchodilators are used in 'emergency' situations i.e. when experiencing a sudden exacerbation of symptoms and are termed 'relievers'. They act immediately on the bronchospasm to relax the muscles around the airway and thus allow more air through. The effects of the medication should last approximately four hours and may also be used before doing exercise or in anticipation of encountering personal triggers such as animals or cold weather.

The most commonly used bronchodilators are β_2- agonists, which are to be taken intermittently. Excessive use i.e. taking them very often and the medication not lasting four hours, often indicates that asthma is poorly controlled. Some people experience side- effects of β_2- agonists, such as tremor and heart palpitations but they usually disappear within a short time.

Children commonly take one or two 'puffs' from their reliever inhaler when they feel it is necessary, although up to ten puffs, preferably through a spacer, can be taken safely if the person is experiencing an acute exacerbation of symptoms (BTS & SIGN, 2003). Salbutamol is the most commonly used β_2- agonist and for this drug (in an MDI) one puff =100 mcg.

Long- acting bronchodilators or 'long- acting relievers' are often prescribed when children's asthma is generally well controlled, but they are experiencing 'breakthrough' symptoms, such as coughing or wheezing at night or during exercise. Salmeterol is often prescribed for a long- acting bronchodilator.

1.6.2 Inhaled corticosteroids

If reliever medication is required frequently, inhaled corticosteroids are commonly prescribed. They are termed 'preventers' because they are prophylactic agents, working by reducing the inflammation in the airways so that there is less hyperreactivity upon contact with an allergen. For maximum efficacy, they need to be taken daily (once or twice, depending on asthma severity and preparation prescribed). However, patient compliance can be problematic with inhaled steroids because, unlike short- acting relievers, they do not appear to give immediate relief. Also, parents can be anxious about their child taking a steroid- based treatment long term, fearing adverse effects on growth and bone strength. Whilst this can be a risk, regular height monitoring can identify early warning signs and research has shown inhaled steroid therapy to be safe at the doses routinely prescribed for childhood asthma (McCowan *et al,* 1998) although there is still some debate. A more common side- effect is oral candidiasis, an infection of the mouth and throat. The risk of developing this is reduced, however, if the patient rinses their mouth out after taking their inhaler (Fishwick *et al,* 1997) and using a spacer can also be of benefit (Levy *et al,* 1997). Overall, however, the BTS and SIGN 2003 guidelines, reflecting high quality research, conclude that "Inhaled steroids are the most effective preventer drug for adults and children for achieving overall treatment goals" (p 18).

1.6.3 Non- stero idal preventer medication

Leukotriene receptor agonists can also be prescribed for children whose asthma is not being adequately controlled with bronchodilator and inhaled steroid medication and are in tablet form. They aim to block the effect of leukotrienes, which are thought to play a role in bronchoconstriction and mucus secretion. Their use at current licensed doses compared with inhaled cortico- steroids has been assessed recently in a systematic review which has raised some questions over their efficacy (Ducharme and Hicks, 2003).

1.6.4 Oral steroids

Oral steroids are used during acute asthma attacks, for example, due to a cold or virus. These tablets are used for the minimum amount of time it takes for the child's symptoms to come under control; it is thought that there may be a risk of systemic side effects, although short courses are generally considered to be safe (Smith *et al,* 2003).

1.6.5 Non- pharmacological treatments

Although pharmacological treatments for asthma are very effective if taken properly, side- effects and expense bring a risk of non- compliance and have led to the investigation of non- pharmacological approaches to asthma management. To avoid developing asthma in the first place, avoidance of known allergens by the mother whilst pregnant has been suggested, along with dietary changes and breast feeding (BTS & SIGN, 2003). In children already exhibiting asthma symptoms, allergen avoidance is often advocated, although research evidence to date has been inconclusive (BTS & SIGN, 2003). There is currently sparse research into the use of complementary therapies for asthma, although yoga and breathing exercises (e.g. Buteko), acupuncture, homeopathy and hypnosis all have their exponents although there is insufficient evidence to recommend them in clinical practice as yet (BTS & SIGN, 2003; Holloway & Ram, 2003; Linde *et al,* 2003; Linde and Jobst, 2003).

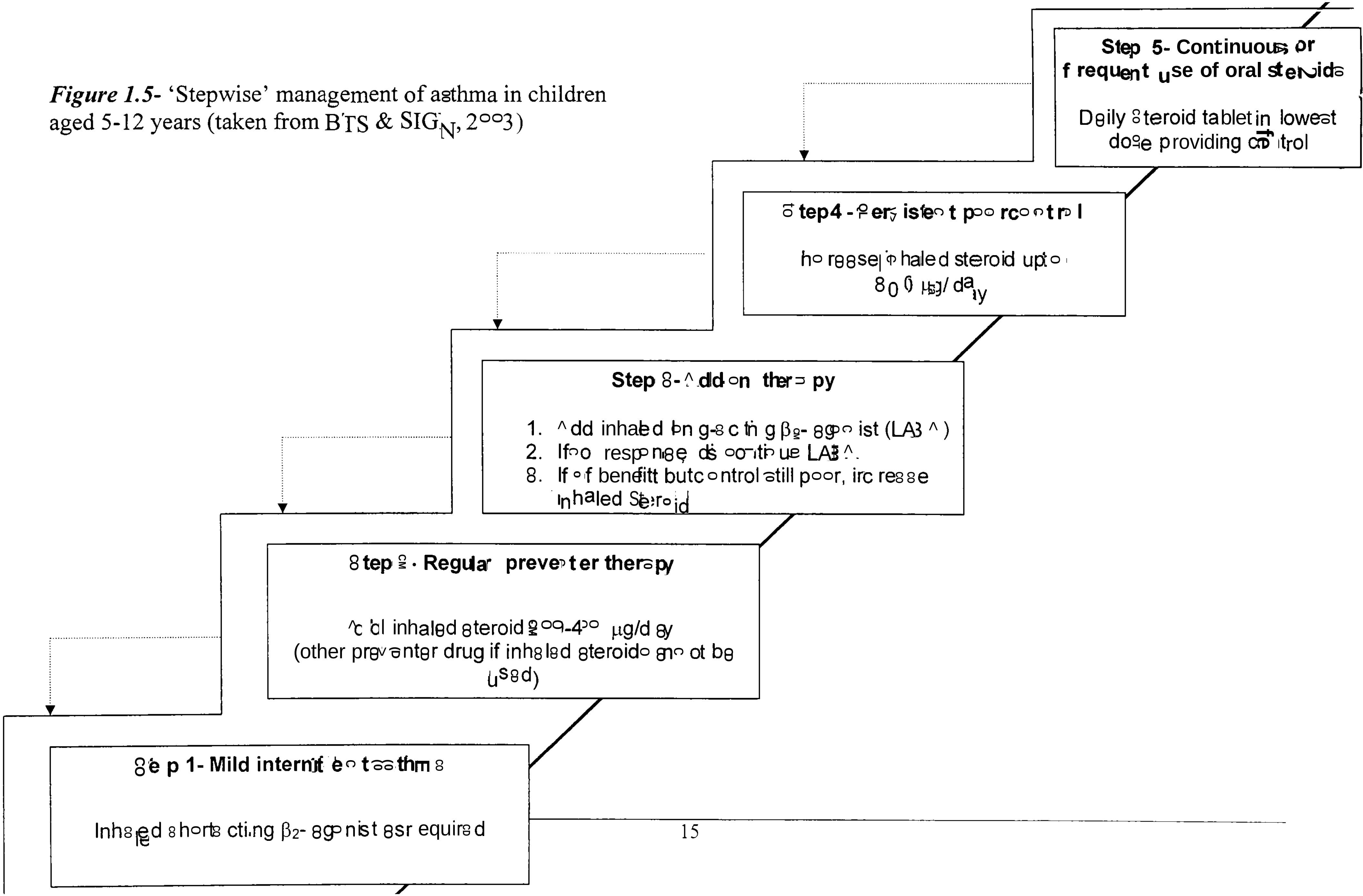


Figure 1.5- 'Stepwise' management of asthma in children aged 5-12 years (taken from BTS & SIGN, 2003)

1.7 Self- management

Management of asthma, along with many other chronic illnesses, used to require a clinician taking full responsibility for all aspects of the patient's care. For example, the patient would visit the doctor to report symptoms and the doctor would make appropriate modifications to their medication. The modern approach is one of 'self- management' which is "...the process whereby individual asthmatic patients make changes to their treatment in response to the recognition of changes in the severity of their asthma in accordance with predetermined guidelines" (Fishwick *et al,* 1997; p s21-22). It represents a less didactic model of care where the patient takes responsibility for monitoring their own health and making judgements on how best to respond.

It has been suggested that self- management comprises two elements: patients acting appropriately on identified symptom exacerbation and patient education (Liljas and Lahdensuo, 1997). The 'mechanics' of self-management will be discussed here, but the education of patients and factors which can affect adherence to asthma management programmes are discussed in detail in Chapter Two.

The guidelines the patient has to help them manage their asthma are called a 'self- management plan' (shortly to be renamed 'action plan') (BTS & SIGN, 2003) and they set out actions to be undertaken at different levels of asthma severity. To assess severity, the patient can blow into a peak flow meter (see Figure 1.6a), which is an objective measure of the extent of airway obstruction; this is particularly important given the inability of many to recognise the severity of symptoms which contributes greatly to the chances of having a life- threatening asthma attack (British Thoracic Society, 1982; Male *et al.*,2000; Jørgensen *et al.*,2003).

The patient records their scores in a peak flow diary, noting precipitating factors and symptoms experienced (an example is depicted in Figures 1.6b & 1.7). Recording peak flow over time can be useful for confirming diagnosis, for example, if there is marked diurnal variation- a variation in the readings of more than 15% over a day is commonly used as the threshold for a diagnosis of asthma, although the exact value is controversial (Jamison and McKinley, 1993). Marked dips in the morning and evening are also characteristic (Levy *et al,* 1997). The bottom row of readings on Figure 1.7 shows poorly controlled asthma: the readings are low and vary widely. Well-controlled asthma is depicted in the top row of readings: this maintains constantly high readings without large variations. A record of recent PEF is also helpful when planning treatment so that it can be individualised to the person's needs.

From the peak flow readings taken over a period of time, the child's 'personal best' score (or a 'predicted' peak flow score calculated using the child's age and height) is incorporated into their self- management plan as a reference point for asthma control. Actions on the plan are then based on percentage reduction of peak flow compared with this predicted or best score and accompanying symptoms.

(a) (b)

Figure 1.6- (a)Two different makes of peak flow meters & (b) The National Asthma Campaign peak flow diary

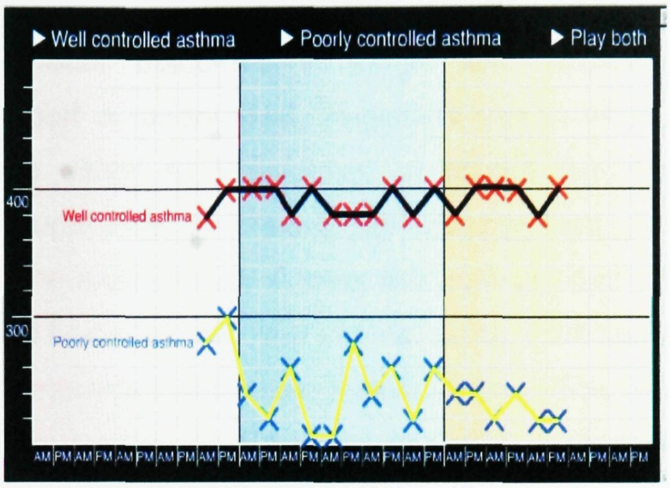


Figure 1.7- Peak flow diary showing well controlled (top row of scores) and poorly controlled asthma (bottom scores) (NAC, 2003)

A self- management plan can include all or some of the pharmacological treatments described previously and also incorporates actions for when contact with triggers are anticipated (e.g. planning to undertake exercise). Underuse of these plans has been identified as a key feature contributing to asthma mortality; therefore guidelines (outlined below in Figure 1.8) for asthma care in the UK have been recommended by the British Thoracic Society and the National Asthma Campaign. National Asthma Campaign materials can be found in Appendix 1.

1. *No symptoms, peak flow normal:* Continue taking medication as normal (may include daily inhaled steroid).

2. *Minor symptoms, peak flow 75-100% or planning to encounter trigger:* Take bronchodilator to relieve symptoms as required.

3. *Getting a cold, nocturnal symptoms, peak flow 50-75%:* Continue inhaled steroid medication. Take reliever 4- hourly.

Emergency *Reliever inhaler not working, too breathless to talk:* Continue taking rehever medication (take up to 10 puffs, preferably through a spacer), take steroid tablets if available. Call ambulance or doctor if symptoms persist.

Figure 1.8- Current recommendations for asthma management (BTS & SIGN, 2003).

Self- management plans such as this have now been widely accepted as resulting in better outcomes in adults with asthma. Lahdensuo and colleagues report a randomised, controlled trial in which 112 adults *were* randomised to either an intervention or control (usual care) group. The intervention taught them to follow a self- management plan over 12 months; this involved the assessment of peak flow and the doubling of their inhaled steroids if it fell below 85% of their optimal score. Participants were instructed to initiate oral steroids if their peak flow fell below 75%. The authors report a reduction in the number of admissions and visits to doctors, as well as days off work and an increased number of 'healthy days' in the self- managing group, compared with the control group. Quality of life also improved in the intervention group. Costs were estimated by calculating direct costs (i.e. time taken to educate patient, peak flow meters) and indirect costs (i.e. days taken off work). Although the direct costs were lower for the usual care group, indirect costs were much lower in the intervention group. The authors conclude that not only was self- management 4.3% more effective than usual care, the total costs were also significantly less for the self- management group (Lahdensuo *et al,* 1996). The early detection of an asthma exacerbation, which was a key element in the self- management plan used in this intervention, also has considerable implications for avoiding potentially fatal attacks (British Thoracic Society, 1982; Lahdensuo, 1999). Similar positive findings for adults with asthma have also been reported, including fewer disturbed nights, decreased use of emergency health services, fewer work absences and improved quality of life (Osman *et al,* 1994; Partridge, 1996; Clark and Nothwehr, 1997; Harrop, 2002). The application of self-management plans to children has encountered some problems (Milnes and Gallery, 2003) although many educational programmes teaching self-management have been successful. These are reviewed in the next chapter.

1.8 Chapter summary

The prevalence of childhood asthma is high and thought to be increasing. The burden of childhood asthma can be immense in terms of reduced quality of life, increased mortality rates and financial strain. The cost of treating asthma attacks accounts for a large proportion of the total expenditure for the illness; preventing asthma exacerbations, then, makes both medical and financial sense. Whilst young children can 'grow out' of early wheezing, many will go on to experience asthma symptoms in later childhood through to adolescence. Teenagers are at a particular risk of asthma morbidity and mortality, and often do not recognise symptoms which may pre-empt a life-threatening attack. A substantial number of adults continue to experience asthma symptoms and demonstrate impaired lung function due to severe asthma exacerbations when younger. Effective treatment is available, although compliance can be poor since it relies greatly on patient understanding and commitment. Therefore, it is essential to promote symptom awareness, appropriate treatment and patient education for childhood asthma.

CHAPTER 2: LITERATURE REVIEW RELATING TO CHRONIC ILLNESS, COGNITION, SELF-MANAGEMENT AND EDUCATION.

2.1 Introduction

This chapter will explore the rationale behind educational programmes for children with asthma, identify children's information needs and discuss how this information should be imparted. Educational programmes described in the literature will be reviewed and the role of multimedia in asthma education examined (a publication briefly summarising research in multimedia and education can be found in Appendix 2).

2.2 Why do children with asthma need health education?

Expansion in the provision of health education for children with asthma has been driven, at least in part, by a growing acceptance that children with chronic conditions should be actively involved in the management of their illness and in decisions about treatment (Tieffenberg *et al.*, 2000). There is also increasing awareness that childhood attitudes toward certain healthcare behaviours, such as smoking and dental care can last into adulthood (Eiser, 1989; Eiser, 1991). Health education for children with chronic disorders is likely, therefore, to result in better health outcomes later in life. In addition to improved clinical outcomes, healthcare information can confer psychological benefits for children who face hospitalisation or other major procedures in terms of reduced levels of fear and distress (Rushforth, 1999). Addressing these psychological aspects of treatment can reduce morbidity and, in some illnesses, mortality (Hardwick and Bigg, 1997).

Such education is particularly pertinent for children with chronic illness who face ongoing contact with healthcare workers and sometimes inpatient stays. It is claimed that giving children information about their illness is crucial for them to obtain a sense of 'control and mastery' over their health, encouraging better self- management and, it is hoped, improved compliance (Yoos, 1988; Baldaia.L, 1996). Research also suggests that adherence can worsen with age, as parents withdraw their input without the child being able to adequately compensate (McQuaid *et al,* 2003). It is necessary, therefore, to teach skills from an early age so that children are more able to manage their illness effectively when required.

In asthma, it is critical that children recognise the onset of their symptoms, such as breathlessness, so that appropriate treatment can be started as early as possible. As we have seen, patients with poor perception of breathlessness often fail to recognise the severity of a situations and do not seek help as early as they should (BTS & SIGN, 2003; Jørgensen *et al,* 2003). This can lead to severe hypoxia which is an indicator of a life-threatening asthma attack (Male *et al,* 2000). It is therefore vital that children are attuned to their asthma symptoms in order to have control over them.

The sense of control over one's illness, or confidence in performing certain activities to achieve a desired outcome has been termed 'self-efficacy' (Bandura, 1989). Children lacking confidence can be taught to respond appropriately and effectively to their physiological symptoms through encouragement, reinforcement and using positive role models. Improving children's self-efficacy in this way can improve compliance in asthma (Lemanek and Hood, 1999) and in other chronic conditions such as insulin dependent diabetes mellitus (Brown *et al,* 1997; Ott *et al,* 2000) and cystic fibrosis (Bartholomew *et al,* 1997).

Conversely, lack of appropriate information can lead to fear and the psychological construction of powerful myths that become embedded in the child's cognitive framework. Young children's beliefs are likely to be shaped by a degree of egocentricity, assuming that by their actions they have somehow caused their illness, or indeed the illness of others (Hardwick and Bigg, 1997). Without education, these myths may persist, especially when reinforced by family belief systems and fostered by miscommunication and misunderstanding (Perrin and Gerrity, 1981). This reinforces Hardwick and Bigg's assertion that "What is heard is more important that what is said" (p156).

Children seek to make sense of the world around them, whether others purposely provide them with information or not. For example, children with leukemia have been observed to create their own information networks with other children on hospital wards. Information gleaned about their illness, for example from parents' and professionals' behaviour, is shared and discussed with others, in an attempt to conceptualise their illness (Bluebond- Langer, 1978). Unfortunately, this independent assimilation and exchange of 'facts' is liable to generate potent misconstructions and false beliefs. This behaviour demonstrates, however, that in the absence of health information, children do not choose to remain passive and ignorant.

2.3 Competence and decision making

Whilst most healthcare professionals now routinely provide information to adult patients and involve them in decision- making about their treatment, the involvement of children in decisions about their own health care has been altogether more contentious. Clinicians' and parents' concerns about the ability of the child to understand complex medical information and their competency to make difficult decisions and communicate these correctly, have traditionally overshadowed issues regarding children's rights to autonomy.

Instead of obtaining information directly from the child, doctors often rely on parents' assessment of symptoms, such as pain, to guide diagnosis and treatment, but such assessments may not be accurate. For example, parents often underestimate pain intensity (Chambers *et al,* 1998) and this is particularly unfortunate as evidence suggests that even very young children are capable of observing and assessing their own symptoms (McGrath and McAlpine, 1993). Picture-based rating scales, developed to allow children to rate respiratory symptoms in asthma (Male *et al,* 2000) and in cystic fibrosis (Henley *et al.* under review), have been found to correlate well with physiological measures. Such scales increase children's involvement in their treatment and therefore fit well with the ethos that children with asthma should take more control by, for example, carrying their own medications (National Asthma Campaign, 1999).

There are also anxieties that children are unable to make the complex decisions required for effectively managing their asthma. However, it has been shown that children do have the ability to make healthcare decisions and that these abilities can be enhanced through education. Training children in health related decision making, for example initiating their own health care, has been shown to reduce stress stemming from perceived vulnerability to illness (Lewis and Lewis, 1982; Lewis *et al.,* 1984; Lewis and Lewis, 1990). This series of studies by Lewis and Lewis and colleagues encouraged children to consider the context of their symptoms (for example, possible causal factors, similar symptoms experienced in the past, potential courses of action) prior to receiving input by the health care professional. Children in these studies demonstrated not only the competency to integrate information and beliefs into a 'personal web of causality', but also an ability to communicate effectively with professionals when given unhurried and non-judgmental conditions.

There is also evidence that children are able to make judgements about their own competence to make decisions about medical treatment. In one hospital-based study, the majority of health professionals, parents and children consulted considered that 11-15 years was the lowest appropriate age range for making a wise decision about surgery. Although a small number of parents, and some doctors, felt that children under 8 years could make such a decision, none of the 120 children asked claimed that they were able, or would have been able, to make a decision at that age (Alderson and Montgomery, 1996). However, communication remains vital, as does involving the child in decisions whilst providing appropriate support.

Self-determination, or the ability to make decisions, exercise choice and take control, is influenced not only by knowledge and skills but also by environmental factors (Field *et al,* 1997). Self-determination can be enhanced both by education (Field *et al,* 1997) and by reducing the demands of the decision-making task (Wong *et al,* 2000). Interactive multimedia has much to offer in this respect, since it can present information about treatment alternatives in an accessible format and allow children to make choices in a safe 'virtual' environment Furthermore, there is evidence from studies with young people with learning disabilities that skills learnt through a desktop virtual environment do generalise to real worid situations. For example, one study demonstrated that young people who had spent time exploring a 'virtual supermarket' on a computer later performed better on a real shopping task than a control group who had spent time playing with shopping lists and common shopping items and who had used alternative virtual environments. When both groups were taken to a real supermarket and given a list of specific items to put in their trolley, those who had used the virtual supermarket had more correct items in their shopping trolley and were faster than the control group (Standen *et al,* 1998). Furthermore, children with physical disabilities have been taught to locate fire exits in a school, which were originally taught in a virtual environment (Wilson, 1993).

2.4 How should we educate children with asthma?

Educating children about their chronic illness can, therefore, result in many positive outcomes. It can increase knowledge about the illness, improve self- efficacy and self confidence, increase competence both in decision making and in practical regime- related skills and improve overall compliance. However, in order to be successful, education must take into account several factors, including the child's developmental age, their information needs, and the methods and style of the programme (Becker *et al.*,1994; Crisp *et al.*,1996; Fielding and Duff, 1999).

2.4.1 Developmental stage

Piagetian approaches to children's understanding of health argue that children's concepts of illness will be determined and constrained by their stage of cognitive development (Bibace and Walsh, 1980) which delineate into 'Pre- Operational' (2-6 years), 'Concrete- Operational' (7-10 years) and 'Formal- Operational' (11 years +). They represent the progress of cognitive development, charting the ability to understand the concepts of self and others, internal versus external and cause and effect (see Bee, 1997).

This framework is highly relevant to the understanding of health and illness information and researchers have investigated whether children's conception of illness follow a pattern concordant with Piaget's stages (e.g. Bibace and Walsh, 1980; Perrin and Gerrity, 1981; Yoos, 1988). Findings suggest that below the age of six, children's concepts of illness tend to be based on an obvious, external cause, often with a magical element which is reflected in the language adults use to explain illness and treatment to young children, for example, referring to preparations used on the skin before an injection as 'magic creams' because of their anaesthetic qualities.

Children's understanding of illness at this age has also been described as the 'contagion' stage (see Yoos, 1988), because they are able to associate becoming unwell with being near an ill person, or taking part in an activity or event. However, young children frequently overextend the concept, believing that all illnesses can be 'caught', which can generate a great deal of fear. Time taken to explain that the illness was not a result of something the child did, or someone they spoke to, for example, may go some way to reducing this stress.

In the following childhood developmental stage, experienced between 7-10 years of age, children usually begin to realise that not all illnesses are contagious and develop a more sophisticated understanding of different causes of illness. They become able to identify a specific external agent as the 'culprit' and thus assign a negative quality to the agent. They also begin to understand how the 'bad' external factors entered their body to cause illness, such as breathing in 'germs'.

By 11 years of age, the child becomes capable of more complex understanding of the body and the way it works. They are able to associate a specific part of the body with a specific illness (for example, appendicitis) and by adolescence (around 14 years), the impact of psychological factors upon health and illness can be appreciated. Their more sophisticated understanding allows assimilation of the implications of current health behaviour for health in the future; studies have exploited this, targeting negative behaviours such as smoking and risky sexual activity (Hawkins *et al,* 1999).

Although this approach has provided a useful framework for investigating children's concepts of illness some theorists have criticised its rigidity, calling for a need to understand the processes *underlying* children's understanding (Eiser, 1989; Gharman and Ghandiramani, 1995; Crisp *et al,* 1996; Eiser, 1996). Adherence to a strictly Piagetian framework such as this may also underplay the effect of other variables, such as illness experience, cultural factors or emotions, on children's understanding and there is evidence that children's comprehension of illness often exceeds that predicted by Piagetian stage. For example, Gharman & Ghandiramani found that children as young as five years old could differentiate between a physical illness (chicken pox) and a psychological one (depression) and describe associated signs and symptoms, a more sophisticated appreciation than the 'stage' model would predict (Gharman and Ghandiramani, 1995).

Piagetian theory also stresses the independence of the child in the learning process, gaining knowledge about the worid through exploration as an individual, negating the effect of adults as teachers (Meadows, 1995; Smith *et al,* 2003). In contrast to this, the theorist Vygotsky proposed a different interpretation of cognitive development, which emphasised the effect of adults and expert peers as teachers, helping children to build on existing concepts to gain a more sophisticated understanding. Unlike Piaget's rather rigid framework, Vygotsky suggested that children were able to extend beyond the boundaries of their 'stage' of development if given appropriate support. He called this potential to learn new material the 'zone of proximal development' (ZPD) (Vygotsky, 1962). Taking into account the child's current level of understanding and providing contingent support, Vygotsky argued, can aid children to achieve a level of understanding that they would be unable to alone (Smith *et al,* 2003). This has significant implications for education; in order to allow maximum development, the child's ZPD needs to be carefully considered so that instruction can continue from the child's existing level of knowledge. Supported problem- solving tasks and interactive learning are essential elements of this process, which can be problematic in settings where children are educated as a group (Smith *et al,* 2003).

Vygotskian theory would appear to be a more flexible and perhaps more optimistic approach to cognitive development than the Piagetian stage model. It lends scope to educate children at different points of development, if information is tailored accordingly. I will later address the educational methods which are most suitable for this purpose.

2.4.2 Information needs of children

There is a strong theoretical and research base to support educating children with chronic illness and children have demonstrated that they have the cognitive ability to understand and use such information, resulting in positive outcomes. However, exactly what information do they need? Unfortunately, here the literature base is sparse. Whilst research has flourished around the information needs of parents of chronically ill children (Morgenstern and Evans, 1997; Dolinar *et al.*,2000; Collier *et al,* 2000), little has focussed on the requirements of the children themselves and how those requirements may change over time, both with increasing age and length of illness. Adults often act as a proxy for children, but as we have seen in pain assessment, their perceptions may not always be accurate (Chambers *et al,* 1998). Nor are misconceptions limited to physical symptoms; parents of children with cancer often anticipate problems in their children's ability to adapt to school life and to cope with social relationships but there is evidence that they do not differ from their healthy peers in terms of popularity and social status (Noll *et al,* 1991). Parents and children also tend to differ in their primary concerns about illness. Most children and adolescents rate personal or bodily concerns to be most important information they want, while parents report information about the prognosis of the disease to be their chief concern (Ohanian, 1993). Similarly, children with asthma often worry about the embarrassment of taking their medications in front of friends (Eiser, 1991; Hendricson *et al,* 1996), while parental anxieties are more likely to stem from the potential effects of steroids on the child's physical growth.

Despite parental fears, provision of information to children about painful or frightening procedures does not appear to reduce their willingness to undergo treatment (Alderson, 1993). Children undergoing major orthopaedic surgery were united in wanting to know the details of their impending operation and the potential risks and benefits, despite the worry that it may cause (or even had caused) them. This was in order to relieve anxiety, maintain confidence, and to anticipate what emotional burdens might be involved (Alderson, 1993). However, Allen *et al.* demonstrated that children given a greater awareness of their diabetes actually became more anxious than those with less awareness (Allen *et al,* 1984). Thus, provision of illness-specific information alone is not beneficial. Children must be given appropriate emotional, social and practical support to be able to deal with the consequences of that information. As with adults, children differ in their need for autonomy. Some want to decide their treatment for themselves, some want their doctor to decide for them, whilst some want to share the decision with their doctor and feel part of the decision making process (Alderson and Montgomery, 1996). This does not suggest less information should be provided, rather that health education should take such individual differences into account.

However, there are factors which can have unpredictable effects when identifying children's information needs. Children with chronic illness, especially asthma, may have been diagnosed at an early age, so have had considerable experience of illness, which differs from their healthier and thus less experienced peers. There is an expectation that children with experience of chronic illness will be better able to understand and retain medical information than children without such experience, although to date, there have been mixed findings. Crisp, Ungerer & Goodnow (1996) found that children with experience of illness (cystic fibrosis & cancer) demonstrated a greater understanding of causes of illness than their less experienced counterparts, although this was restricted to specific ages, suggesting that age and experience interact in some way. However, in a separate study, when children with diabetes and matched healthy peers were interviewed about general beliefs and definitions of health, few differences between them were found in terms of general illness knowledge (Eiser ef *al,* 1984). A study by Krishnan, Glazebrook & Smyth found that there was significantly less information understood and retained about a novel illness in children with chronic illness & high verbal IQ than their healthier peers; they hypothesise that chronically ill children employ various defences against any further anxiety associated with being given medical information. They also concede that children who have spent much of their lives receiving medical information may reach 'saturation point' and become bored through overexposure (Krishnan *et* a/., 1998).

Although it is clear that the role of illness experience and its effects on children's information needs are not completely straightforward, attempts to provide information should be sensitive to the child's existing knowledge levels, taking into account their experience.

Cultural factors may also impact upon a child's information needs (Thorensen and Kirmil-Gray, 1983). Asthma morbidity has been associated with ethnic minorities for several reasons, including language barriers, poor quality living environment, low standard medical treatment and cultural beliefs (Hendricson *et al,* 1996; Perez ef a/., 1999; Bartholomew *et al,* 2000; Jones ef *al,* 2001). When Hendricson and colleagues developed their educational programme for Hispanic children (the Childhood Asthma Project- CAP), they incorporated participants' knowledge and expectations into the project in an attempt to enhance the programme's efficacy. Seventy- three, mostly Hispanic participants took part in an education programme which used videotapes to model positive asthma- related behaviour and 'hands on' practice of asthma management behaviours, such as measuring peak flow and taking inhalers appropriately. Piloting of the information covered by the educators was undertaken with children being treated for asthma and their families who were not involved in the project, which the authors report as being very helpful in tailoring education to the specific needs of their Hispanic audience. Feedback from the participants during the programme suggest that watching people perceived to be similar to themselves engaging in activities and positive healthcare activities was particularly enlightening. Post-programme measures of participant satisfaction rated highly, which was also demonstrated in the study's low attrition rate- 92% children and families completed the whole programme. The authors report an 80% follow- up rate at one year; the majority of respondents identifying the GAP project as being the single most useful thing associated with their child's asthma management in the year post-programme. The authors conclude that including children & parents in the development stage is vital to the success of an educational programme such as theirs, as is tailoring an intervention to the preferred language of the participants, whose first language may not be English. Despite positive feedback, the authors did not make any knowledge or clinical assessments so it is unknown to what extent the programme impacted upon their asthma management at home.

In addition to the child's stage of cognitive development and their individual information needs, the actual content of the educational programme is important. Becker and colleagues identify several criteria which they feel a high quality educational programme should meet, such as including accurate & up to date information, as well being free from cultural, sexual, racial, age & disability biases, be easy to obtain at a reasonable cost as well as be interesting and attractive to children (Becker *et al,* 1994). They further suggest that a programme should give the child an opportunity to practice skills they will need to control their asthma, linking in with social learning theory which suggests that skills obtained in simulated conditions can transfer to the real world (Bandura, 1989). Practising important skills in a safe environment is part of several educational programmes; for example, Gebert and colleagues included field trips in their education programme so that the children got used to taking their medication in public. Children who had been given the opportunity to practise their self-management skills in this way demonstrated better coping strategies and better control of their medication (Gebert *et al.,*1998).

It is clear that any educational programme should be accurate and appropriate for the child's circumstances. Assumptions should not be made based on one-dimensional information. So, what methods should be used, given these complex needs? The following section looks at the outcomes of a variety of self-management programmes in the light of their modes of teaching.

2.5 How effective are health education programmes for children with asthma?

The positive outcomes from patients managing their own asthma have been briefly discussed in Chapter One: lower morbidity and mortality are associated with monitoring symptoms and lung function, responding with medication and avoiding triggers (a synthesis is available in BTS & SIGN, 2003; NAC, 2002; Boulet ef *al,* 1994; Lenney, 1997). Because self-management has behavioural tenets, it is open to educational intervention. Educational programmes have thus been devised to promote efficacious self- management skills to improve both physical and psychological outcomes in people with asthma.

There have been a number of educational self-management programmes devised for children with asthma (Lewis *et al,* 1984; Hendricson ef *al,* 1996; Madge *et al,* 1997; Gebert ef *al,* 1998; Perez *et al,* 1999; Bartholomew ef *al,* 2000; Tieffenberg *et al,* 2000), but also other illnesses where compliance is crucial for effective control of disease and prevention of acute emergencies, for example, diabetes (Wolanski ef *al,* 1996) and cystic fibrosis (Bartholomew *et al.*,1997).

The central focus of the majority of educational programmes for children with asthma has been the self- management plan or 'action plan': this is the set of guidelines given to the patient so that they know how to respond to changes in their symptoms and lung function (see Chapter One for further details). It is widely accepted that following a self- management plan results in better outcomes, with a reduction in symptoms, medication use and hospitalisations (BTS & SIGN, 2003).

The early- to mid- 1980s saw a sudden expansion of self-management programmes for children with asthma, partly triggered by a British Thoracic Association document emphasising home assessment of symptoms and self- treatment (British Thoracic Society, 1982). Many of the eariy self-management programmes have been reviewed in an article by Rachelefsky (1987), later updated and comprehensively reviewed by Wigal ef *al.* (Wigal ef *al,* 1990) and evaluated for scientific merit (Greer *et al,* 1990) and readers are directed toward these reviews for a broad overview of eariy self-management programmes. This review will explore which factors of self-management programmes appear effective in that they produce clinical, behavioural, cognitive or quality of life changes.

The well known 'Asthma Care Training (A.G.T) for Kids' by Lewis *et al* aimed to give children aged 7-12 years more involvement in the management of their asthma and to give them control over their symptoms (Lewis ef *al,* 1984). A traffic light analogy was used to explain the different treatment steps according to asthma severity and children's ability to control their asthma, rather than to *be* controlled by *it* was the main ethos of the programme. Children were identified from files in two clinics who matched the inclusion criteria and were randomised into either the experimental or control group. Seventy- six children participated, 48 in the intervention group and 28 in the control group. The intervention group of children and parents were taught in interactive group sessions to assess symptoms and take appropriate measures, in addition to relaxation techniques and decision making skills. A second group received similar information during passive lectures. At one year, the follow- up rate was around 70%. Both groups showed an increase in knowledge of asthma symptoms and a reduction in the perceived severity of their asthma. However, a greater proportion of the intervention group reported that their compliance behaviours had improved (i.e. remembering to take extra medications when necessary), and this was borne out by fewer emergency hospital visits and days in hospital. Educating children with asthma and their parents clearly had positive effects on knowledge and perceptions of asthma, but it appeared that the interactive nature of the intervention was more likely to result in behaviour change.

Many other studies educating groups of children and parents in this way asthma about symptoms, physiology, triggers, medications and asthma have also shown favourable results in terms of knowledge (Fireman *et al,* 1981; Hindi- Alexander and Gropp, 1984; Robinson, 1985; Gebert *et al,* 1998; Tieffenberg *et al,* 2000), reported self-management behaviours (Lewis *et al,* 1984; Wilson- Pessano and McNabb, 1985) and health locus of control (Parcel *et al,* 1980; Hindi- Alexander and Gropp, 1984; Taggart *et al,* 1991; Tieffenberg *et al,* 2000). This methodology has also been successfully adapted to target specific groups i.e. low income families (Clark *et al,* 1986) and Hispanic families (Hendricson *et al,* 1996; Perez ef *al,* 1999; Jones *et al,* 2001). A recent systematic review examined 32 trials of self- management education programs for children with asthma and concluded that they were of benefit; physiological function, school absence, reduction in activities, feelings of self- control and use of emergency care all improved as a result of the self- management education programs examined, when compared with children receiving usual care (Wolf *et al,* 2003; Guevara *et al,* 2003).

In addition to educating families solely about asthma management, Hendricson and colleagues (Hendricson ef *al,* 1996) also attempted to reinforce 'desirable parent-child interaction', including the use of videos and role models. Other researchers have also highlighted the vital role that family dynamics play in the management of chronic illness (Hardwick and Bigg, 1997; Barakat and Kazak, 1999; Tieffenberg *et al,* 2000) and indeed, Homer ef *al.* remark that "...it seems unlikely that enhancing child self-management alone, without affecting parental behaviours as well would affect outcomes, particularly among younger children" (Homer *et al,* 2000; p214).

Tieffenberg and colleagues conducted an educational programme aimed at children and their parents so that positive attitudes and beliefs could be reinforced consistently throughout the family (Tieffenberg *et al,* 2000). They used a range of interactions to engage children with asthma and epilepsy, promoting observation, decision- making and communication skills which were then related to Lewis ef a/.'s 'traffic light' code of asthma management (Lewis *et al,* 1984). The authors report using a cluster randomisation schedule, stratifying for a number of variables including age, sex, hospitalisations and mother's perception of severity.

By the end of the programme, the authors hoped that the children would demonstrate effective self- management skills and be more confident in their ability to prevent symptoms where possible and respond appropriately in the event of having an exacerbation. To do this, they adopted a child- centred approach, so that parents were taught to be "...facilitators, instead of managers" (p284). That is, the parents were provided with the basic self- management skills necessary for managing their child's chronic illness, but were also taught to trust their child to make health- related decisions for themselves and take responsibility for their own healthcare. It has previously been suggested that children are less compliant if they feel coerced, resulting in resistance and low motivation (see Tieffenberg *et al,* 2000). Therefore, the goals of this programme were to enhance child compliance through mutual co-operation.

Despite the attrition (8.3%) and moderate follow- up rate (51.3% in experimental group, 70.4% in control group), the programme resulted in a number of positive outcomes for the experimental over the control group: knowledge levels and school attendance significantly increased and crises and unscheduled medical visits reduced. In addition to feeling more in control of their illness, children became more autonomous; parents reported reduced feelings of anxiety regarding their child's health and ability to manage their illness themselves, which manifested in such behaviour as allowing children to sleep at friends' houses more often.

The longevity of many group- based programmes have been called into question, however. Few studies have found long-term effects of these training programmes, and Gebert *et al.* report a study which compared 3 groups, one which had received asthma training and been followed up on a monthly basis for 6 months, one which had just received the training, and a control group who received usual care. At follow- up, although both of the training groups fared better than the control group in terms of perceived lung function and knowledge of preventative measures, the training plus follow-up group had the best control of medication. Both training groups had improved coping strategies, although again, the training plus follow-up fared best of all. However, when knowledge was re-tested one year later, the improvements were no longer demonstrated, leading them to conclude that "refresher courses are necessary after one year in order to maintain a high level of competence in asthma behaviour" (Gebert *et a/.*, 1998; p217).

Residential camps for children with asthma are also a useful method of providing support for children as they go about their daily tasks, including monitoring their own symptoms and taking their medication, thus allowing them to improve their skills in a safe environment. An example of this is the Gamp SUPERTEEN programme (Alaniz and Norstrand, 1999), which was aimed at adolescents, who often experience difficulties complying with treatment regimes (Roye, 1995; Anderson and Collier, 1999; Buston and Wood, 2000; Bjorksten, 2000). The goal of the camp was to improve self efficacy, i.e. the confidence someone perceives themselves to have in their ability to carry out certain activities in various situations (Bandura, 1989; Kaplan ef a/., 1993). By encouraging the campers to imagine situations where they might be afraid or angry, for example, and developing efficient coping strategies, it was hoped that they would then have the confidence to cope better in the real worid when faced with similar situations.

Practising skills in a safe environment is particulariy relevant in computer programs, which allow the user to 'experiment' in ways that they never could safely in the real world. For example, Brown *et al* developed an educational computer game for children with diabetes where they had to monitor a character's blood glucose, take the right amount of insulin, plan meals and engage in other appropriate self care behaviours (Brown *et al,* 1997). In the real world, it would be extremely dangerous for them to go without meals or inject the wrong amount of insulin, but through the computer program they could learn the consequences of those actions without putting their own health in danger.

A meta- analysis of randomised, controlled trials evaluating educational programmes for children with asthma published before 1992 concluded that such programmes for children with asthma had little effect on asthma morbidity as measured by emergency visits to the doctor, hospitalisation (including number of hospital days) and school absence (Bernard- Bonnin *et al,* 1995). However, the number of studies included in the analysis was small (11) and many more educational programmes have been published since that time. An updated systematic review has recently been published which analysed 32 trials involving 3076 participants (Wolf *et al,* 2003; Guevara *et al,* 2003). Wolf, Guevara and colleagues used four categories of outcomes with which to assess the educational interventions: physiological function, morbidity and functional status, self-perception measures and healthcare usage. They found that educational programmes resulted in improvements on all outcomes: lung function improved, school absenteeism was reduced along with the number of days experiencing limited activities and number of disturbed nights. Emergency visits to a doctor declined although rate of hospitalisation did not change. All levels of asthma severity benefited from the educational programmes, although some outcomes were stronger in studies recruiting children with more severe asthma.

Despite educational programmes producing positive outcomes in the systematic review, there are some problems with the methodology commonly used in traditional educational programmes. Staff time and running costs of education programmes can be immense and busy lifestyles often mean that parents cannot find the extra time to participate in evening or weekend health education. Levels of literacy can hamper leaflet-based education, restricting access for those who may need the information most (Davis *et al,* 1990; Evans ef *al,* 1998; Dolinar *et al,* 2000). In response to the difficulties involved in traditional education programmes, a number of researchers have employed computer technology to impart information for a range of illnesses, for example, diabetes (Brown *et al,* 1997; Gastaldini *et al,* 1998), hypertension (Gonsoli *et al,* 1995), nocturnal enuresis (Evans ef *al,* 1998), as well as asthma (Rubin *et al,* 1986; Osman *et al,* 1994; Homer *et al,* 2000; Bartholomew ef *al,* 2000).

An important aspect of modern multimedia packages is that they can be individualised to the user and can easily store information about the user's triggers, medication, peak flow etc. Indications that individualised education is efficacious as opposed to traditional group education which "...teach[es] the same skills regardless of the characteristics of the child and of his/her asthma" (Bartholomew *et al,* 2000; p270) resulted from work carried out by Madge, McGoll & Paton (1997). They used a written booklet containing practical information about asthma to promote successful self- management in children over 2 years old who were currently hospitalised due to asthma. Over a one year period, they recruited 201 children into the trial, 96 of whom were randomised into the intervention group and 105 into the control group. For those in the intervention group, an asthma nurse individualised the information in the booklet for managing the child's asthma and discussed the parents' experiences of the signs and symptoms of an asthma attack. A written summary of the agreed plan was provided for the parents and the asthma nurse was available by telephone for advice. Families were encouraged to attend a follow-up appointment 2-3 weeks later. The authors suggest that the timing of the intervention is likely to have been an important factor in this study: families were more receptive to education because they had just experienced an asthma crisis resulting in hospitalisation. However, the dramatic reduction in subsequent hospitalisations, which was statistically lower in the intervention group (8.3%) than the usual care control group (24.8%), is also likely to have been due to the personalised plan and the support of healthcare workers at the clinic and by telephone.

Computer programs can also provide support, albeit in a more limited fashion than an asthma nurse; Computer Aided Learning (GAL) programs are becoming common for assisting decision making in medical contexts (for example, (Takabayashi *et al.*,1999; Sefton *et al.*,2000). However, the main strength of computerised programs is that they are ideally suited to provide cognitive support, by presenting complicated tasks in a more simplified manner, for example, breaking down into simple steps how to use a peak flow meter. This approach complements the Vygotsky-inspired theory of 'scaffolding' (Wood, 1998) which provides a flexible yet supportive structure within which the child can enhance their current level of understanding (Smith *et al,* 2003). Furthermore, the appealing, interactive nature of many computer programs can encourage the user to engage with the task or information long enough for them to absorb it for themselves.

However, it is still vital that computerised programs are pitched at an appropriate stage of development. Following use of their 'Watch, Discover, Think & Act' computer program in which players make decisions about managing a game character's asthma, Bartholomew ef *al.* found that knowledge was increased in older children and those who had higher knowledge levels prior to using the program. Despite having screened for reading ability prior to the program, they felt that the results indicated that it was too complex for younger and less able children (Bartholomew *et al,* 2000). Having programs which contain different 'levels' of information can circumvent this problem; in essence, tailoring information to the child's ZPD, albeit crudely.

Evaluations of multimedia are increasing and eariy indications are that they can be of benefit in educating children about asthma management. However, it is unlikely that they will prove to be superior to individualised teaching from an expert. Homer *et al.* describe a randomised controlled trial demonstrating that their program, 'Asthma Control' was effective in increasing knowledge in children, reducing emergency visits, improving child behaviour and use of peak flow meters and realigned the child's perception of the severity of their symptoms (Homer *et al,* 2000). However, only knowledge about asthma was significantly greater in children in the computer group than children in the comparison group who had returned to the hospital to review an asthma booklet and play on a non-educational computer game. In practical terms, however, if both are broadly equivalent in producing positive behavioural change, then a computer program could be far more cost-effective. How generalisable these findings are to other populations is uncertain due to low recruitment rates (25%) and considerable dropout during the study- less than a third of both groups attended a second visit to the hospital. Another evaluation also found equivalence when children either looked through a leaflet on nocturnal enuresis (bedwetting) or covered the same information incorporated into a multimedia package (Redsell *et al,* 2003). However, the authors report that no attempt was made to pilot the package with children prior to commencing the study; Hendricson ef *a/.*'s experience detailed earlier demonstrated the importance of piloting all information to be imparted in an educational programme to ensure its relevance and acceptability to participants (Hendricson *et al.*,1996).

2.6 Conclusion

Health education for children is important in order to set positive attitudes to take into later life. This is especially important for children with asthma, who need to be able to recognise symptoms and respond appropriately in order to manage their asthma effectively. Educational programs for asthma are now widespread and have been shown to produce positive outcomes: stress, self-efficacy and coping strategies can all be improved through education, which has significant implications for reducing medical resource usage. Transmission of knowledge and reinforcement of positive beliefs and behaviours are central to this process.

There has been a great deal of work investigating children's understanding of illness although researchers do not totally comprehend what processes underiie the acquisition of health concepts. There are significant clinical implications regarding children's competence to consent to treatment: although many studies have demonstrated children's ability to make health- related decisions from an early age, many clinicians still choose to exclude children from the treatment decision-making process. Interviews with children themselves indicate that they wish to feel involved in communications. Ironically, withholding information often leads to greater fears through misunderstandings (Alderson, 1993).

Research has reported wide variations in the ages at which children understand health and illness concepts. Both overestimating and underestimating a child's understanding and ability to make decisions can have a significant psychological impact upon the child, which in turn can affect their physical health. Therefore, it is vital that clinicians assess each child individually and tailor information given accordingly (Wertz *et al,* 1994). This may mean that clinicians must "put information gathering before information giving" (Brewster, 1982; p361). Family dynamics also play a huge part in children's conception of health and illness, and attempts to communicate with a child must take into account their family's beliefs about illness and treatment (Eiser, 1991).

Innovative means have been sought to make health education more appealing to children and improve compliance. Interactive group work and tailor-made, child-focused education programmes have been popular and effective, but have significant time and resource implications. Computer programs certainly have many advantages for paediatric education, presenting information in an engaging manner and using technology that most children are familiar with these days. Multimedia technology can also provide an 'expert' role and help children understand information or concepts which they might not be able to alone. This is congruent with Vygotskian theory and there is evidence that teaching in an interactive manner taking into account the child's zone of proximal development can facilitate children's learning (Meadows, 1995; Wood, 1998). Multimedia is flexible and sensitive to different levels of knowledge; programs can be tailored to suit a wide range of information needs. Pressure on staff and parental time is also somewhat ameliorated by using computer programs in asthma education and may offer a feasible option for 'booster session' work. However, rigorous evaluations of multimedia programs are somewhat lacking. Many have low follow- up rates whilst others restrict participation to those who already own computers which is unlikely to result in a sample representative of all clinic attendees.

The emergence of multimedia in paediatric education offers exciting possibilities, but it is not suggested as a replacement for more traditional methods; instead, it can be seen as an additional tool to help educate children with asthma and promote self-management. To this end, there needs to be much more research into predicting which children will benefit most from such programs, so that a wide range of information needs can be accommodated. Furthermore, observing the way children use computer programs may lead to more effective education, for example, by encouraging collaborative learning and peer tutoring (Foot *et al.*,1990).

2.7 Chapter summary

Children need information about health and illness to form positive health-related behaviour in adulthood. Children with chronic illness are especially vulnerable to stress and fear through lack of information and exclusion from healthcare descisions, although most children are capable of partaking in decisions or can be taught how to do so. Theory suggests that the information given to a child should account for current levels of understanding and that tailored education is desirable. Educational programmes for children with asthma have demonstrated a range of positive outcomes, both medical and psychological. Multimedia has been embraced to provide a new approach to education, which has several benefits: it can be tailored to a child's understanding, save resources and 'boost' knowledge levels at varying intervals.

CHAPTER 3: REVIEW OF THE LITERATURE RELATING TO 'LOCUS OF CONTROL'.

3.1 Introduction

Locus of control (LOG) refers to an individual's beliefs about how their actions and those of other people will affect outcomes in various situations. The concept, initially called 'internal versus external control of reinforcement' is rooted in social learning theory which has been attributed to Julian Rotter (Rotter, 1954; Rotter, 1975). Rotter described four classes of variables involved in social learning theory: behaviours, expectancies, reinforcements and psychological situation, such that "...the potential for a behaviour to occur in any specific psychological situation is a function of the expectancy that the behaviour will lead to a particular reinforcement in that situation and the value of that reinforcement" (Rotter, 1975; p57). Therefore, it takes into account not only how likely an individual believes that a certain behaviour will cause a particular response, but also how important the person holds this reinforcement to be. The learning process, then, is surrounded by people's expectations about the results of their actions. People who believe that outside forces, or luck, have a strong influence over outcomes have been called 'externals' and those who feel able to influence outcomes by their own actions termed 'internals'.

The role of prior experience is key in social learning theory because expectancies are developed and shaped through it, whether directly or vicariously. Rotter describes how "expectancies in each situation are determined not only by specific experiences in that situation, but also, to some varying extent, by experiences in other situations that the individual perceives as similar" (Rotter, 1975; p57). Therefore, the extent of experience someone has in one situation relates directly to the strength of his or her expectancies of another, similar, situation, as does the specificity of the experience. Thus, knowledge of the nature and amount of prior experience could theoretically be used to predict future expectancies and behaviour. How the expectancy is defined will give more or less predictive power:

knowledge of general expectancies will allow prediction across a range of situations but not in any detail. For example, if a person reported taking regular exercise and sleeping well, we may predict that their general health is relatively good but we would not be able to predict whether they see a doctor or dentist regularly. Conversely, if detailed information about expectancies in a specific situation is available, there is the possibility of predicting someone's behaviour reasonably accurately on that aspect, but not generalising this to any other types of behaviour. Using the above example, we may predict better dental health if someone reports brushing their teeth regulariy but we would not be able to comment on their general state of health from the information we had on their dental hygiene.

Rotter described how the internal- external construct came into being, a result of observing that people's expectancies after reinforcement were not uniform, but were "...depend[ent] on the nature of the situation and... [the] consistent characteristic of the particular person who was being reinforced" (Rotter, 1975; p56). So, these external or internal orientations were conceptualised to be part individual trait and part situational. Individual differences determined how people interpreted the reinforcement of their expectancies and thus, affected their behaviour in what they would perceive to be a similar situation in the future. In support of the personality trait aspect of LOG, Joe reports externals to be more anxious and aggressive and have little confidence in themselves, as well as being less trustful of others; internals, on the other hand, are reported as having greater insight, less debilitating anxiety and being more likely to describe themselves as achieving, independent and industrious (Joe, 1971). There is the danger, however, for external orientation to be seen as 'bad' and internality as 'good' because of the apparent associations of internality and adaptive behaviour such as problem- solving and information seeking (Joe, 1971; Rotter, 1975; Walker, 2001). There are situations where this does not hold; for example, if having an operation, it would seem desirable for a person to place his/her trust in the surgeon, so an external LOG may be the most adaptive behaviour in that situation. Then again, this may be situation- specific and in matters unrelated to health problems, the person may generally feel in control of the outcomes of his/ her actions.

A similar concept to locus of control is that of 'self- efficacy', which was developed and by Albert Bandura (1977; 1989) and refers to "...beliefs in one's capability to organise and execute the courses of action required to produce given attainments" (Walker, 2001; p77). This self- belief of personal capacities to succeed in a situation can affect not only how a person behaves, but also their motivation and emotional responses to a situation (Tobin, 1987). Some research has looked at the impact of self- efficacy on health behaviour; for example, O' Leary (1985) suggested that compliance with medical advice can be affected by self- efficacy through its impact on motivation and perceived ability to carry out the appropriate health-behaviour. It is unclear, however, how much predictive power assessing self-efficacy actually provides because it focuses on specific skills in particular situations. In comparison, locus of control relates to a relatively stable set of beliefs relating to the likely consequences of their and others' actions and are generalisable to a wider range of situations (Walker, 2001). Self- efficacy can be seen as a mediating variable rather than a measurable outcome in itself; therefore specific behaviours can *interact* with locus of control to result in outcomes but self- efficacy cannot *replace* locus of control (Wallston, 1991). Knowledge about how 'internal' or 'external' someone is, therefore, a crucial factor in predicting, and shaping, future health behaviour.

This chapter will go on to discuss the development of measures for assessing LOG, firstly the generalised version for adults and then its equivalent for children. The movement towards health-specific scales will then be described, again starting with adults and moving on to children. The rationale for studies utilising these measures to improve children's health behaviour will then be discussed.

3.2 Assessment of locus of control

One of the first attempts to formally assess these beliefs of internal Vs external control came in 1966 with Rotter's Internal- External (I- E) scale for adults (Rotter, 1966), based on an eariier version by Phares (1957) (Walker, 2001). In this, he attempted to test people's beliefs of control in a range of situations and developed a 23- item instrument, using college students as his sample, where people were asked to agree or disagree with statements. The questionnaire attempted to cover as broad a view of people's beliefs as possible and thus was not designed to predict behaviour in specific situations- the scale was treating locus of control more as a stable personality trait. Rotter's I-E scale was designed to have a low correlation with social desirability (as measured by the Marlowe- Growne Social Desirability Scale), which resulted in many items being removed from the eariier 60- and 100- item versions. For this same reason, Rotter reports that some questions of academic achievement were removed. To ensure internal consistency and for inclusion in the final scale, items had to correlate with the total of the other items.

Battle and Rotter later developed a children's version called the Children's Picture Test of Internal- External Control and discovered that greater internality was related to older age and higher socio-economic status (Battle and Rotter, 1963). However, Nowicki and Strickland (Nowicki and Strickland, 1973) felt that this and the other locus of control scales that existed for children, had sufficient shortcomings to warrant the development of a new scale. In it, they used Rotter's internal Vs external concept as the basis for a 40-item yes/no questionnaire. This had been reduced from an original pool of 102 items by asking psychologists to complete the questionnaire in an external direction and removing any items where there was not complete agreement. Item analysis was also conducted based on the answers of a pilot group of children.

To validate the 40-item version of the questionnaire they got 1017 children aged 8-17 years to complete it and gathered information on socio-economic, social desirability and intelligence variables. They then used item analysis to produce two scales that discriminated well between ages, resulting in one scale for ages 7-11 year olds and one for 12-17 year olds. Their findings supported previous work which had found internality to be related to older age and higher socio-economic status, as well as higher achievement in intelligence tests, although the latter finding was almost exclusively for males. Other studies who have employed the Nowicki & Strickland Children's locus of control scale have reported showing internality to be associated with higher self-esteem, better performance on visual recognition tasks, involvement in extra- curricular activities in females and popularity in males (as assessed by class president votes) (Nowicki and Strickland, 1973). The authors conclude that "...an internal score on the Nowicki- Strickland scales is significantly related to academic competence, to social maturity and appears to be a correlate of independent, striving, self- motivated behaviour" (p153-4).

3.3 Locus of control and health

It is clear that, theoretically, a carefully constructed measure of locus of control could be utilised to predict a number of variables such as academic competence. However, as we have already seen, generalised and specific expectancies can have varying predictive power and so far, the role of situational factors has not been taken into account. Rotter himself highlighted the importance of this but also said that developing a different quesfionnaire for every situation would be extremely costly in time and money given the thorough validation procedures required. Nevertheless, he suggested that "...it would be worth developing such a specific measure if one's interest is in a limited area and particularly if one is seeking some practical application…" (Rotter, 1975; p59). Furthermore, Lefcourt argued that people may have different levels of confidence about their control over events in different situations i.e. in work and health contexts, which strengthened the call for situation- specific measures (Lefcourt, 1982).

Health professionals often encourage their patients to take an active role in their own care, particularly those with chronic illnesses, so developing a health- specific locus of control was proposed as a more formal way of evaluating these beliefs and their effect on health- related behaviour (Walker, 2001). Wallston and colleagues developed their Health Locus of Control (HLOG) scale for adults in 1976 to test the hypothesis that health- related locus of control would be a more specific predictor of subsequent health behaviours than a general LOG scale (Wallston *et al,* 1976). They devised an 11-item measure (reduced from a pilot version with 34 items) utilising a 6-point Likert scale, scored in an external direction, so that higher scores indicated a more externally orientated person and lower scores represented a more internally orientated person. The authors report an internal consistency correlation of 0.72 and that the scale did not correlate with scores on a social desirability measure (which may have confounded findings), both positive attributes. The 98 college students who acted as their pilot subjects also completed Rotter's I-E scale, with which their HLOG correlated moderately (r= 0.33). The authors argued that this showed concurrent validity as, although the constructs measured may have overiapped, the two scales weren't measuring exactly the same thing (which would render the new version unnecessary). There were no differences between males and females in any of their test samples, but the Gronbach's Alpha co-efficients for 3 subsequent college samples with 100 subjects in each sample were reasonably low at 0.40, 0.50 and 0.54.

Following their initial development phase, Wallston ef *al.* used their HLOG scale in a study to test whether people with high internal locus of control and who valued their health highly would be more proactive information- seekers than internals who put a low value on their health or those with an external locus of control. Eighty-eight students completed a hypertension knowledge questionnaire, HLOG scale, I-E scale and a measure of health value. Participants were then offered a range of 16 booklets about hypertension and the number they chose was taken as a measure of information seeking behaviour. The authors reported that internals who valued their health highly chose more booklets than low value internals, high value externals and low value externals. There were no differences between these latter three groups in number of booklets requested. The authors report that the I-E scores failed to interact with health value, so that the findings would have not emerged had they relied solely on the I-E scale for internal/ external classification.

Lewis, Morinsky & Flynn attempted to extend the work by Wallston *et al,* using their health locus of control scale with a clinical population of adult patients actually with hypertension (Lewis *et al,* 1978). Their hypothesis was that, if the patient felt they had support from a partner at home and they put a high value on their own health, they would become more internalised, which would lead to better compliance with medications and health behaviours. The authors utilised a number of measures in addition to the HLOG scale which assessed the importance placed on health (in relation to work, money and family), support given at home and self- reported medication compliance. When the internal consistency of the HLOG scale was examined, Gronbach's Alpha value was just 0.36, which suggests that responses to the items in the scale were inconsistent, although correlations with a social desirability score were low. Demographic details also did not correlate with the HLOG score. Their hypothesis of an interaction between greater social support and high value placed on health to produce higher internal score and better medication compliance was not altogether borne out in the analysis because, although higher HLOG score and support at home did significantly contribute to better self- reported medication compliance, the value of health did not. When categories were collapsed for a 2 x 2 comparison of high- low home support and internal- external score, the most positive medication compliance scores were for internals with high-perceived social support, which is to be expected. Interestingly, the next best compliance ratings were for externals with low perceived social support, which the authors suggest could possibly be explained through people believing that they *could* improve their health but being frustrated that no-one at home was helping them; the dissonance caused by these two standpoints produced the appearance of an external although their actual behaviour at home was more internal. The third highest were internals with low social support which suggests that clinicians should not solely use an internal score as a guarantee of compliance. Finally, those with high levels of social support but who were largely external in their feelings of control were very poor compilers, which further highlights that looking at just one element of a person's feelings and circumstances is insufficient in predicting adherence. Despite the low- moderate internal consistency co-efficient, the authors felt that the HLOG scale was a useful measure for predicting a persons self- reported health behaviour although advised caution when interpreting results.

The studies described above all used a unidimensional scale, where external and internal control were perceived to be the diametric opposite of each other. However, Levenson argued that internal and external control beliefs were actually orthogonal to each other and that external control could be split up into 'chance' and 'powerful others' variables (Levenson, 1974). This, Levenson suggested, would enhance prediction of behaviours, and, after she had developed a generic multidimensional locus of control measure, Wallston and colleagues developed their health- specific multidimensional locus of control scale (MHLOG) (Wallston *et al,* 1978). Starting with the original 11 items from their unidimensional LOG scale, they wrote additional items for each of the three dimensions, culminating in 81 test items, with responses measured on a 6- point Likert scale. To avoid the pitfalls of using a homogenous group of college students as in previous studies, a researcher asked people visiting an American airport to complete a booklet containing the test items, as well as Levenson's MLOG scale and a test of social desirability. Although anyone over 16 years of age was eligible to participate and the intention was to approach as wide a range of people as possible, the sample characteristics showed a bias towards white respondents with some college education who were in their mid 40's, although males and females were equally represented. From 115 returned booklets (282 distributed), the authors developed two equivalent health locus of control forms, A and B, both of which contained 18 items: 6 items each for internal, chance and powerful others dimensions. Items for inclusion had to have a mean close to the midpoint, be answered differently by a number of respondents, correlate significantly with the original scale score (minus that item) and have a low correlation with the social desirability score. The authors report that, "The intercorrelations of the MHLG scales and the I, P & G scales are such that each MHLG scale correlates most highly with its theoretical counterpart among Levenson's scales" (p165). Studies have largely confirmed Form A's validity and structure, although less work has been done with Form B (Norman and Bennett, 1996). However, despite finding that the two forms correlated well, one study only found the predicted 3- factor structure for females, with a 2- factor structure for males (O' Looney and Barrett, 1983). There is still a little uncertainty as to the true utility of a multidimensional LOG scale; in his paper discussing some of the misconceptions and pitfalls of using the concept of internal- external control of reinforcement Rotter himself addresses the move towards a MLOG and highlights that it is little help, as well as contrary to social learning theory, to view a measure in absolute terms i.e. that it must be multidimensional *or* unidimensional. Rather, he suggests that using a measure with particular samples or to answer certain research questions may result in finding sub-classes of variables which relate to each other, but that it does not invalidate the scale if this is not found in other populations. He concludes "It would be surprising, indeed, if such clusters of items did not appear in any scale of personality, particulariy when the scale attempts to sample over a broad area of behaviours or situations" (p63). Despite their strong support for using mulfidimensional scales, Wallston *et al.* note that such scales may not be the best choice in some circumstances, where examining only one or two dimensions may be appropriate.

3.4 Development of locus of control

Having identified people's beliefs about the consequences of their actions as being broadly 'internal' or 'external', the next quesfion which arises is how do people obtain or develop those beliefs in the first place? Lau discusses the origins of health locus of control in detail and uses as his starting point Rotter's role of experience reinforcing expectancies (Rotter, 1975) to postulate that more serious, long- lasfing and personally experienced illnesses have a greater role in shaping HLOG than mild, shorter illnesses or those of other family members (Lau, 1982). He also debates the effect of the timing of experience- do more recent illnesses have a stronger effect on locus of control than those in the past? To test these hypotheses, 270 college students provided information on eariy health habits, illness experience and demographics in addition to completing a health locus of control scale at two time- points. The HLOG scale he used had previously been developed with a multidimensional structure containing self- control over health (internal), provider control over health (powerful others) and chance variables (Lau and Ware, 1981). It also contained an extra dimension, called 'general threat to health' which related to beliefs such as susceptibility to illness. Early health habits enquired about included being taken for check-ups, having vaccinafion injections, eating healthily and taking regular exercise.

Lau found that belief in self- control was positively correlated to self- care behaviours and that belief in provider- control was positively related to having regular check ups. Furthermore, belief on the 'general threat to health' sub-scale was negafively correlated with having regular check-ups, suggesting that they were perceived to be 'protective' in some way. High rates of illness experience, both personal and in the wider family context, contributed to beliefs of chance health outcomes, although early experience had a stronger effect than more recent illnesses, which the author uses as evidence for the stable and constant nature of HLOG beliefs, in other words a personality 'trait'. However, as eariy illnesses reported are more likely to have been more serious (making them more memorable) than recent illness experience, he concludes that "...health locus of control beliefs are not affected by common, fairly minor ailments and illnesses" (Lau, 1982; p332).

The finding that socio-economic status was positively related to health behaviour, in that high socio-economic status parents were more likely to take children regulariy to dentists and doctors for check-ups, further supports the necessity of actively encouraging all families, but especially those with low socio-economic status, to engage in positive health behaviours. Not only must the immediate benefits that such behaviours engender be reinforced, but also the longer term effects on children's feelings of control over health and lifetime health behaviours.

One of the strongest associations found in Lau's study is the negative relationship between illness experience and feelings of self- control over health. The author suggests that different findings may have emerged from an older sample, not as generally healthy as young college students who were possibly more likely to take their healthy status for granted. However, Lau highlights that "...the attributions people make after getting sick are crucial in determining what effects that illness episode will have on related health beliefs and health behaviours" (Lau, 1982; p333) thus supporting the case for educating young people with chronic health conditions in order to negate the effects of extensive health-related experience and boost their feelings of self- control.

There were some flaws in the study, however: there was no evidence that 'general health threat' was a distinct variable, given that some of the general health threat items grouped with 'chance' whilst the others did not group with any other variables at all. Furthermore, when Marshall *et al.* compared the multidimensional measures developed by Lau and Wallston *et al,* they queried whether the two scales were really measuring the same thing as the correlations between the two were less than ideal (r= 0.32- 0.38), despite being statistically significant (Marshall *et al,* 1990). The authors report that this may have been due, in part, to the low internal consistency found for Lau's scale, as this was considerably below that of Wallston *et al, even* though Lau himself had reported internal consistency alpha co-efficients of 0.87, 0.84, 0.51 & 0.45 for self- care, provider- control, chance and general health threat respectively (see p327). Wallston ef *al.* reported co-efficients of 0.67- 0.77 although this rose to a = 0.86 when forms A & B were combined. Thus, multidimensional measures have a place in the assessment of HLOG, but attempting to delineate into too many dimensions appear to reduce the reliability and thus, the predictive power, of the tool.

A complicated relationship evidently exists, then, between health experience and locus of control. Despite this, it seems clear that experiences in eariy life play a vital role in reinforcing expectancies. In an attempt to understand children's LOG in a health context, Parcel and Meyer developed a child focussed HLOG scale (Parcel and Meyer, 1978). Nowicki & Strickland had already demonstrated that a generic children's locus of control scale could be used reliably and researchers had used health- specific scales in both healthy and clinical adult populations with some success (e.g. Lewis ef *al,* 1978; Wallston *et al.,* 1976). Parcel and Meyer (1978) commented that health education programmes for children generally centred around promoting responsibility over health care but 'measurement' of this was often an assessment of knowledge and/or attitudes towards the health behaviour. This approach involves making significant assumptions about the relationship between knowledge and behaviour and does not take into account the concept of 'health motivation' as described in the Health Belief Model. Therefore, a more direct assessment method was proposed.

They developed a pilot instrument which comprised 30 statements that could be answered by either Yes (agree) or No (disagree). Some statements were adapted from Wallston *et al.*'s 1976 scale for adults and others from a health educafion textbook commonly used with children at the fime. Responses in an internal direction were given a score of two and external a score of one; thus, the higher the score, the more internally orientated the child. The authors used the scale with children from two elementary schools aged 7-11 years. The proportion of males and females between the schools was roughly equal, although the children from one school had lower overall socio-economic status (as measured by proportion receiving subsidised school lunches) and were exclusively black. The ethnicity of children from the other school was mixed, but the majority were white and had a higher socio-economic status overall. There were no differences between sexes on the Children's Health Locus Of Control scores. The authors found that children became more internal as they progressed through the school grades, which was consistent with findings from Nowicki & Strickland's previous study (Nowicki and Strickland, 1973). They also found that children with lower socio-economic status scored lower on the scale, thus making them more externally orientated than children with higher socio-economic status, who were more internal, concurring with previous work (Nowicki and Strickland, 1973; Parcel *et al.*,1980; Lau, 1982).

Parcel and Meyer then revised their scale by removing 10 of the items which did not discriminate between high and low scorers, resulting in a 20-item scale with an internal consistency co-efficient of around 0.73, representing moderate- high internal consistency. The revised scale was administered to a new sample of children at 2 intervals, 6 weeks apart, in order to ascertain test- retest reliability. Nowicki & Strickland's generic children's locus of control scale was included in the 2nd testing session and the scores correlated with those on the CHLOC, which the authors suggest determined construct validity. Again, scores did not differ significantly between sexes and showed increasing internality with age. Overall, the test-retest reliability coefficient was consistent between administrations: 0.72 for the first and 0.75 for the second. However, the co-efficients between administrafions for specific school grades were not always consistent, often becoming more internal on second administration. The authors suggested that this reflected the lack of practice in completing the scale prior to the first administration. The correlation between the CHLOC and Nowicki & Strickland's LOG was moderate yet significant at 0.50 ($p < 0.01$), demonstrating that the revised CHLOC scale did relate to the original measure of locus of control. However, the authors concluded that further work was needed in order to assess its true ability to predict health behaviour.

Recent work has used alternative methods to Parcel & Meyer's CHLOC scale. Bases & Schonfeld argue that children are more likely to appear 'external' on Parcel & Meyer's LOG scale because they simply acquiesce to the mostly (17/ 20) external items (Bases and Schonfeld, 2002). They suggest that young children are unlikely to 'challenge' authority by disagreeing with a statement regarding the effectiveness of an adult, for example *"It is my mother's job to keep me from getting sick".* They may also be unhappy selecting an alternative without it being specified. Instead of agree/ disagree (AD) design, Bases & Schonfeld used a 'choice of attribution' (GA) format, which provided the child with two alternative sentences and required the child to choose the one best matching his or her sentiments. For example, Parcel & Meyer's first item reads *"Good health comes from being lucky* and the child is asked to agree or disagree. Bases & Schonfeld reworded this so that children were presented with *"Good health comes from..."* and they were provided with two options: *a) "being lucky"* or *b) "taking care of yourself.* Both the Parcel & Meyer's AD and the authors' GA formats were used in Bases & Schonfeld's study with 444 children aged 7-8 years in US schools to investigate the validity and reliability of the choice of attribution scale. Randomisation occurred at the classroom level and the order of questionnaire presentation was also randomly assigned. Both formats were read aloud in classrooms to the whole class and children asked to circle the appropriate response.

A mean total score of 32 (instrument range: 20-40) was found for both the AD and GA formats and the two questionnaires correlated moderately yet significantly ($r= 0.56$, $p< 0.01$). The authors reported that on a substantial number of questions, children answered external AD items affirmatively and then answered the corresponding GA item in an internal direction. They also report that on a quarter of items the converse was true: children would agree with internal items on the AD scale and select the external response on the GA scale. They use these findings as evidence to support their hypothesis that children are unhappy rejecting items when not given an alternative.

These findings are both interesting and potentially convincing for using alternative formats to those with agree/ disagree responses. However, the reliability of Bases & Schonfeld's revised locus of control scale is under some quesfion; the authors report low kappa values for the 20 items (-0.005- 0.41), which suggest poor agreement between corresponding items on the two scales. Furthermore, factor analysis revealed factors which explained only a small proportion of the variance (around 25%). Critics also highlight the lack of difference between the mean total scores and the moderate internal consistency values (0.50- 0.74) which differed little from the AD scale as further evidence that the GA format "...was no more psychometrically defensible than the original" (Baranowski, 2002) p163). However, Bases & Schonfeld have been successful in highlighting the issue of scale format and this should encourage other researchers to investigate optimal testing formats when working with children.

3.5 Promoting locus of control

By utilising a social learning theory framework, Parcel and Meyer were adhering to the notion that solely providing health information to children is insufficient in improving their health behaviour through taking greater responsibility (Parcel and Meyer, 1978). Teaching children the skills to make decisions about their health should be central to the education process rather than just teaching facts. Health educafion programmes should be tailored depending upon the children's age so that the amount of responsibility taken on by the child is gradually increased at appropriate intervals. Vulnerable groups, for example children with low social-economic status, could also be targeted in order to teach and reinforce positive health behaviours and thus promote a sense of internal control.

Parcel and colleagues used the children's HLOG scale within an educational setting, this fime with a specific clinical population- children diagnosed with asthma- to investigate links between HLOG and knowledge (Parcel *et al,* 1980). Having screened a school population for those with doctor- diagnosed asthma, children were interviewed using several measures: an asthma knowledge test, the HLOG, an illness anxiety scale and a scale of self-concept. They were then clustered by school so that children from one school took part in an asthma education programme based round a book about asthma whilst the others were used as a comparison group with no intervention. However, a crossover method was employed so that those in the second group later received the educational package in an attempt to replicate, and thus confirm results found with the first group. The authors found that, having gone through the educational programme, the first group of children were significantly more internally orientated at follow-up than the comparison group and this was verified when the comparison group became more internal after subsequently receiving the asthma educafion package. Alongside this, children's knowledge scores improved and illness anxiety diminished after receiving the educafion. The mean change in HLOG scores was found to be affected by ethnicity: Caucasian children exhibited a greater change than black children, who in turn demonstrated greater mean changes than Mexican- American children. The authors comment "...health locus of control, more than the other educational variables, is probably more affected by cultural and social environmental conditions" (p130). This has significant implicafions for the treatment and education of people from different cultural backgrounds. People from ethnic minorities often have lower socio-economic status (Taggart ef *al,* **1991),** which we have seen is linked to lower feelings of control, but in addition, they may also have lower locus of control through cultural factors, which some researchers have addressed by creafing asthma education programmes targeted at children from particular cultures (Taggart *etal,* 1991; Perez ***et al.*,**1999; Tieffenberg ***et al.*,**2000).

Tieffenberg *et al*.'s recent study, described in Chapter Two, used similar concepts to Parcel *et al.* as a framework for educating children with asthma and epilepsy (Tieffenberg *et al,* 2000). The programme attempted to teach children how to make positive health- related decisions and, with parents as facilitators, encouraged them to take responsibility and autonomy in their health care. They cite Piaget when they describe two different models of adult- child interacfion: heteronomous where the adult is highly prescriptive, and autonomous, which is more co-operative. Although, in the short term, the outcomes of both modes of working may seem similar i.e. the child takes his/her medication, in the long term, the authors highlight Piaget's warning that a child is more likely to lack confidence and motivation to look after his/her own health if not involved in decisions. Furthermore, the prescriptive approach may engender a hostile response or superficial conformity where the child only adheres under adult supervision. Thus, according to social learning theory, the experience of their ability to control their health behaviour will be negative, leading to their locus of control becoming externally orientated. It is clear that this is not conducive to long- term compliance to important medical regimes. A child with either of these illnesses may have to manage their illness for years, if not a lifefime, so providing management tools and enhancing children's internal locus of control eariy in life is vital.

Specially trained teachers outside the hospital environment delivered Tieffenberg *et al*.'s education package, with clinicians taking an advisory, rather than a dictatorial role. Participants were randomised into either the experimental or control group after being recruited at home and completing HLOG scales and a sociocultural quesfionnaire. In **addition** to teaching the children about the medical aspects of asthma, their decision- making skills and confidence in managing their asthma were also developed, within a peer- supported environment.

At baseline, the authors reported that children with both illnesses were more externally orientated than a healthy comparison group. It is likely that children with illnesses such as epilepsy or asthma will have experienced high levels of parental or adult control over their health and health- related decisions. Furthermore, their acfivifies and thus, wider experience of the worid, may have been restricted, resulting in low levels of perceived control. This fits in with both Piagetian theory and social learning theory whereby lack of autonomy in health care decisions leads to low motivation to participate in future decisions, as there appears little to be gained in doing so. Healthy children are unlikely to have experienced this control to such an extent and thus, are less likely to be as externally orientated. However, this may vary between illnesses; children aged 9-13 years with diabetes mellitus have been reported to have very similar scores on the CHLOC scale to healthy children in the same age range (Moffatt and Pless, 2002) although youngsters with renal, oncological, cardiac and rheumatological illnesses have been found to be more externally orientated that those with diabetes and cystic fibrosis (Kellerman *et al.*, 1980).

In Tieffenberg *et* a/.'s study however, despite being externally orientated prior to the programme, the experimental group became more internally orientated as they progressed and were more internal than controls at 6 months, significantly so at 12 months, even after controlling for age. Knowledge improved in parents and children across both illnesses and, compared with the control group, the experimental children reported fewer 'crisis visits' to doctors and fewer days off school. With growing autonomy and internal control, daily activities and, thus, family functioning was reported to have improved in the experimental group. This study lends credence to the suggestion that autonomy and internality can be facilitated or 'taught', given an appropriate theoretical framework and supportive educational methods.

So far, both generic and health- specific LOG scales for adults and children have been described, including their use with both healthy and clinical samples. Although the HLOG was a more focussed measure than the original, generic, scales, it still took a very general approach to health: examples from Parcel & Meyer's GHLOG include "Accidents just happen" and "There is nothing I can do to have healthy teeth" (Parcel and Meyer, 1978). As described eariier, this version has subsequently been used with children with a variety of illnesses, although it is probable that such general questions are unlikely to elicit precise informafion on the child's feelings towards their particular illness; thus, better predictive power has been sought by devising more specific LOG scales. Norman & Bennett discuss the theorefical rationale for developing behaviour- specific scales; they use the example of a smoker who does not feel in control of his smoking behaviour but has internal beliefs over regular exercise, to illustrate that people may have different control beliefs in different situations (Norman and Bennett, 1996), echoing Leftcourt's views discussed eariier. The second underiying principle is that tapping generalised beliefs regarding health usually only works in novel situations (Rotter, 1982; Wallston, 1991), because, with no prior experience, the individual has to refer back to some generalised knowledge. Given that most health behaviours are not new, the argument goes, using generalised HLOG scales will not provide sufficient information for predicfing future health behaviour (Wallston *et al,* 1976). A number of illnesses and health- related behaviours have attracted specific LOG scales, for example, diabetes (Peyrot and Rubin, 1994), dental care (Rachelefsky, 1987), as well as smoking cessation (Georgiou and Bradley, 1992), weight control (Holt *et al,* 2001) and high risk behaviour in men with AIDS (Kelley ef *al,* 1990).

With a similar theorefical basis in mind, Dupen *et al* developed an asthma-specific locus of control scale for adults and set out to assess its reliability and validity, as well as look at the relationship between locus of control, asthma knowledge and illness severity, amongst other variables (Dupen *et al,* 1996). The Asthma Mulfidimensional Locus Of Control (AMLOG) contained 24 items- eight each for 'Internal', 'Powerful Others' and 'Chance' items- and had been modified from the MHLOG developed by Wallston *et al* ('Form G') which can be tailored to specific illnesses by inserting the appropriate word into each quesfion (Wallston ef a/., 1978). Thus, each question on Dupen *et* a/.'s LOG measure included the word 'asthma' i.e. 'I deserve the credit when my asthma improves and blame when it gets worse'. The respondents had to choose from a six- point Likert scale ('strongly agree' to 'strongly disagree') which best matched their answer. The authors administered their AMLOG to 186 people with asthma recruited from pharmacies In the New South Wales area of Australia. Although the eligible age range was 13- 55 years, the average age was 33 years, making theirs an essentially adult populafion. The asthma knowledge questionnaire they used had 27 questions, six of which required short answers from respondents, for example *"What are the three main symptoms of asthma?"* and *"Write down two asthma treatments which are taken every day on a regular basis to prevent attacks of asthma from occurring".* The remaining 21 quesfions were a true/ false format (Fitzclarence and Henry, 1990). The quesfionnaire had previously been validated with 138 parents and shown to discriminate between those expected to have high knowledge levels (with children attending a respiratory clinic) and those expected to have low knowledge levels (with children attending a non- respiratory clinic and with no experience of asthma) (Fitzclarence and Henry, 1990). A measure of doctor-patient relafionship quality was also taken, where the pafient had to rate the quality of the fime they spent with the clinician. Individual lung function was assessed through the pafient keeping a daily diary of their Peak Expiratory Flow (PEF), although the reliability of this method is variable, given its reliance on individuals remembering to consistently measure their lung funcfion and the possibility of manipulafing entries (Chowienczyk ef a/., 1994; Verschelden *et al,* 1996). As well as using PEF, asthma severity was also estimated using information provided by the pafient regarding emergency visits to a hospital or doctor in the previous 6 months and whether they'd ever used corticosteroids.

The authors hypothesised that age would be inversely associated with internal locus of control and positively associated with external locus of control, arguing that older people would have more experience of being treated by the medical profession and place their trust more readily in them. However, their results ran counter to this; age was not significantly associated with internal control but was significantly, negatively associated with chance HLOG ($r = -0.19$, $p < 0.01$).

Asthma knowledge was hypothesised to have a positive relationship with internal scores, but this failed to materialise in the analysis; asthma knowledge scores did not significantly correlate with internal scores although there were significant negative associations between asthma knowledge and the study's two external locus of control variables (chance and powerful others). The authors suggest that the negative relationship between 'chance' and knowledge shows "...that those who had less knowledge about the causes, physiology, and treatments of asthma considered uncontrollable factors to be the biggest influence on their illness" (Dupen, 1996; p500). Interestingly, internal locus of control was not associated with any variables with the excepfion of relationship with doctor, which was moderately correlated in a positive direcfion ($p < 0.05$). As expected, there were stronger associations between relationship with doctor and both measures of external control (most strongly on 'powerful others').

The correlafions between the clinical measures and locus of control scores also revealed some unexpected relationships. Peak flow and use of corticosteroids were not significantly correlated with any LOG constructs, whereas requiring emergency medical help was positively and significantly correlated with internal scores. Therefore, people who were more internal visited doctors and hospitals for emergency help more than people who were more external.

The authors conclude that their asthma locus of control scale has construct validity having found three disfinct dimensions through factor analysis. They also use the dimensions' different relationships with several variables as evidence of the multidimensional construct of the measure, for example the positive relationship between age and powerful others and the negafive relationship between age and chance.

There are several issues which should be considered when interpreting the results from this study. It was surprising that knowledge did not relate to locus of control as found in previous studies (Tieffenberg ef *al.,* 2000), although the choice of knowledge questionnaire could partly explain the lack of association. It had not been validated in the population used in Dupen's study, but in parents of children with asthma severe enough to warrant attendance at a hospital respiratory clinic (Fitzclarence and Henry, 1990). It had discriminated between those with high and low expected knowledge levels but the sample had little in common with Dupen *et a/.*'s mostly adult community sample. Furthermore, reproducibility data had been obtained from only 12 participants in the original study, limifing its reliability. More work looking at highly internal individuals and the pattern of their knowledge scores may prove to be helpful, and a description of the relationship between knowledge and lung funcfion would also be of interest and aid validafion of the measure. Internal consistency in Dupen *et a/.*'s study was moderate; after weak items had been identified through item analysis and deleted, alpha coefficients ranged between 0.71- 0.74 and item- total correlations 0.45-0.48.

Dupen *et al* report that the 'profile' of their community sample was scoring highly on Internal and powerful others and low on chance scales. They hypothesise that this reflects the nature of asthma, which can be self-managed very effectively in certain situations i.e. if their triggers are things like cigarette smoke or animals, but not so much in others, for example if their triggers are weather or pollen. Most people with asthma do, however, usually require the expertise of doctors at some point in their life. These factors may produce a specific 'type' of LOG in adults with asthma and thus warrant using a disease specific scale. Although this lends considerable weight to the call for illness- specific scales, the authors have not sufficiently demonstrated that a multidimensional measure is necessary in all circumstances. Indeed, they themselves highlight that the characteristics of the populafion being sampled are important when selecfing a multidimensional or unidimensional approach to assessing locus of control.

Assessing locus of control, then, will allow us to investigate the links between feelings of self- control and knowledge and also the effect it has on self-management skills. From the literature, it is clear that internal locus of control is desirable for positive health behaviours, which is particulariy apt in people with chronic illnesses. Social learning theory **also** suggests that the positive health behaviours should be reinforced from an eariy age and thus, teaching children how to feel confident making health- related decisions would seem vital. Again, this is of specific relevance to children with a chronic illness like asthma, where symptoms require monitoring, treatments or behaviour need to be adapted accordingly and prevenfion measures are key. Although some triggers will not be controllable, asthma, in contrast to some other paediatric chronic conditions, affords plenty of scope for children to develop mastery of their health, including deciding when to self- manage an attack and when to seek medical help. A strong sense of one's ability to control asthma symptoms, it is argued, should be a key outcome for any educational intervention for children with asthma. An illness- specific Locus of Control Quesfionnaire has been designed and validated for this UK study to assess the extent to which 'The Asthma Files' intervention develops internal control in children.

3.6 Chapter Summary

How much control people feel they have over events is reinforced throughout life; some people tend to feel that they have some degree of control over events (termed 'internals') whereas others may feel that, in some situations, outside forces or other people are able to exert more control over events than they are (termed 'externals'). This has been invesfigated in health contexts and an 'internal' locus of control has been associated with higher knowledge and more posifive health behaviours. Research has shown that an internal locus of control can be promoted through education, with associated improvements in health outcomes. The characteristics of asthma may be disfinct from those of other chronic illnesses; therefore a 'general' locus of control instrument may not be sensitive enough to detect factors which could predict asthma- related behaviour. Development of an asthma- specific locus of control measure for children is warranted.

CHAPTER 4: VALIDATION OF AN ASTHMA LOCUS OF CONTROL SCALE

4.1 Introduction

Pafients with chronic illness are often taught how to manage their illness themselves in order to avoid exacerbations and aid well- being. With an illness such as asthma, it is crucial that patients monitor their symptoms and respond appropriately; if done effecfively, it can reduce both morbidity and mortality (BTS & SIGN, 2003). Taking preventafive acfions, such as using anti-inflammatory medications and avoiding known triggers, can also reduce the severity of asthma attacks and hospital admissions (Madge *et al,* 1997; Perez *et* a/., 1999).

Such patients need a good working knowledge of their medicafions, the effects and their method of administration but they also need a degree of confidence in their own ability to manage their regime successfully and a belief that their actions will be effecfive (Dupen *et al,* 1996). Chapter Three outlined Rotter's concept of Internal-External Control of Reinforcement which seeks to describe and measure the expression of this type of confidence within a social learning context (Rotter, 1954; Rotter, 1966). In a medical context, internal locus of control has been associated with greater information seeking behaviour, improved self- management skills and fewer health crises (Joe, 1971; Lau, 1982; Tieffenberg *et al.*,2000).

Locus of control has been measured and evaluated in different ways in the fifty years following Rotter's original Internal- External Control of Reinforcement Scale. Most relevant to this study is the Children's Health Locus of Control Scale developed by Parcel and Meyer in 1978. This scale drew on exisfing research on generalised locus of control in children (Nowicki and Strickland, 1973), alongside work on the health beliefs and health locus of control in adults (Wallston *et al,* 1976; Lewis *et al,* 1978). Parcel & Meyer's scale has been used widely since its publicafion and revised versions have been devised. Other formats have been developed, for example Bases & Schonfeld's Choice of Attribution configuration (Bases and Schonfeld, 2002) but unproven reliability and a limited target age range have restricted the uptake of such novel measures and they have failed to replace the original Children's Health Locus of Control Scale (Baranowski, 2002).

Around the fime Parcel & Meyer were publishing their Children's Locus of Control Scale, a revised version of Wallston *et* a/.'s adult Health Locus of Control Scale was being developed (Wallston ef *al,* **1978)**. It was intended to be adapted for specific illnesses, in an effort to increase its ability to predict specific health behaviours. Having used it in their adult community sample, Dupen *et al.* (1996) concluded that the pattern of findings with their sample leave many unanswered quesfions regarding adult asthmafics' beliefs about their condition, illness management and attitudes toward carers. It seems that illness-specific scales need to be tailored and finely-tuned if they are to probe the often subtle complexities of health behaviour prevalent in illnesses such as asthma, which are prone to unpredictable patterns of symptom exacerbation whilst being responsive to careful self- management at other fimes.

Other requirements are important when tesfing children. Item structure and response formats must be simple for comprehension, repetitious items should be avoided to maintain attenfion and language should be both contemporary and culturally appropriate.

Given these considerations, it was believed that an updated locus of control scale for children with asthma was warranted. A brief, simple scale- the Asthma Locus of Control Scale- was designed for children and young people with asthma and used in the investigation reported here.

4.2 Aims and Hypotheses

The aim of this study was to evaluate the validity and reliability of the Asthma Locus Of Control (ALOC) scale in a sample of children with asthma. The validated 'generic' Children's Health Locus of Control (GHLOG) scale (Parcel and Meyer, 1978) was used as a comparable scale against which to assess the validity of the ALOC.

Hypothesis 1- The relationship between the ALOC and CHLOC scales will be significantly positively but not highly correlated.

Hypothesis 2- Children with more internal locus of control will have better controlled asthma.

Hypothesis 3- Children's scores on the ALOC will demonstrate good test-retest reliability..

4.3 Method

4.3.1 Design

A cross- sectional survey.

4.3.2 Sampling

The sampling frame in this study was a weekly children's respiratory clinic held at an outpatients clinic at Derby Children's Hospital, East Midlands, UK. Here, one consultant sees all attendees and an asthma specialist nurse is also available. The clinic covers a wide catchment area and caters to all socio-economic groups. The data were collected over a nine- week period between October 2001 and December 2001 by a third year medical student under the supervision of the author. Ethical approval had been granted by the Derbyshire Local Ethical Research Ethics Committee (see Appendix 12 for approval letter).

4.3.3 Inclusion criteria

For inclusion into the study children had to be between 6 and 14 years of age, have doctor- diagnosed asthma and be prescribed medications to improve asthma symptoms. Children also had to speak and understand English. First referrals were excluded although they were given the opportunity to participate on subsequent visits. Children were excluded if a parent or consultant reported severe learning or behavioural difficulties.

4.3.4 Measures

4.3.4.1 CHILDREN'S ASTHMA LOCUS OF CONTROL SCALE

The Children's ALOC is a ten- item forced choice questionnaire. The respondent is asked to listen to or read a sentence and then decide whether they agree or disagree with it. They are then required to circle a tick or a cross depending on whether they agree or disagree. Two practice items serve to orientate the child prior to completing the scale. The quesfionnaire items are derived from Parcel and Meyer's *Health Locus of Control Scale* for children (Parcel and Meyer, 1978); however, they have been re- written to reflect standard UK- English phraseology. The number of items has been reduced from Parcel and Meyer's original twenty questions to ten. Most crucially, however, every item is asthma- specific. Children are asked about their beliefs regarding causes and prevention of asthma exacerbafions and about their sense of control over their symptoms. Six items are written in an internal direction and four in an external direcfion; two of the external items relate to other people's acfions and two relate to chance or luck. The scale is intended to be scored unidimensionally, so that each internally- orientated answer is awarded one point and externally oriented answers score zero. Thus, higher scores indicate a more internal orientafion. The scale can be found in Appendix 3.

4.3.4.2 CHILDREN'S HEALTH LOCUS OF CONTROL SCALE (CHLOC)

The CHOLG (Parcel and Meyer, 1978) is composed of twenty items for measuring children's health locus of control, selected by Parcel and Meyer from an original pool of thirty items. Children are asked to respond with either 'yes' or 'no' to each health- related question. As part of their validation protocol, Parcel and Meyer compared the GHLOG with the Nowicki-Strickland generalised Children's Locus of Control Scale (CLOG) (Nowicki and Strickland, 1973). They claimed that this demonstrated the construct validity of their scale- that is, that it constituted a valid measure of locus of control due to the stafisfically significant correlafion ($r= 0.50$, $p<0.01$) between relevant item scores on the two instruments. In addition, the GHLOG was reported to have a superior internal consistency coefficient ($r= 0.73$ compared with the CLOG $r= 0.63$) and both scales had similarly moderate test- retest intraclass reliability coefficients ($r= 0.62$ and $r= 0.63$ for the GHLOG and the CLOG respectively).

The GHOLC scale can be scored as a unidimensional measure to obtain a single score of internality, or used as a multidimensional scale to obtain scores for internality, chance and powerful others. The unidimensional scoring protocol has been used in this study to enable direct comparison with the ALOC, which is a more concise measure containing fewer multidimensional items and thus more appropriate for the time available. A unidimensional measure was also deemed appropriate because of the sample's broad age range. Consequently, each response in an internal direcfion scored one point and external responses scored zero. Thus, higher scores indicate a more internal locus of control. The GHLOG can be found in Appendix 4.

4.3.4.3 ASTHMA CONTROL QUESTIONNAIRE (ACQ)

The primary goal of asthma treatment is to obtain asthma control, which involves using the minimum medication to keep symptoms under control and ensuring symptoms do not affect everyday functioning or quality of life (Levy *et al,* 1997). In order to assess this control over asthma, Juniper developed a brief questionnaire which assesses day and night-time symptoms, limitafion of activities and use of bronchodilator medicafion (Juniper ef *al,* 1999). The questionnaire was intended for self- complefion by adults (17-70 years) in a clinic setting to give a measure of their asthma control over the previous week. As there is no questionnaire for assessing asthma control for children, Juniper's questionnaire for adults was adapted for complefion by the parent, with guidance from the child if necessary. It contains six questions referring to the child's asthma control over the previous week, or, if their asthma has been unrepresentative in the previous week (i.e. more severe than normal because of a cold or virus), then parents were asked to complete it for a 'typical' week, if possible. The answers were based on a Likert scale, with answers ranging from zero (never, no symptoms, etc.) to six (very severe symptoms, very limited) (see Appendix 5 for whole schedule and mark scheme). A higher score indicated poorer control, with a maximum possible score of 36.

4.3.4.4 CLINICAL MEASURES

The child's peak expiratory flow (PEF) was recorded, and expressed as a percentage of their predicted PEF score, derived using a standard formula which uses norm values taking into account height and age (Polgar and Weng, 2003).

4.3.4.5 DEMOGRAPHIC QUESTIONNAIRE

A brief demographic information questionnaire asked parents for details of the child's asthma durafion and age at onset, as well as family details and history of familial asthma.

4.4 Procedure

Children were recruited in an idenfical manner to that described in the main study (see 'Procedure' in Chapter Six). This involved firstly identifying children in the appropriate age range (i.e. between 6 and 14 years) from clinic lists in the week prior to the clinic in quesfion and sending them an informafion pack explaining the study. On visifing the clinic, both parent and child were given the opportunity to ask quesfions before parental consent and child assent were sought. As part of clinic routine nurses weighed and measured the child and assessed his/ her peak flow. Parents and children were then taken to a quiet area where the parents were asked to complete both the demographic questionnaire and the AGO, whilst their child was being interviewed by the researcher. Children completed both the ALOC scale and the GHLOG scale independently or with assistance from the researcher, as necessary. The order of presentation of the two scales was randomly assigned on each occasion. Upon complefion, children were thanked and returned to the waiting area before their usual scheduled appointment with the respiratory consultant.

One week after completing the two scales at the clinic, the parents arranged for their child to complete the ALOC scale for a second fime by telephone interview.

4.5 Assessment of Validity and Reliability

4.5.1 Face and content validity

Face validity is perhaps the most superficial form of validafion, but important nonetheless. It refers to the extent to which, *subjectively,* the instrument appears to be measuring what it purports to measure, and the relevance of the questions. Esfimates of content validity seek to establish more systematically whether the constituent questions seem appropriate to the topic in quesfion, and also whether the test as a whole is comprehensive, balanced and appropriate to the situation where it is intended for use (Bowling, 2002).

4.5.2 Criterion validity

Criterion validity can be investigated by looking at the level of agreement between the scores generated by the test itself and scores generated by an established and previously validated test (Bowling, 2002). Since the content of the ALOC was broadly based on the GHLOG (adapted with clinical advice to reflect control of asthma) which had already been validated in the appropriate age-range and been widely used in practice, the CHLOC was held to be the most appropriate benchmark for assessment of concurrent validity, which is a type of criterion validity.

4.5.3 Construct validity

Construct validity refers to the extent to which the instrument captures a certain trait or theoretical concept, in that it should correlate with variables that they should relate to (Reber, 1985; Bowling, 2002). This was assessed in this study by investigating the relafionship between locus of control scores and factors such as age and durafion of asthma. Older age and longer duration of illness would, on the basis of previous research be expected to be associated with greater internality (Battle and Rotter, 1963; Tieffenberg *et al,* 2000). Furthermore, locus of control scores should not differ on gender (Wallston *et al.*,1976; Parcel and Meyer, 1978).

4.5.4 Reliability

Test- retest reliability was assessed by calculating a coefficient for test-retest reliability, where scores from completed ALOC scales at Time 1 (in the clinic) and Time 2 (one week after clinic visit) were correlated to assess how replicable and stable the measure was (Reber, 1985; Greer, 1991). An intra-class correlation was also performed on Time 1 and Time 2 scores to assess whether the scores not only increased or decreased in similar proportions, but also that the intervals between the data points followed the same pattern. An alpha (a) coefficient (Gronbach, 1951) was calculated for internal consistency, which is a measure of the homogeneity of the items in assessing a certain dimension (Bowling, 2002). A test-retest correlation co-efficient of above 0.8 is considered desirable (Kline, 2000) whilst an internal consistency a coefficient above 0.5 is considered acceptable (Bowling, 2002).

4.6 Results

4.6.1 Analysis

Analysis was performed using SPSS version 11.0. The data were normally distributed so parametric tests were used. The probability level was set at p=0.05.

4.6.2 Characteristics of the group

4.6.2.1 RESPONSE RATES

Thirty- seven letters were sent out during the nine- week study period to children meeting the inclusion criteria. Nineteen children participated, giving a response rate of 51.4%. Four children refused (10.8%), 11 did not attend their appointment (29.7%) and 3 were missed due to time constraints (8.1%).

4.6.2.2 SAMPLE

The mean age of the participants was 9.26 years (sd= 3.18) and ranged from 6- 14 years. There were 11 males (57.9%) and the mean duration of asthma was 6.67 years (sd= 3.84). Social class was calculated using the Standard Occupational Classification (Office of Population Censuses and Surveys, 1990) and is depicted in figure 4.1.

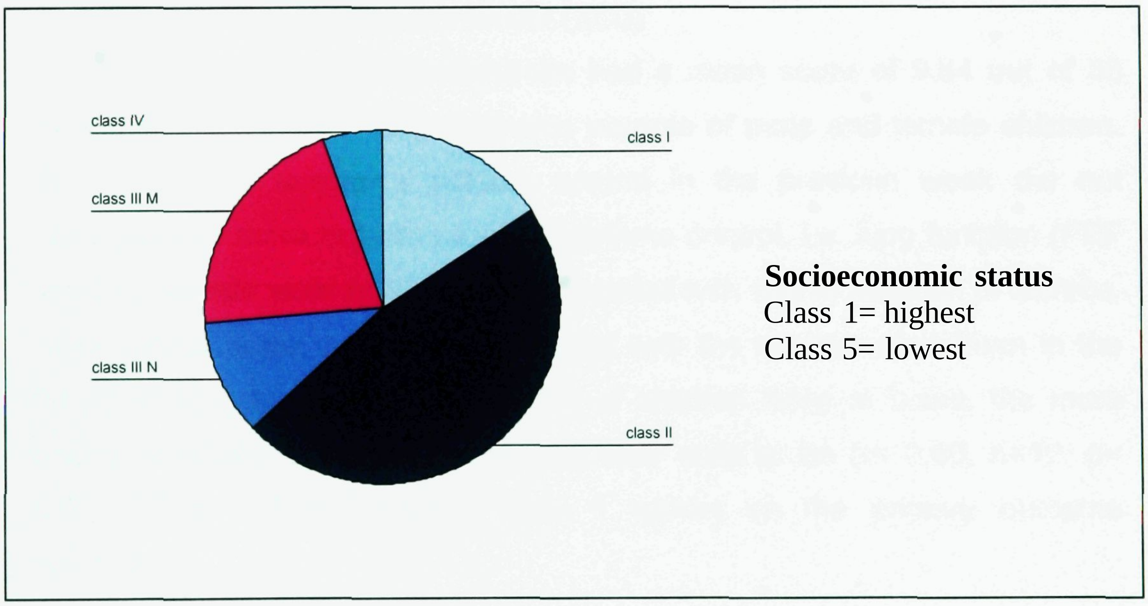


Figure 4.1- Distribution of socio-economic status in sample (n=19).

4.6.3 Characteristics of measures

4.6.3.1 ASTHMA LOCUS OF CONTROL (ALOC)

The mean ALOC score at baseline was 7.94 out of a possible 10 points (sd= 1.78). Age was significantly correlated with ALOC score, with older children scoring higher on the ALOC ($r= 0.63$, $n=19$, $p< 0.01$). Duration of asthma was not significantly correlated with ALOC scores. Neither gender nor socio-economic status affected ALOC scores.

4.6.3.2 CHILDREN'S HEALTH Locus OF CONTROL (CHLOC)

The mean GHLOG score at baseline was 12.21 out of 20 (sd= 3.68) and did not differ between males and females. GHLOG scores were significantly correlated with age (r= 0.69, n= 19, p< 0.01) as well as durafion of asthma (r= 0.46, n= 19, p< 0.05). However, when age and durafion were entered as independent variables into a linear regression model, with CHLOC scores as the dependent variable, asthma duration no longer contributed to the variance in GHLOG scores. Age explained the majority of the variance in GHLOG scores, with older children being more internally orientated (adjusted R^2= 0.44).

4.6.3.3 ASTHMA CONTROL QUESTIONNAIRE (ACQ)

This parent- completed questionnaire had a mean score of 9.84 out of 36 (sd= 8.42) and did not differ between parents of male and female children. The reports of children's asthma control in the previous week did not correlate with more objective tests of asthma control, i.e. lung funcfion (PEF scores). Neither were ACQ scores associated with age or duration of asthma. ACQ scores `were, however, associated with the number of children in the family so that the greater the number of children living at home, the more poorly controlled the parent perceived their child to be (r= 0.50, n=19, p= 0.03). Table 4.1 summarises Time 1 scores on the primary outcome measures.

4.6.4 Validity of Asthma Locus of Control measure

4.6.4.1 HYPOTHESIS 1 - THE RELATIONSHIP BETWEEN THE ALOC AND CHLOC WILL BE SIGNIFICANTLY BUT NOT HIGHLY CORRELATED

A Pearson's correlafion coefficient was calculated using ALOG and GHLOG scores, which demonstrated that they were significantly associated (r= 0.47, n= 19, p= 0.04). This was in a positive direcfion, indicafing that a child achieving high scores on one scale would be expected to score highly on the other scale (see Figure 4.2). In this case, higher scores on both scales demonstrate greater internality. The modest correlation coefficient would suggest that both scales are measuring a similar construct without replicating each other (which would produce a coefficient of 1).

Table 4.1- Time 1 scores & relationship between child characteristics and primary outcome measures.

	ALOC	CHLOC	ACQ
Mean (sd)	7.95/10(1.78)	12.21/20(3.68)	9.84/36 (8.42)
Range	3-10	6-19	0-32
Age	R= 0.63, p= 0.004	R= 0.69, p= 0.001	NS
Asthma duration	NS	R= 0.46, p=0.047	NS
Gender	NS	NS	NS
Social class	NS	NS	NS

ALOC- Asthma Locus of Control; CHLOC- Children 's Health Locus of Control; ACQ- Asthma Control Questionnaire (parent completed)

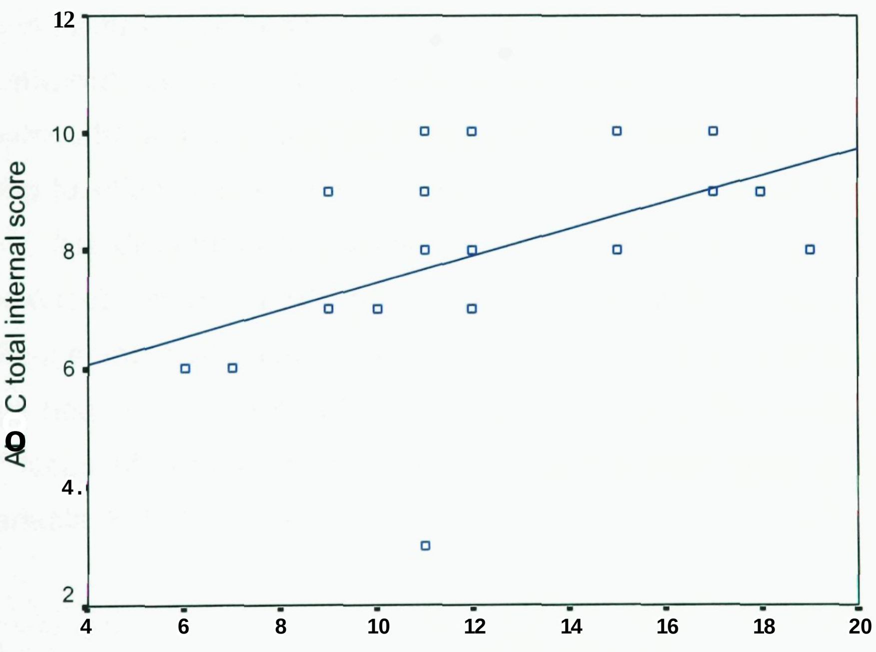


***Figure** 4.2*- Relationship between ALOC and CHLOC internal scores

4.6.4.2 HYPOTHESIS 2- CHILDREN WITH MORE INTERNAL LOCUS OF CONTROL WILL HAVE BETTER CONTROLLED ASTHMA.

Pearson's correlations were carried out with total scores for both the ALOC and the GHLOG and the child's peak flow scores. Correlation coefficients revealed that there was no significant association between either the ALOG or GHLOG scores and lung funcfion.

Scores on the parent- completed Asthma Control Questionnaire (ACQ) were not associated with either the Asthma Locus of Control scores or the Children's Health Locus of Control, showing that children's sense of control was not related to the severity of asthma as rated by parents .

Parents were also asked how severe they thought their child's asthma was on a five- point Likert scale (from 'strongly agree' to 'strongly disagree'). This correlated significantly with ACQ scores ($r= 0.46$, $n=19$, $p< 0.05$) but not with objective measures of lung function (PEF). This variable also did not correlate with either ALOG or CHLOC scores.

In order to explore further whether children who are more internal have better controlled asthma, the sample was split into two groups, represenfing 'externals' and 'internals' which were then compared for severity ratings and lung function scores. Internals were those with ALOG scores greater than 7 and this dichotomous internal- external variable was then entered as the fixed factor in an ANOVA, with age as the covariate. There was no significant effect of locus of control on the severity ratings given by parents (AGO) once age had been controlled for: $F\ (1,\ 16)= 0.12$, $p= 0.74$. Neither was an effect of locus of control found when PEF scores were used at the dependent variable: $F(1,\ 13)= 1.93$, $p= 0.19$.

4.6.4.3 HYPOTHESIS 3- CHILDREN'S SCORES ON THE ALOC WILL REMAIN STABLE OVER TIME

At Time 2, the mean ALOG score was 7.74 (sd= 1.76) which correlated highly with Time 1 ALOG scores (r= 0.81, n=19, p< 0.01), demonstrating that if a child scored highly on first testing, then they were likely to achieve a high score on the second tesfing (see figure 4.3). Time 1 GHLOG scores and Time 2 ALOG scores were also significantly associated (r= 0.70, n=19, p<0.01), indicafing that the relationship between the two measures also remained stable. The relafionship was, in fact, stronger at Time 2 which is encouraging, because the two variables were more independent than the Time 1 ALOG scores and CHLOC scores, which were obtained at the same testing session.

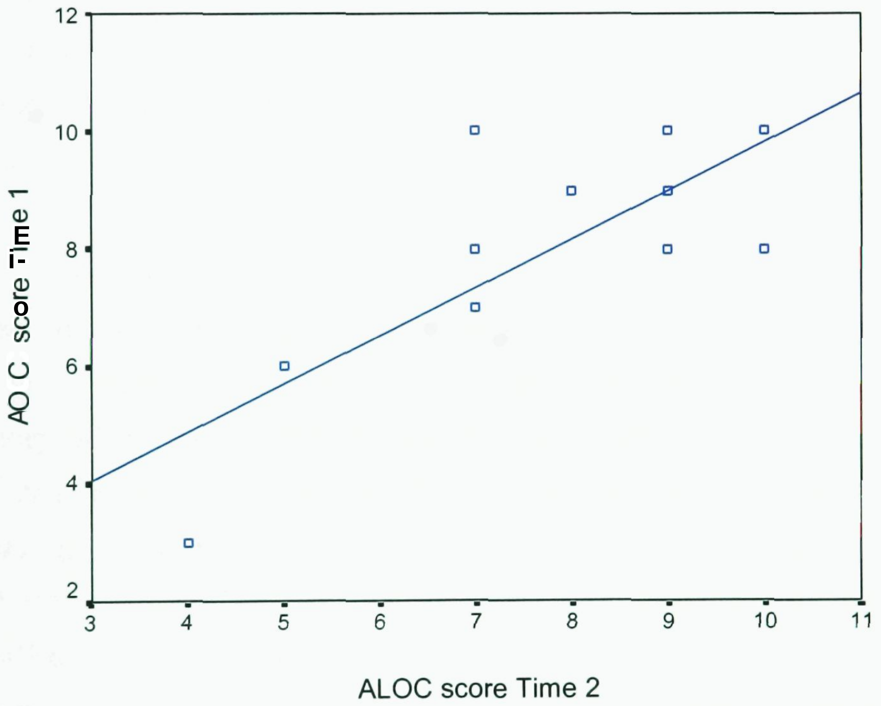


Figure 4.3- **Relationship between ALOC scores at Time 1 and Time 2**

An intraclass correlation was carried out to assess how much variance in ALOG scores could be explained by individual differences. A two- way, mixed effect model was employed, because it was assumed that the children in the study were representative of other children with asthma, but the ALOG items were deliberately written to focus on a specific topic or aspect of asthma, so only one source of variance was known (SPSS inc., 1999). 'Absolute agreement' was selected so that items could be accurately compared. The test- retest correlafion coefficient in this case was 0.90 (p< 0.01; 95% Gl= 0.74- 0.96).

4.6.5 Internal consistency

To determine the internal consistency of the ten items in the Asthma Locus of Control, Gronbach's Alpha was calculated, which was 0.61. Analysis suggested that this Alpha could be increased to 0.73 with the removal of Question 7: 7 *can choose how to look after my asthma'.*

4.7 Discussion

This study aimed to evaluate the validity and reliability of a locus of control measure designed specifically for children with asthma (ALOC), an aim which sought to consider face, content, construct and concurrent forms of validity and test- retest and internal reliability.

4.7.1 Validity

Face and content validity were assessed with reference to the time and place of administrafion and relevance of items to the children for whom it had been designed (Bowling, 2002). Project team members who are experts in the field of children's asthma deemed face validity acceptable. The tesfing context was appropriate as the children completed the measure at the asthma clinic where they were likely to be focused on their symptoms and asthma control. Furthermore, the test drew on a wide range of situations that children managing asthma are likely to face, such as whether to go to a doctor or nurse when feeling wheezy or to manage it themselves. As these kinds of decisions are key to good asthma control, it would seem vital that they are assessed directly rather than by inference from general health beliefs, as measured by the GHLOG. As far as general structure and domains, however, the items broadly matched the GHLOG and thus benefited from its validation process; for example, all of the 'internal' questions on the ALOG were interpretations of those on the GHLOG.

The *Children's Health Locus of Control* was employed to establish the concurrent validity of the ALOG. It was hypothesised that the two measures would reveal a similar pattern of findings, although the ALOC measure would be able to provide more specific information about the children's internal-external orientation relating to asthma management and associated behaviour. The findings showed that the two measures were broadly comparable- a correlation coefficient of 0.47 was produced (p= 0.04), which demonstrates moderate, yet significant associafion. Although it was necessary to show that the measures were significanfly associated, it was important that they did not correlate very highly, which would have meant that the ALOG had merely replicated the GHLOG. The ALOG measure can therefore be said to have demonstrated concurrent validity.

Construct validity was invesfigated by looking at the patterns of association between ALOG scores and other variables. The literature reports a strong relafionship between locus of control and age, whereby children tend to become more internal as they get older (Battle and Rotter, 1963; Nowicki and Strickland, 1973; Parcel and Meyer, 1978; Tieffenberg *et al,* 2000). This is consistent with developmental theories that outline how children's perception of the worid becomes more sophisticated with age, as they begin to develop awareness of self and the ways in which their actions impact upon themselves and others (Bee, 1997; Smith *et al,* 2003). The associafion between age and locus of control as measured by the ALOG was posifive and stafisfically significant, such that as children got older, they become more internally orientated. It is possible that this finding emerged simply because younger children had difficulty understanding how to complete the measure. However, the items on the ALOG were deliberately simplified from eariier scales to aid understanding and practice items were provided to help orientate the child at the start. It is important, however, for researchers using tools with children to remain vigilant to cases of possible misunderstanding which can induce inappropriate age- effects.

ALOG scores did not vary significanfly as a funcfion of gender of the child, again in accordance with previous research (Parcel and Meyer, 1978). Unlike prior studies, there was no effect of socio-economic status on ALOG scores, even though all social classes were represented in the sample (Battle and Rotter, 1963; Nowicki and Strickland, 1973; Parcel *et al,* 1980; Lau, 1982). The top two classes (Higher and Lower Managerial and Professional occupations) were predominant, however, accounfing for approximately 60% of the sample. The study also had a rather low response rate, recruiting fewer participants than anficipated. It is possible that the parents in this study who actually attended the clinic communicated a more proactive approach to their children regardless of their socio-economic status and so may not have been entirely representative. Targeting the non- attenders with lower socio-economic status is cleariy an important area but beset with difficulties.

Previous studies have found that children with more internal beliefs exercise better control over their disease (Pike ef a/., 1991; Tieffenberg *et al,* 2000) so it was expected that children with external control would exhibit evidence of more poorly managed asthma. Therefore, it was surprising that neither ALOG nor the CHLOC scores were associated with objective asthma control as measured by peak expiratory flow (PEF). This lack of association between locus of control and lung funcfion was also observed by Dupen *et al,* leading them to contend that patients' locus of control should be assessed directly because it cannot be assumed from determining asthma severity from measures of lung funcfion (Dupen *et al,* 1996). Although lung function scores *can* be a sign of asthma severity, equally they may just reflect the quality of the patient's self- management skills. Also, using a single fime- point for assessing PEF does not reflect diurnal variation, which provides greater information on the variability of lung funcfion in that individual. Finally, there was no control over children taking their inhaled medicafion before coming to the clinic, which could have had a substanfial impact on the lung funcfion scores obtained. More work comparing internals and externals may reveal more subfle differences in asthma control between the two groups, but this was hampered in the current study by the small number of participants and a bias toward internality in the sample. It may be that those who attend clinics are more likely to have an internal locus of control, for which Lau has previously found some evidence (Lau, 1982).

Assessing asthma severity proved problematic, as scores on the parent-completed Asthma Control Questionnaire were not associated with peak flow scores. However, previous researchers have noted that objective and subjective measures of children's asthma do not always correspond, for example, with nocturnal coughing (Usherwood *et al.*,1990). This complicated relationship warrants further investigation, as it is likely that interactions between severity and locus of control do exist.

The relafionship between number of children in the family and parent's severity rating suggests that either the parent's percepfions are influenced by family circumstances or that families where there is more stress are likely to have more poorly controlled asthma. It is possible that the restricted sample size in this study was insufficient to control for background factors and there was inadequate power to detect independent relafionships between locus of control and asthma severity.

It has already been stated that the measure in this study was intended for use in a unidimensional manner. Unidimensional measures have been criticised in the past (Levenson, 1974; Wallston *et al,* 1978; Parcel and Meyer, 1978) and many researchers have preferred to use a mulfidimensional approach to assessing locus of control, where external control is broken into 'powerful others' and 'chance' (e.g. (Dupen *et al,* 1996). Of course, the ALOG scale *can* be scored in a mulfidimensional manner but there are only two items each relating to 'powerful others' and 'chance' and so differentiation of external locus of control might be difficult to validate. The unidimensional locus of control scale is particularly appropriate for children over a broad age range, as in this study; as outlined in Chapter Two, a great deal of cognitive development occurs between 6 and 14 years, whereby health beliefs develop from having a somewhat 'magical' basis to the formation of beliefs that all illness is contagious before moving to a more sophisticated, psycho-physiological level of understanding (Bibace and Walsh, 1980). For the purposes of this study, it was more appropriate to treat 'external' beliefs as a single construct, against which to compare 'internal' beliefs, which are, after all, the beliefs we want to assess and promote.

Furthermore, this had the practical benefit of keeping the ALOG a brief measure that does not necessitate particular conditions or lengthy testing sessions.

In addition, Rotter himself suggested selecfing a unidimensional or multidimensional approach to assessing locus of control according to the sample being used and the specific research questions being asked, rather than using one form consistently over the other (Rotter, 1975). When conducting research with children with chronic illness, it is appropriate to use a simple, unidimensional approach to assessing locus of control, especially if evidence of change in an internal direcfion is desired. In this case, it does not seem relevant whether children become more oriented towards a 'powerful others' or 'chance' part of external control, when it is the internal orientation which is mostly under quesfion.

4.7.2 Reliability

The *Asthma Locus Of Control Scale* performed well on test- retest reliability, with a high Pearson's correlation co-efficient between scores at Time 1 and Time 2 (r= 0.81). The intraclass correlafion coefficient was also high (α= 0.90), which is particularly notable due to the stringent boundaries ('absolute agreement') applied to the reliability model. Therefore, there is considerable evidence to suggest that scores on the ALOG remain constant over time in the short term.

Internal consistency on the ALOG was moderate with a Gronbach's Alpha co-efficient of a= 0.61. It is known that children can produce lower reliability scores on locus of control measures due to a tendency in young people not to value their health as much as adults (Lau, 1982). This 'value' put on the behaviour to be reinforced is a vital component in Rotter's original concept of internal versus external locus of control (Rotter, 1954; Rotter, 1975). Asthma, however, is a central part of the lives of children attending asthma clinics and thus the argument is less applicable to illness- specific scales such as the ALOG. Item by item analysis showed that the internal consistency alpha coefficient could be substantially increased (to 0.73) if the item 7 *can choose how to look after my asthma'* was removed. This figure would then be comparable to the internal consistency reported by Parcel and Meyer for the Children's Health Locus of Control measure (a= 0.73). It seems likely that this item confused a number of the children tested, who interpreted the item as a question over their degree of choice in the medications they were *prescribed.* Rewording of the item such that it alludes to a behavioural domain potentially within their control, - e.g., 7 *can choose when to take my medications'* - may serve better as a measure of the control the children feel they have over their asthma medication. However, the item was retained for tesfing with a larger sample to confirm the finding before any rewording took place.

4.7.3 L im itations of study

The response rate in the study (51.4%) was lower than anticipated over the nine-week period and the sample had a wide age- range, which suggests caution in interpreting some of the findings. However, the sample was sufficient to examine criterion validity; the two measures (ALOG and GHLOG) showed a posifive association at a level appropriate for measures assessing similar concepts. It appeared a little small, however, to examine the relationship between asthma control and locus of control. Furthermore, the effect of illness durafion on locus of control could be scrutinised more closely with greater numbers. Although the sample came from all social groups, it is likely that they were not enfirely representative of the true spectrum of socio-economic status. A larger and more representative sample would aid invesfigation of some of the relationships between variables only hinted at in this data.

4.8 Conclusion

This study has demonstrated that the Asthma Locus of Control scale, with a little caufion, is a valid and reliable measure which could be integrated into future research seeking to assess locus of control in children with asthma.

CHAPTER 5: VALIDATION OF AN ASTHMA KNOWLEDGE QUESTIONNAIRE

5.1. Introduction

Most interventions aimed at reducing asthma morbidity in children have an educafion component at their core (Rubin *et al,* 1986; Howland *et al,* 1995; Hendricson *et al,* 1996; Bartholomew ef *al,* 2000). The benefits of improving children's knowledge about asthma include reduced fear (Rushforth, 1999), improved sense of control (Tieffenberg *et al,* 2000) and better adherence to treatment (Gebert ef *al,* 1998; Homer *et al,* 2000). Researchers have also suggested other potential benefits of educating children and parents: symptoms may become less frightening if the physiology is understood, taking medication and performing peak flows may be more acceptable if there is an understanding of what they do, and knowledge about asthma triggers may encourage avoidance of precipitating factors (Eiser *et al,* 1988; Schmidt, 2001).

Studies that have attempted to capture the true breadth and depth of children's understanding of asthma and its management have employed a range of methods, including interviews, drawings, models of body parts and role-playing (Hardwick and Bigg, 1997; Holzheimer *et al,* 1998). These studies have suggested that a number of factors may influence knowledge about illness, such as experience, which may involve direct or indirect exposure (Eiser, 1991) and IQ (Kury and Rodrigue, 1995). However, in addifion to concentrafing on general illness principles rather than illness specific knowledge, such methods are essenfially qualitative, and it is difficult therefore to establish their validity and reliability. Thus, whilst they may be useful for describing children's knowledge, they may be less effective for monitoring knowledge change or identifying those factors which shape knowledge and knowledge acquisition.

structured knowledge questionnaires with a true/ false format (e.g. the asthma questionnaire by Parcel *et al,* 1980) avoid these disadvantages and can have a high degree of reproducibility, but there is a danger that tests such as these rely on recognition, not recall of information, and so represent only surface knowledge. Furthermore, certain methodologies are not appropriate for use with a wide age-range, making it difficult to capture the development of children's understanding about their health as well as factors influencing that development.

A reliable and valid measure of asthma knowledge would be helpful not only in determining the effectiveness of educafional interventions but also in identifying children's level of expertise and their informafion needs. To date, few studies have investigated factors associated with low levels of knowledge and fewer still have described actual levels of knowledge and information gaps in children with asthma tending instead to concentrate on parental education (Fitzclarence and Henry, 1990; Ho *et al,* 2003). Those that have involved children have often adopted a rather narrow focus, for example, inhaler technique (Gleeson, 1995; Kamps *et al,* 2000). To this end we have developed the Asthma Knowledge Assessment which uses a combination of semi-structured and structured questions to provide not only a quantitative measure of knowledge about asthma and its management but also a more detailed insight into the depth of children's knowledge. Such a broad-based assessment could represent the child's true knowledge about asthma and obviate many of the difficulties encountered by previous researchers. Assessing the measure for reliability and validity before drawing conclusions, however, is paramount.

5.2 Aims and Hypotheses

The aims of the study were to develop a reliable and valid tool (the Asthma Knowledge Assessment) to measure asthma knowledge.

Hypothesis 1. The AKA will discriminate between children with asthma (expected to have high knowledge levels) and without asthma (expected to have lower knowledge levels)

Hypothesis 2. Higher scores on the Asthma Knowledge Assessment will be associated with older age and higher verbal IQ.

5.3 Method

5.3.1 Design

A cross-sectional survey of children attending asthma outpafient clinics and schools in Nottinghamshire & Derbyshire, Midlands, UK.

5.3.2 Clinics & schools

5.3.2.1 NOTTINGHAM CITY HOSPITAL

A respiratory clinic is held weekly in the children's outpatient department at Nottingham City Hospital with a consultant in paediatric respiratory medicine. A specialist asthma nurse is in attendance to review inhaler technique and provide information. A school nurse also attends (during term time), who can liaise with schools if necessary. The clinic receives referrals from primary care teams in the North and West of Nottingham. The typical weekly clinic list comprises approximately twelve pafients.

5.3.2.2 QUEEN'S MEDICAL CENTRE

Respiratory clinics are held in the children's outpatients' clinic at Queen's Medical Centre, Notfingham, under three clinicians. Children are referred from primary care teams in the South and East of Nottingham or through hospital wards, if they have been admitted via Accident and Emergency with an acute asthma attack. A specialist respiratory nurse attends the clinics to review inhaler technique and self- monitoring of symptoms. The number of children with asthma on the clinic list varies between three and ten children.

5.3.2.3 DERBY CHILDREN'S HOSPITAL

Respiratory clinics are held weekly at the outpafients clinic at Derby Children's Hospital, under one consultant with an asthma specialist nurse. There is a wide catchment area covering all socio-economic groups. Each clinic list comprises approximately 18 children.

5.3.2.4 SCHOOLS

Five schools in Nottinghamshire were approached to take part in the study, of which 2 of the 3 Junior schools (7-11years) and 1 of the 2 Comprehensive school (11-18 years) agreed. School populafions were representative of Nottinghamshire educafion standards and achieved exam grades consistent with nafional UK standards.

5.3.3 Inclusion criteria

Clinic group: The study sample consisted of children, aged 7 to 14 years, attending one of the paediatric out- pafients clinics described above. For inclusion into the study children had to have doctor- diagnosed asthma and be prescribed medicafions to improve asthma symptoms. Children also had to speak and understand English. First referrals were excluded as it was assumed that anyone attending the clinic for the first time would improve their knowledge levels, which may have distorted any effect of informafion provided during the study. These children were, however, invited to take part on subsequent visits. Children were excluded if a parent or consultant reported severe learning or behavioural difficulfies.

Comparison group: Children were required to be aged between 7 and 14 years, attending one of three participafing Nottinghamshire schools and have parental consent for participafion.

5.3.4 Measures

5.3.4.1 ASTHMA KNOWLEDGE ASSESSMENT (AKA)

The Asthma Knowledge Assessment was developed by the author, with advice from the team of medical and psychological professionals, to assess children's knowledge about asthma and its management and also to evaluate the effectiveness of a mulfimedia asthma education program (see Chapter 6). The assessment is in two parts, which use different techniques to obtain an accurate profile of the child's asthma knowledge. The full measure with scoring protocol can be found in Appendix 6 (clinic version) and Appendix 7 (school version).

Asthma Knowledge Questionnaire Part 1 (AKQ1)

Six open questions were asked about the basic physiology of asthma i.e. 'Which part of your body is affected by asthma?' 'What are the symptoms of asthma?' or (for younger children) 'How does asthma feel inside your body? The scoring was devised so that each component of a 'perfect answer' scores one mark. For example, one mark was allocated for menfioning wheezing as a symptom of asthma, one for coughing, one for breathlessness and one for tight chest. They were also asked to list as many triggers as possible. In total, the semi- structured quesfions have a maximum score of 22, with higher scores representing better knowledge.

In addifion, the clinic children were asked to describe their current inhalers (by colour) and dosage (i.e. how many puffs they took and when) and explain the inhalers' physiological action. Again, 'model answers' were written for each secfion and individual components given one mark each, i.e. for the quesfion 'how does the reliever inhaler work inside your body to make you feel better?' one point was awarded for each of the following components: 'stops wheezing', 'works quickly', 'relaxes muscles round airways'. This information was used for descriptive purposes only and not included in the Part 1 score due to the problems in assessing the informafion provided without detailed knowledge of the child's medication regime. Furthermore, as it would not be relevant to the children without asthma it would artificially inflate the scores of those with asthma.

Asthma Knowledge Questionnaire Part 2 (AKQ2)

This comprised fifteen True/ False questions capturing a broad range of asthma informafion, including treatment (e.g. 'Preventers are blue inhalers'), management (e.g. 'A peak flow meter can help to tell you when your asthma is getting bad'), and causation (e.g. 'You can catch asthma from other people'). Each correct score was worth one mark; thus a higher score represents greater knowledge.

5.3.4.2 BRITISH PICTURE VOCABULARY SCALE (BPVS)

The BPVS Version 2 (Dunn *et al,* 1997) was used in the study to assess the verbal ability of each child. The test is suitable for children aged 3- 15 years and is a norm-referenced test of hearing vocabulary for Standard English. It contains four training plates (or pages) followed by 14 sets of 12 items. Each plate/page contains 4 numbered black and white line drawings arranged in a 2x2 format, from which the child has to select the appropriate picture to match the stimulus word provided by the tester (see Appendix 8). Each set of twelve plates increases in difficulty and testing continues until the child gets eight or more incorrect out of the set of 12. The raw score is converted to an age- adjusted standardised score from which verbal IQ is calculated. It would be expected that the scores of a population would be normally distributed around a mean score of 100 with a standard deviafion of 15, which would thus illustrate average verbal IQ.

5.3.5 Procedure

5.3.5.1 CLINIC GROUP

Participants meefing the inclusion criteria were identified from clinic lists and contacted by post in the week prior to their appointment with information about the study and an invitafion to take part (Appendix 9). When they attended the clinic appointment, they were approached and initially screened for entry to the study using the above inclusion criterion. Written parental consent and verbal child assent were obtained (see Appendix 10 for consent form).

Whilst waifing to see the doctor, the child was taken to a quiet side room and made comfortable and the parent was given a form to complete: parents were asked to provide demographic details and informafion about how the child's asthma was usually managed at home, as well as the durafion of the child's asthma. The child was interviewed by the researcher who completed the Asthma Knowledge Assessment using the child's answers. Finally, a measure of the child's verbal ability was taken, using the standardised British Picture Vocabulary Scale (BPVS).

5.3.5.2 COMPARISON GROUP

Parent and child information letters (Appendix 11) were distributed to children in the appropriate age range with a slip for parents to return to school confirming consent for child participafion. Consent slips were collected 2-3 weeks after the letters had been distributed. With the school's permission, children were withdrawn from their lessons individually for approximately 15 minutes. Verbal assent from the child was obtained prior to tesfing. Children were taken to a quiet room where they were interviewed as above, using the AKA (without quesfions regarding medications on AKQ1) and the BPVS. A demographic quesfionnaire was sent home with the pupil to be returned in a freepost envelope. Parents who did not return the form within a fortnight were interviewed over the telephone. The data for the comparison group were collected by a third year medical student under the supervision of the author.

5.3.6 Eth ical cons ideration

The ethics committee at each of the participafing hospitals approved the protocol for the study. The University of Nottingham Medical School ethical committee gave ethical approval for the data collecfion in schools. All letters of approval can be found in Appendix 12.

5.3.7 Assessment of validity and reliability

5.3.7.1 FACE & CONTENT VALIDITY

Items for inclusion in the Asthma Knowledge Assessment were reviewed for content validity by a consultant in paediatric respiratory medicine and an experienced asthma nurse. Face validity, the extent to which the measure appears to measure what it is supposed to measure, was also assessed.

5.3.7.2 CONSTRUCT VALIDITY

Construct validity, the extent to which a test correlates with related variables (Bowling, 2002), was assessed by examining the relafionship between knowledge levels as measured by the AKA and age, verbal ability, gender and, for the clinic sample, durafion of asthma. These findings would then be compared with previously published work. Discriminant validity was established by assessing the extent to which the questionnaire disfinguished between people with expected high and low knowledge levels

5.3.7.3 CRITERION VALIDITY

Criterion validity, the extent to which two measures administered at the same time relate to each other is commonly assessed by comparing a new measure with an exisfing 'gold standard' (Bowling, 2002). The AKA was developed due to a lack of valid knowledge assessments for children with asthma and thus, a 'gold standard' was unavailable. In this study, a correlation was calculated using scores on the two parts of the assessment (AKQ1 &AKQ2).

5.3.7.4 RELIABILITY

Internal consistency - the extent to which people answer questions in a consistent manner- was assessed for the true/ false secfion by calculating a Gronbach's alpha co-efficient (a). To assess inter- rater reliability for scoring the semi- structured quesfions (Part 1), a second assessor independently scored a random selecfion of completed questionnaires (10% of all cases) using a proforma devised by the primary researcher. Kappa (K) values were then calculated to assess the agreement between the two sets of answers. In addifion, a small selection of interviews with the children was audiotaped. The independent marker then completed a questionnaire using the children's answers and scored the answers, again with the proforma.

5.4 Results

5.4.1 Response rates & sample characteristics

In the clinic populafion, letters were sent to 192 children in the appropriate age range. One hundred and sixty three were eligible using the above inclusion criteria, out of which 101 children took part in the study (61.9%). Twenty-one (12.9%) children did not attend their appointment, 19 (11.6%) refused to take part and 17 (10.4%) children were missed due to fime constraints in the clinic.

In the comparison group, 960 letters were sent to parents of children in the appropriate age range, of which 235 (24.5%) were returned providing consent. Twenty-five children from the two Junior schools and 50 children from the Comprehensive school were selected using random stratified sampling using year and age group. Out of these hundred children, nineteen respondents indicated that their child was treated for asthma by their GP and four did not return the demographic quesfionnaire so no details were available on their asthma status. These 23 participants have been excluded from this analysis, leaving 77 children in the comparison group. This provided a total sample of 178 participants.

5.4.2 Analysis

Data were analysed using SPSS for windows Version 11. Data for duration of asthma were normally distributed although data for age, BPVS, Part 1 and Part 2 knowledge scores were not normally distributed, so non- parametric tests were employed.

5.4.3 Sample characteristics

In total, the children that took part had a median age of 10 years (range 6-14 years[1]). Eighty- five (47.9%) were male and 93 (52.2%) were female. There were no differences between the three clinics or hospital/ school groups in terms of age or gender. The mean length of fime since being diagnosed with asthma was 7 years (sd= 3.4), and this did not differ significanfly between clinics. The mean verbal IQ for the sample was 102.7 (sd= 15.14) and again, there were no differences between clinics or groups. Table 5.1 displays the characteristics of the two groups. Social class was calculated using Standard Occupational Classification 2000 manual (Office of National Statistics, 2000) and banded into three groups: there were no differences between the groups. Figure 5.1 shows the social class for the whole sample.

Table 5.1- Characteristics of sample by group

	Schools N=77	**Clinics** N=101	**Total** N=178
Gender (%)	31 (40.3) male	**54** (53.5) male	85 (47.9%) male
Median age (range)	11 (7-14)	**10** (6-14)	10(6-14)
BPVS (sd)	103.3(14.8)	102.1 (15.5)	102.7(15.14)

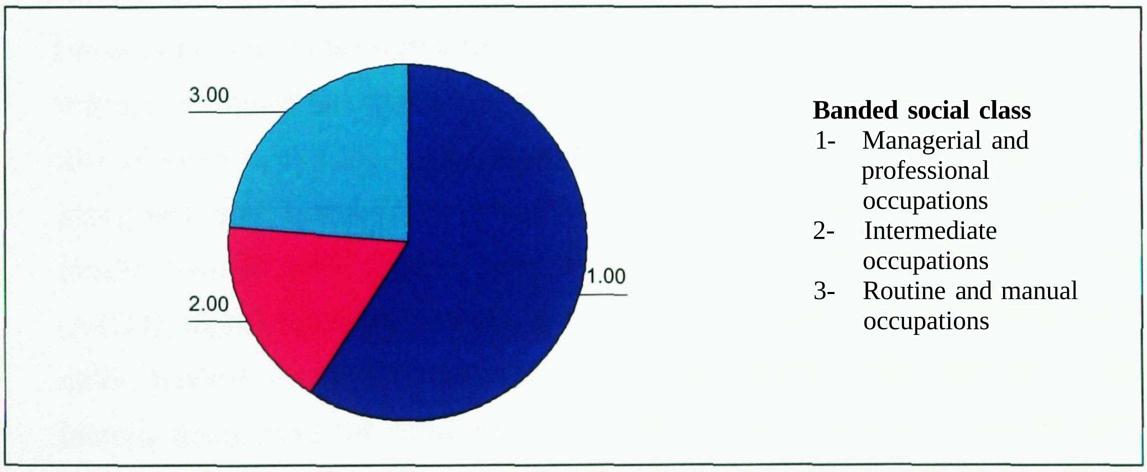


Figure 5.1- Socioeconomic status of sample (n= 169)

[1] One rising 7 year old girl was mistakenly included in the sample, although her data are included in the analysis as her verbal age was equivalent to 8 years and 8 months and she did not appear to demonstrate any more difficulties than the seven year olds in the sample.

5.4.4 Validity

5.4.4.1 Construct validity

Age and verbal ability both correlated significantly with knowledge levels such that older children and those with higher verbal IQ levels had higher knowledge scores on AKQ1 and AKQ2. Gender did not relate to knowledge scores. Having a family member with asthma contributed to higher knowledge scores on Part 1 but not Part 2 (see Table 5.2).

Table 5.2- Relationship between knowledge scores and four factors

Factor	AKQl score	AKQ2 score
Age (n=178)	R= 0.44**	R=0.50**
Verbal IQ (n=175)	R= 0.20*	R= 0.24**
Family member with asthma (n= 17 8)	U=2544.0**	U=3526.0
Gender (n= 178)	U=3664.5	U= 3528

* Significant at the 0.01 level
** Significant at the 0.001 level

As age, BPVS score and having a family member with asthma all contributed towards higher knowledge scores, the variables were entered into a stepwise regression model to determine which contributed most strongly. This showed that whether or not the child had asthma strongly affected knowledge scores along with age, followed by verbal IQ. In the case of Part 1 scores, having a family member with asthma also played a part. For the qualitative scores (AKQ1), higher knowledge levels were associated with having asthma, being older, having a higher IQ and having a family member with asthma. These factors accounted for approximately 60% of the variance in scores (See Table 5.3).

Table 5.3- Regression analysis of factors contributing to Part 1 and Part 2 AKQ scores

	Cumulative adjusted R square	Beta	t	Sig
Part 1: Qualitative Knowledge Score				
Asthma group	0.271	0.554	10.80	0.000
Age	0.540	0.527	10.93	0.000
Verbal IQ	0.593	0.246	5.097	0.000
Family Member with Asthma	0.602	0.114	2.228	0.027
Part 2: True/False Knowledge Score				
Age	0.252	0.548	9.284	0.000
Asthma group	0.328	0.296	9.284	0.000
Verbal IQ	0.403	0.279	4.747	0.000

Scores on the knowledge quesfionnaire were calculated so that comparisons between the 'novice' and 'expert' groups could be made.

The group to which a participant belonged (asthma/ no asthma) had a significant effect on both Part 1 (Mann Whitney U= 1494.50, p< 0.001) and Part 2 (Mann Whitney U= 2958.50, P< 0.01) knowledge scores, such that those with asthma had higher knowledge levels than those without asthma (See Table 5.4).

5.4.4.2 Criterion validity

Scores on the two parts of the assessment were highly correlated with each other (n= 178, r= 0.54, p=0.000) indicafing that they were measuring similar concepts i.e. children who scored highly on one part of the assessment could be expected to score highly on the other part of the assessment.

Table 5.4- Knowledge scores between groups

Group	N	AKQ Part 1 Median	AKQ Part 1 Range	AKQ Part 2 Median	AKQ Part 2 Range
No asthma (schools)	**77**	**4**	**0-9**	**11**	**6-15**
Clinic treated asthma	**101**	**6**	2-12	**12**	**7-15**
Whole sample	**178**	**5**	0-12	**11**	**6-15**

5.4.5 Reliability

A Gronbach's Alpha co-efficient was calculated for Part 2 questions to measure how consistently the participants were answering. For all fifteen quesfions, the Alpha co-efficient was 0.503. The analysis indicated that the removal of three quesfions (Quesfions 10, 13 and 14) could increase this co-efficient to 0.57.

Agreement between scorers was calculated for individual item agreement (K=0.93) and total score agreement (intra-class correlation= 0.96).

5.4.6 What do children know about asthma?

Having established that the AKA was a valid and reliable tool for assessing children's asthma knowledge, the knowledge levels could be examined in more detail.

5.4.6.1 CLINIC SAMPLE

Ninety-four children (93.1%) knew that the lungs and/or chest were affected by asthma, although only 6 (5.9%) stated that airways (or 'pipes'/ 'tubes') were affected. Roughly half the sample recalled that breathlessness (47.5%) was a symptom of asthma, whereas wheezing was menfioned by 42 (41.6%) children and 59 (58.4%) named coughing. However, 93 (92.1%) were able to list at least one of the above symptoms.

When asked to list as many triggers as possible, the median number named was 2 (range 0-5). Activity/exercise was the most cited trigger (62.4% children), followed by animal fur (31.7% children).

The effect of asthma duration was invesfigated for children in the clinic sample, which was shown to correlate with scores on Part 2 (n=101, r= 0.24 p= 0.02) but not Part 1 (n=101, r= 0.20, p= 0.50) of the AKA. As age correlated with knowledge scores and could be a potential confounder, a stepwise regression was performed using Part 2 knowledge scores as the dependent variable and age and durafion as independent variables. Once age had been accounted for, durafion did not contribute towards variance in knowledge scores.

5.4.6.2 SCHOOL SAMPLE

As highlighted before, children in the school sample scored significantly lower than the children from the clinic sample in both Part 1 and Part 2 of the quesfionnaire. Although 72.7% named lungs/ chest as being affected, only one respondent named the airways as being involved in asthma. The majority (71.4%) were able to name at least one symptom of asthma, although the median number of triggers named was 1, none naming more than three triggers.

5.5 Discussion

This study sought to establish the validity and reliability of a measure of asthma knowledge, the Asthma Knowledge Assessment (AKA). The discriminatory power of the measure was tested by involving children being treated for asthma in an outpatient respiratory clinic who were expected to have high levels of knowledge and healthy school children who were not expected to know very much about asthma.

5.5.1 Validity

Content validity was confirmed by healthcare professionals experienced in paediatric respiratory conditions; they confirmed that the assessment encompassed the range of topics that children between 7 and 14 years should know in order to look after their asthma adequately and that the test did not emphasise one area over another. Face validity, perhaps the crudest form of validity, was confirmed by the children's ability to complete the test, as well as the verbal feedback received by the researchers and the opinion of experts in the area.

The Asthma Knowledge Assessment demonstrated construct validity as the relationship between knowledge levels and several other factors concurred with previous work; older children obtained higher knowledge scores (Eiser *et al,* 1984; Gharman and Ghandiramani, 1995) as did children with higher IQ (Kury and Rodrigue, 1995). Gender did not have an effect on knowledge levels, which is also consistent with previous work (Krishnan *et al,* 1998). It was interesting to note that *any* asthma experience contributed to higher scores, whether personally or in the wider family. Clearly the influence of 'experience' in its many forms on knowledge needs to be researched further.

Discriminant validity of the measure was suggested since those who might be expected to have low asthma knowledge (children without asthma) achieved significantly lower scores (almost 10% difference on Part 1) than those who would be expected to know more about asthma (children from the asthma clinic). Despite the statistical difference, however, the groups' scores differed by a small number of items- two items for Part 1 and one item for Part 2. It is likely that this was because of the aforementioned low levels of knowledge as assessed by Part 1 and a 'ceiling' effect on the true/ false section of the questionnaire. However, more work needs to invesfigate how clinically meaningful these small differences are to establish true discriminant validity.

The two parts of the assessment correlated strongly suggesting that the two parts of the AKA were measuring similar concepts, thus demonstrafing concurrent validity. It was not possible, however, to compare the AKA with an established measure of asthma knowledge due to the lack of an existing measure, which had prompted the development of the AKA originally.

Some previous researchers have used judgement analysis as a method of assessing knowledge- for example, **Kolbe** and colleagues provided their adult asthma patients with two scenarios describing an evolving asthma attack- one where the severity gradually increased and one where the exacerbation developed rapidly. Pafients' responses to the scenarios were then rated as an indication of their pracfical knowledge (Kolbe *et al* 1996). The AKA did include a section which asked children with asthma what they would do in the event of a low peak flow score and worsening symptoms. However, responses to this situation were minimal- very few children were able to suggest a course of action and those who did commonly stated that they would tell their parents. This may be meaningful informafion in understanding what responsibility children take for their asthma management. However, it does not provide the breadth of informafion that using an instrument such as the AKA can provide. Whilst, this form of appraisal can increase the relevance of the assessment for children, it can also be reliant on the confidence of the child.

5.5.2 Reliability

The Gronbach's Alpha co-efficient calculated to determine the internal consistency of the questionnaire was above 0.50 which is taken as an indicator of good internal consistency although others regard 0.70 as the minimum acceptable level (see Bowling, 2002). However, "...a low co-efficient alpha indicates that the item(s) does not belong to the same conceptual domain" (Bowling, 2002; p149) **not** that the measure lacks validity as a whole. As menfioned in the Methodology section, we designed the assessment to cover several domains, and thus the children were being tested on different types of knowledge which may not necessarily be consistent with each other. Previous studies have also demonstrated that knowledge is not a single, unified dimension (Ho ef *al,* 2003).

The Gronbach's alpha co-efficient could be increased with the removal of three questions but would reduce the scope of the questionnaire considerably. The agreement of scorers on both individual items and total scores for Part 1 (semi- structured questions) was high, suggesting that the marking criteria can be applied consistenfiy and therefore can be used reliably in other studies.

5.5.3 Knowledge levels in clinic & school populations

Knowledge levels in school children were extremely low suggesting a need for educafion. Most children will come into contact with peers with asthma given that it is the most common childhood condition in Britain (Department of Health, 2000). Therefore, it is advantageous to provide asthma education for all pupils: information on triggers that exacerbate asthma and what to do in an emergency would be particularly useful and potenfially life- saving. Although children with asthma scored higher than those without the illness, they still demonstrated rather low levels of knowledge, especially when asked to recall facts, which has previously been reported (Eiser *et al,* 1988). Most children with asthma (93%) did, however, know that their lungs and/or chest was affected by asthma, which is higher than previously reported (Gleeson, 1995).

Knowledge levels increased when complefing the true/ false section which would suggest that testing knowledge solely with structured formats requiring only recognition may provide artificially high scores and fail to identify informafion gaps. Although, for this reason, the true/false scale may be not be as useful Part 1 in identifying children's information needs, it is quick to complete and easy to score. The true/false scale may therefore be a useful research tool to assess the effectiveness of educational interventions or to evaluate factors associated with low levels of knowledge.

It was notable that longer duration of asthma did not significantly contribute to higher knowledge scores. Previous studies invesfigafing the role of illness experience and understanding of illness concepts have reported mixed findings, although most have concentrated upon comparing 'experts' (someone with a chronic illness) and 'novices' (someone without that illness) on understanding of **general** illness concepts (Eiser *et al,* 1988; Crisp *et al.,* 1996) rather than the effect of illness duration on illness- specific knowledge. The fact that longer duration of illness and, therefore by inference, more exposure to asthma information from paediatric services, does not confer an independent advantage in terms of knowledge is of some concern. It may reflect assumptions by health professionals that children with long- standing illness are likely to have fewer information needs. The importance of confinued educational support for children who have had asthma for a long period of fime must, therefore, be emphasised.

5.6 Conclusion

This study has striven to design and utilise measures which are sensitive enough to detect small but significant differences in children's asthma knowledge, thus providing a detailed view of the factors which influence that knowledge.

CHAPTER 6: RANDOMISED CONTROLLED TRIAL OF A MULTIMEDIA INTERVENTION FOR CHILDREN WITH ASTHMA

6.1 Introduction

This chapter will attempt to draw the literature together from the previous review chapters and outline the rationale for this thesis. The study's aims and objectives will then be stated, the methodology described and results presented. A discussion of the main findings will then follow.

The literature is clear that childhood asthma is a widespread problem, represenfing a substanfial proportion of medical illness in industrialised countries, especially the UK. Asthma symptoms and treatments can limit children's activities and cause school absence, as well as cause stress and anxiety in the whole family.

Despite the considerable burden experienced by some people with asthma, monitoring and responding to symptoms and fluctuations in lung funcfion (termed 'self- management') can result in good asthma control in the majority of cases. Written 'self- management plans' are of particular help, providing the patient with clear instructions about what to do in the event of an exacerbafion, which can be tailored to their particular needs. However, compliance with these plans is often poor.

Educafional programmes using a variety of methods, have been developed since the 1940's although there has been a particular surge in the last 10-15 years; a recent systematic review concluded that there is sufficient evidence to believe that educational programmes for children with asthma do result in improved outcomes, both medical and psychological. Despite this work, the information needs of children with asthma remain largely unknown. The use of multimedia in health education programmes is becoming more mainstream, but few programs have been thoroughly evaluated to determine their efficacy in improving knowledge and other psychological outcomes. This chapter describes the development of a multimedia program for children with asthma and the evaluation of its impact on asthma outcomes as evaluated by a randomised, controlled trial.

6.2 Aims and hypotheses

The hypotheses for this current study were drawn from the literature where possible, but some were of an exploratory nature. This study had three main aims, under which the hypotheses were drawn;

Aim 1. To invesfigate knowledge levels in children with asthma.

Aim 2. To invesfigate factors associated with higher knowledge levels and successful self- management.

Hypothesis 1. Greater knowledge will be associated with older age and higher verbal IQ but not longer durafion of asthma.

Hypothesis 2. Those with a more internal locus of control will have higher knowledge levels.

Hypothesis 3. Those with better control of their asthma will have a more internal locus of control.

Aim 3. To investigate the impact of an educational CD-ROM and written informafion on knowledge levels, locus of control and clinical outcomes of children with asthma.

Hypothesis 1. Children using the CD-ROM will have greater knowledge increases than those viewing only the booklet.

Hypothesis 2. Children using the CD-ROM will show a greater increase in internal locus of control than those viewing the booklet.

Hypothesis 3. Children using the CD-ROM will demonstrate a greater increase in responsibility for monitoring and responding to asthma symptoms than those viewing the booklet.

Hypothesis 4. Children using the CD-ROM will demonstrate increased control over their asthma.

Aim 4. To invesfigate the acceptability of an educational CD-ROM to users.

6.3 Methodology

6.3.1 Design

A randomised, controlled trial with measures at baseline, one month and six month follow- up.

6.3.2 Clinics

The participating respiratory clinics were the same as for Chapter Five, comprising two Nottinghamshire respiratory outpafient clinics and one Derbyshire clinic. Ethical approval had been granted from all three hospital ethical committees (Appendix 12).

6.3.3 Inclusion criteria

The inclusion criteria were;

- aged 7 to 14 years
- have doctor diagnosed asthma
- be taking treatments for asthma
- speak and understand English.

Children were excluded if it was their first visit to the clinic or if a parent or consultant reported severe learning or behavioural difficulties.

6.3.4 Sample size

To reliably demonstrate a 0.5 SD difference in knowledge scores, a minimum group size of 50 was needed ($p<0.05$, power= 0.80). It was estimated that the target of 100 participants (in total) within one year was feasible.

6.3.5 Measures

6.3.5.1 ASTHMA KNOWLEDGE ASSESSMENT (AKA)

Due to the lack of suitable measures to assess knowledge, the Asthma Knowledge Assessment was developed particulariy for this study, which is detailed in Chapter Five (see scale in Appendix 6). To summarise, the aim was to assess children's knowledge about asthma and its management which would also help evaluate the effectiveness of the mulfimedia asthma educafion program. The assessment, which is in two parts, uses a range of techniques in order to obtain an accurate profile of the child's asthma knowledge.

Asthma Knowledge Questionnaire Part 1 (AKQl)

- Six open questions about the basic physiology of asthma
- Name as many triggers as possible
- Maximum score 22 points
- In addifion, describe the inhalers used & doses/ frequency/ action.

Asthma Knowledge Questionnaire Part 2 (AKQ2)

- Fifteen True/ False questions
- 3 different content domains (treatment, management & causation)
- Maximum score 15 points.

6.3.5.2 PARENTAL DEMOGRAPHIC AND KNOWLEDGE QUESTIONNAIRE (PDKQ)

This quesfionnaire had two funcfions. Firstly, it was used to obtain demographic details, such as age, gender and ethnicity of the child and parental age. Parental occupation was used as an indicator of socioeconomic status. Information covering family history of asthma, length of time since diagnosis and days off school due to asthma in the previous month was also collected. Parents were asked to give details about their child's medication and list their asthma triggers along with any measures they took to counter/ prevent them.

The second part of the quesfionnaire assessed how knowledgeable parents were about asthma management and acfing in an emergency. Six brief scenarios were provided, requiring the parent to indicate which would prompt them to seek urgent medical help. Three of the six scenarios were judged by a clinician to warrant emergency medical help;

- Child has blue lips
- Child not able to talk
- Peak flow below 50% (of best peak flow).

The three remaining scenarios were judged to require monitoring, but not immediate medical help;

- First puff of reliever not helping
- Child feeling unwell, peak flow above 75% but below best peak flow
- Peak flow falls below 75% but returns above 75%.

The parent received one mark per correct response to the scenarios, with a maximum of 6 marks.

The quesfionnaire contained a further eight quesfions assessing asthma knowledge, covering basic physiology, symptoms and triggers of asthma, requiring either a 'true', 'false' or 'don't know' response. The scores were coded so that one mark was allocated for every correct answer, with both incorrect and 'don't know' responses scoring zero. The maximum was eight marks with a higher score representing higher knowledge.

Because these two parts measuring parent knowledge were fairiy brief, the two scores were combined to give a total score out of 14 which became the parent knowledge score. A higher score indicated a higher level of knowledge.

It was hoped that the computer program would promote greater responsibility for asthma management on the part of the child so, in order to assess how much responsibility the child took for their asthma already and to measure any change, the parents were presented with a grid which presented different aspects of asthma management;

- Measuring peak flow
- Completing a peak flow diary
- Taking daily preventer and reliever medication
- Following a self- management plan
- Altering medication doses when necessary
- Reducing triggers in the home

They then had a range of five choices from 'parent/ adult mostly responsible' to 'child mostly responsible' with varying degrees in between to indicate how much responsibility their child took for each aspect. A copy of the *PDKQ* is in Appendix 13.

A version of the questionnaire was used at follow-up, which contained the same questions but omitted the demographic details. It also contained a section which asked about marked exacerbations (or improvements) of asthma in the preceding month and how they had been managed, for example, if inhaler doses were increased or oral steroids required. A short section asked about whether the child had used the information since they had received it (in both computer and booklet groups) and whether the parent felt it was appropriate and acceptable for their child.

6.3.5.3 ASTHMA CONTROL QUESTIONNAIRE (ACQ)

Parents were asked to complete this six- item measure indicafing the level of asthma control their child had demonstrated over the previous week. The minimum score on the Asthma Control Quesfionnaire was zero, which would indicate no asthma symptoms or limitafions at all i.e. very well controlled asthma. A maximum score of 36 would indicate very poorly controlled asthma. A full descripfion of the measure can be found in Chapter Four and the measure itself in Appendix 5.

6.3.5.4 ASTHMA LOCUS OF CONTROL (ALOC)

This was a 10- item, forced choice questionnaire where children agreed or disagreed with statements concerning how much control they felt they had over their asthma management. The ALOG score was calculated on a unidimensional basis by scoring one point for every answer demonstrafing internality. Therefore, a higher score indicated that the person had a more internal locus of control, and if lower, more external. The development of the children's asthma locus of control measure used in this study has been described in detail in Chapter Four and can be found in Appendix 3.

6.3.5.5 BRITISH PICTURE VOCABULARY SCALE (BPVS)

The BPVS Version 2 (Dunn *et al,* 1997) was used in the study to assess the verbal ability of each child. Readers are referred to Chapter Five for a full description. The measure can be found in Appendix 8.

6.3.5.6 CLINICAL OUTCOME MEASURES

The primary clinical outcome for the study was lung funcfion, an increase in which would indicate that self- management had improved. This was measured by Forced Expiratory Volume in the first second (FEV_1) and Peak Expiratory Flow (PEF). The fonner was measured using a Micromedical Super- Spiro spirometer using the child incentive where possible. The child incentive opfion uses a picture of a boy with some bubble gum, which he blows into a bubble when the child blows into the mouthpiece of the spirometer. The user's name, date of birth, height and ethnic origin are used to calculate what the user should be ideally achieving (their 'predicted' score). If the child achieves 90% of his or her predicted score, the bubble will burst. On subsequent manoeuvres, the bubble will burst only if the child blows 105% of their previous best, thus motivafing the child to blow as hard as possible. Ideally, the child should perform the manoeuvre three fimes and the best FEV_1 score out of the three manoeuvres recorded. Peak Expiratory Flow (PEF), which measures how hard a person can expire, was assessed using a standard Mini- Wright peak flow meter, with the best of three scores recorded. This score was then expressed as a percentage of their predicted PEF score (i.e. 100% would be ideal), derived using a standard formula taking into account gender and height (Polgar and Weng, 2003). This gave an indicafion of their current lung funcfion.

Use of medication was also assessed as a measure of self-management. Good management of asthma is usually indicated by taking the lowest possible level of medicafion whilst maintaining good lung funcfion, indicated by absence of symptoms and minimum impact on quality of life. Thus, a reduction in medication whilst maintaining adequate lung funcfion would indicate an improvement in asthma control. The details of the children's medications were obtained from both child and parent at recruitment (Time 1) and one- month follow-up (Time 2), although the accuracy of their self- report was not independenfiy verified.

Other 'proxy' measures of self- management were also used, namely, the number of days off school due to asthma and how many courses of oral steroids had been needed in the previous month. High numbers of either would indicate that recent asthma management had been sub-optimal.

6.3.5.7 PARENT TELEPHONE INTERVIEW SCHEDULE (SIX- MONTH FOLLOW-UP)

A brief form was designed for completion over the telephone to record significant events relafing to the child's asthma in the six months since receiving the booklet or CD-ROM. Events questioned about were hospital admissions, unscheduled visits to the hospital consultant or General Practitioner and use of oral steroids. An estimate of the number of days taken off school due to asthma in the previous six months was also recorded. See Appendix 14 for schedule.

6.3.5.8 CD-ROM EVALUATION FORM

A crucial part of the development of a new computer program is that end users find it acceptable and easy to use. As the CD-ROM was in the beta testing phase when it was used in the study, feedback was sought from the children who used it. Originally, open ended questions were used in an attempt to obtain more qualitative feedback, but it became clear that the children did not find it very easy to spontaneously critique different aspects of the program. The more prescriptive evaluation form was introduced a short time into the study to remedy this. It required children to indicate if they agreed or disagreed with sentences about the program. The sentences referred to both the program's content and its usability (e.g. navigation). Examples of sentences were;

- Looking at The Asthma Files was a waste of time
- I know more about my asthma now I've looked at The Asthma Files
- There should be more interactive bits in the program.

Children were also asked to describe the sections they found most useful and those which were less helpful, in addition to any parts they particulariy enjoyed or disliked. They were encouraged to be honest and were assured that *all* comments about the computer program would be of use, both positive and negative. This informafion was collated and used to inform the final version of the CD-ROM for general release. The full form can be found in Appendix 15.

6.4 Information provided

6.4.1 Development of an educational CD-ROM for asthma

Since 1996, teams from the Section of Behavioural Sciences at the University of Nottingham and Paediatric Outpafients department at Nottingham City Hospital have collaborated to produce educational computer packages for childhood health problems such as diabetes and nocturnal enuresis (bedwetting). These were well received by children visifing the clinic at City Hospital and staff working in the respiratory clinic felt that an educafional program aimed at children with asthma may also be beneficial. The aim was to complement exisfing educafion- in the form of an asthma nurse and leaflets- with an interactive computer package that would attract and motivate children to find out more about their condifion.

The choice of 'theme' for the package was considered very carefully. Appealing to a wide age-range was vital; thus, images commonly used in paediatrics were dismissed, for example, spacemen and cartoon animals, to avoid patronising the older users. After extensive discussions, the theme for the multimedia package deemed most appropriate was that of a 'secret agent' gathering information about asthma and its management. Users would be encouraged to independently explore the package and use problem solving skills, which foster the ability to extract relevant material from broader information and apply it meaningfully (Oliver and Perzylo, 1994).

The first draft of a 'script' covering information felt to be most important to asthma management was written by the group members, which comprised a consultant respiratory paediatrician, an asthma nurse, a GP with an interest in childhood asthma and two behavioural scienfists, including the author. The software developers came from Showme Multimedia Ltd., who had considerable experience producing health education mulfimedia packages for both children and adults.

The information that the program contained was organised into eight secfions;

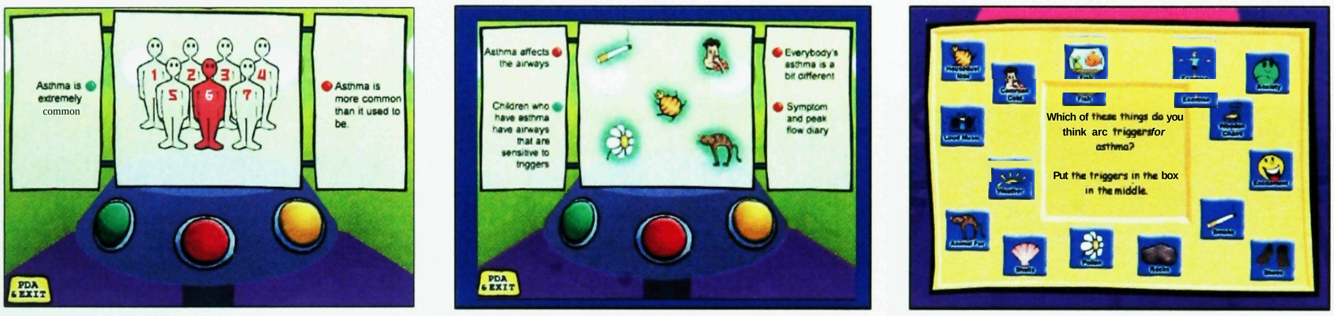
1. *What is asthma?*
2. *What happens inside the body when you have asthma?*
3. *What does it feel like to have asthma?*
4. *What triggers asthma?*
5. *What treatments are **there for**asthma?*
6. *How to use an inhaler.*
7. *How to manage asthma.*
8. *How to cope with an asthma attack.*

Each section of information became a 'room' within an 'asthma research facility' which could be explored. The first script contained preliminary storyboards for different screens and ideas for interacfions. This was shown at a meefing with the National Asthma Campaign, who were happy to be cited as having provided advice during the development of the program.

It was vital that the package was piloted whilst being developed, to ensure that the final version was acceptable and effective for users. The author was responsible for the pilot work which informed the development of the program. The following is an account of the CD-ROM development over the period of a year.

Months 1-2

The first version of the graphics were produced for sections one (What is asthma?) and four (What triggers asthma?) Figure 6.1 shows 'screenshots' from these rooms.



(a) (b) (c)

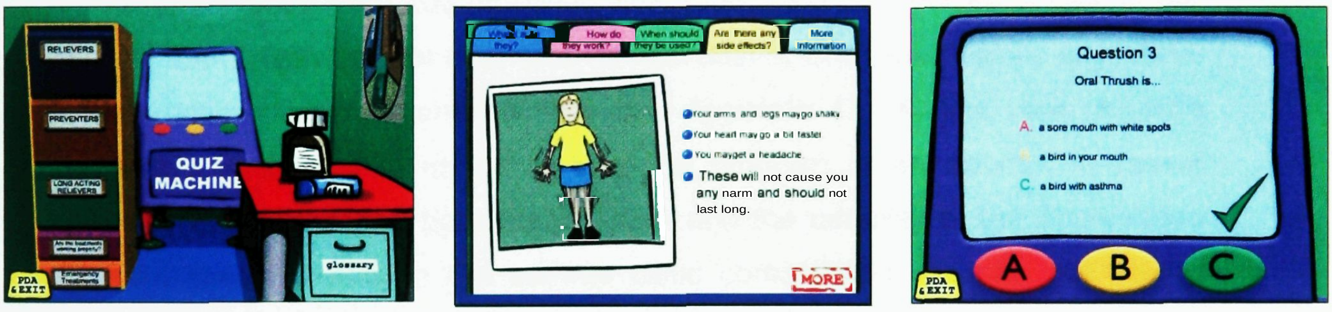
Figure 6.1 - **(a)** & **(b)** Screenshots taken from Room 1 'What is asthma?' where brief information is provided when button is selected. (c) Room 4 ('Triggers') contains the 'trigger board' where children have to select potential triggers and 'drag' them into the box in the middle. They can then indicate which are their own triggers.

The team planned to pilot the program with a small number of children of varying ages, both with and without asthma. Through this, the ease with which the program was used could be observed i.e. whether it was targeted at an appropriate age group and whether the information was generally accessible. Ethical approval was sought from Nottingham City Hospital ethics committee for this work (approval letter is in Appendix 16). There was some discussion regarding how to assess and evaluate the pilot work; video- taping the computer screen was considered although this would give one-dimensional data solely on navigation which would neglect the satisfaction of the user and how much assistance they had required. Furthermore, simply measuring time spent on different sections of the program would not have given a realistic picture of usage, as different interactions were designed to require varying levels of input in order to retain interest.

Temporary sound for the first sections of the program was recorded and the program was loaded onto a laptop computer for easy transportation to clinics and homes for testing.

Months 3-4

Preliminary versions of section five (What treatments are there for asthma? Figure 6.2) and section six (How to use an inhaler, Figure 6.3) were finished and added to sections one and four on the laptop computer.



(a) (b) (c)

Figure 6.2- (a) Inside the Treatment room. This room was substantially redesigned as a result of pilot work (updated screen shown) (b) A file taken from the treatment room. Each type of treatment (i.e. reliever, preventer etc.) has its own file. Children can select level of information. (c) A screen fi-om the multiple choice quiz machine which was very popular- children used it repeatedly in an effort to improve their score.

Interactions demonstrated complex tasks, such as taking reliever correctly or performing a peak flow, which were broken into a series of steps which the child could watch and then practice for themselves. Figure 6.3 shows correct use of an inhaler and spacer.

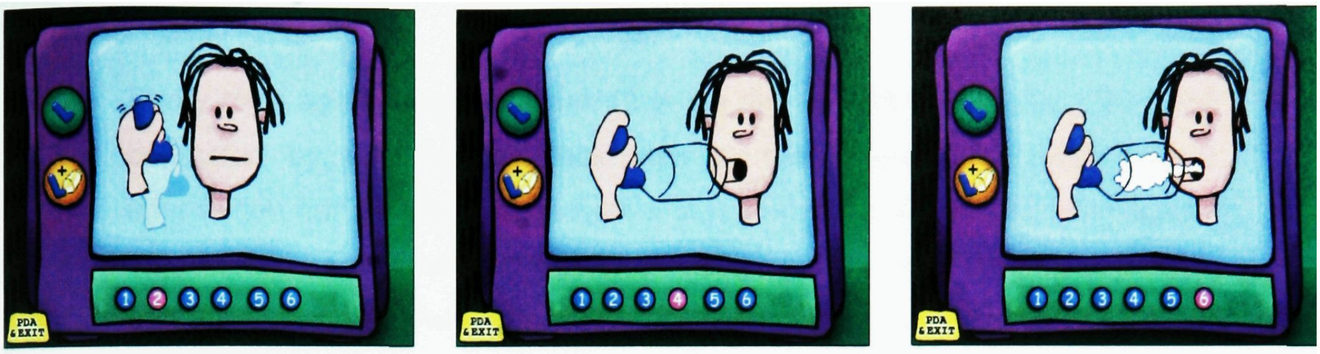


Figure 6.3- Images taken from 'Inhaler Test Centre' demonstration of correct inhaler use (three of the six steps).

An initial impression of the program by the group was that there were very few instructions on how to use it or where to go. This had been a deliberate strategy to maintain intrigue and user motivation, utilising children's natural tendency to explore (Fasick, 2001). Only pilofing it with children would reveal whether additional assistance with navigation was necessary.

An observation form was designed which rated the frequencies of researcher and user behaviour, for example, navigafional errors, task specific quesfions, instructions, prompts and pointing (see Appendix 17). A nine year old child without asthma was invited to use the program in an attempt to reveal potential problems in both the program and the usability of the observation form before testing in the asthma clinic commenced. Despite not having asthma, he was able to contribute valuable comments on the design and usability of the program. It was also clear that the laptop computer's mouse pad was too sensitive for children to use, and a 'trackball' mouse substituted. Children subsequently found the trackball problemafic and fared much better with a normal computer mouse.

Pilofing began in the children's asthma clinic although it was decided to restrict pilofing to only children attending the clinic (and not involve 'healthy' children) because the sections currently stood as discrete units. Although it was planned for all the sections to link together eventually, it would be difficult to understand each section without any knowledge of asthma.

Every child aged between 7 and 16 years due to visit the asthma clinic was contacted by post in the week prior to their appointment with project information and an invitation to take part in the study (letters are in Appendix 18). In the first clinic visit, five children used Sections one (What is asthma?) and four (Triggers) whilst waiting for the doctor. These comprised three females and two males ranging from 7 to 14 years. The following clinic saw six more children using the program: three females and three males, ranging between 11 and 16 years.

Feedback from all 11 users was positive and reasonably consistent. Two predominant themes emerged: firstly, the older users felt that the program would be of great help to younger users and/or those newly diagnosed, but that it was not providing novel information for them. They felt that 14 years would be an appropriate upper age limit, and this was borne out by further pilot work. Hence, the age- range was restricted to 7-14 year old children for the main study.

Secondly, many users found navigafing round the program problematic, which is a noted barrier associated with mulfimedia (Gollis, 1991) and some felt that more 'signposts' would be helpful. Quantitafively, the observer rafing sheets revealed that navigation-related problems (navigational errors and queries about how to go about a task [e.g. *"Where do I go now?"])* were the most commonly **observed** behaviours. Researcher prompts (e.g. *"Have you tried all the cabinets?")* were the next most common category rated.

Some children, however, liked the explorafion element, for example, one girl of 11 said *"I liked finding out the information, rather than just being told the facts".* Interactive sections and the quiz were also popular. However, long spoken sections received more negative feedback *-"It's a bit boring listening to loads of facts" {Sarah,* 11). This is wholly supported by educational theory and research which suggests that children learn as a result of interacting with their environment and should be engaged in active participafion as much as possible (Becker ef *al,* 1994). Thus, providing sufficient instructions for the younger users, whilst not making the program too patronising for the older age group was a key issue. To compromise, additional 'signposts' were included to draw attention to important sections whilst the remainder of the program allowed more independent exploration (see Figure 6.4).

Figure 6.4- Examples of 'signposting' added into the program, which were simple but proved effective in improving navigation. The rest of the program was left for the children to explore independently.

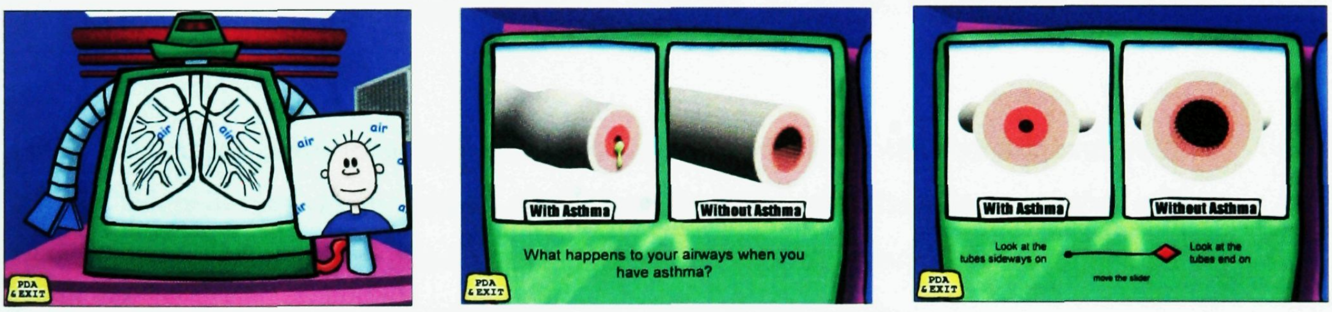
Months 5-6

There were no new sections of the program completed at this juncture and continued piloting of sections one, four & five was not yielding much novel feedback. Instead, children were tested on their knowledge of asthma before and after using the program. The questions used to test the children were initially based on fairiy broad asthma information, although they were subsequently simplified and made more explicit after it became obvious that more open ended questions confused the children and elicited rather vague answers which were difficult to score. Furthermore, it was unrealisfic to look for a broad change in knowledge after the child had used only one specific part of the computer program. Therefore, the questions were restricted to triggers of asthma. The child then used the triggers section of the program and the quesfions were repeated afterwards; children subsequently demonstrated significant improvement in their knowledge of triggers.

The methods of the knowledge testing and the results are described in more detail elsewhere (see McPherson *et al.* (2000)- *The Asthma Files: a multimedia package for children's asthma education.* Appendix 19).

As a result of the pilot work, voiceover sections were shortened and, where possible, broken down into several shorter sections. The Treatments room, which children had found very frustrating, was completely redesigned so that the 'files' were easy to identify. Although this section became less exploratory, it was felt that information about the different treatments for asthma should be made as accessible as possible.

Section two (What happens inside your body when you have asthma?) was completed and piloting with clinic children started immediately. Parents were very enthusiastic, reporting that they felt the program simplified informafion about lungs, airways and breathing in an understandable manner (see Figure 6.5). However, children were less enthusiastic and were unsure where to look due to the lack of instructions. They often had to be prompted to explore the room further to find the other interactions. The children found two out of the three interactions in the room very fiddly, and had to be given assistance with both them and general navigation.



(a) (b) (c)

Figure 6.5- Screenshots from Room 2 'What happens inside your body'. (a) The 'Lungbot' explains the process of breathing. (b) & (c) Depiction of airway hyper- reactivity associated with asthma. Children can view the airways from different angles.

Months 7-8

Preliminary versions of all sections were complete and available for pilofing in the asthma clinic. Due to concerns about recruitment numbers, only children who had previously used the computer program were invited to look at the newly developed sections. It was hoped this would ensure as many 'naïve' children as possible for the main evaluation study. However, waifing for people to return to clinic only yielded three participants over several weeks, so all children who had previously taken part in pilofing were contacted by post to arrange using the program at their home.

Four children were visited at home for a second viewing of the program. From these subsequent tesfing sessions (three in clinic, four at home), consistent feedback emerged:

- The entire program took roughly 1 ½ hours to complete. Those children visited at home were generally quite happy to spend that fime on it.
- The games were very popular
- There was confusion about which sections had already been visited.
- The directional cursors which had been introduced were a great help, and reduced navigational errors substanfially.
- Further signposting was needed, as some interacfions were still missed.

A major problem which emerged was that children **still** did not understand what a self-management plan was. As this was the thrust of the enfire program, it clearly needed reconsideration. The software developer agreed to redesign this section which was then piloted thoroughly.

Months 9-10

It was crucial that informafion about self-management plans could be easily found and understood. To aid this, it was planned to divide the informafion into smaller sections to maintain interest.

The self- management plan was explained using a 'traffic light' analogy for initiafing different actions (see Figure 6.6).

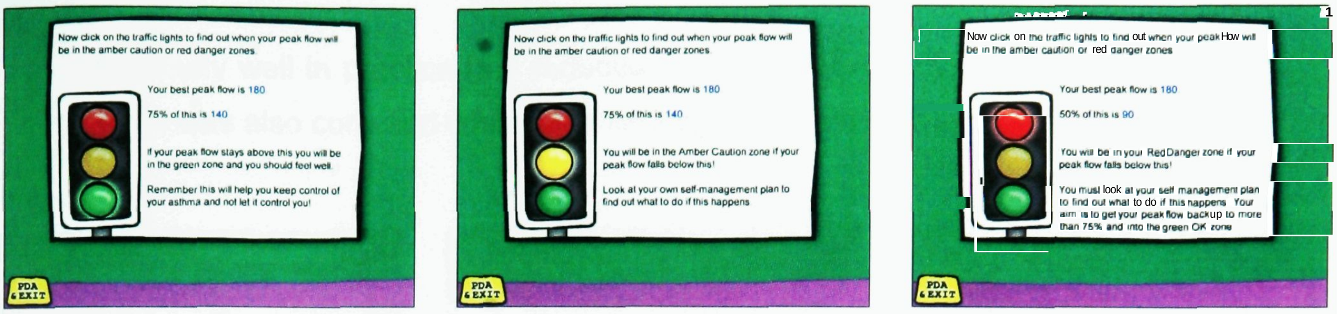
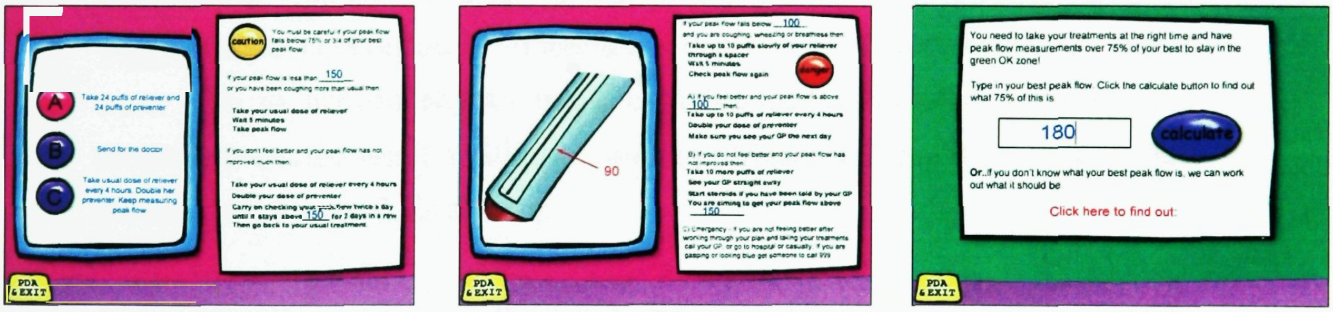


Figure 6.6- The three stages of the self- management plan, based on 'traffic light' analogy.

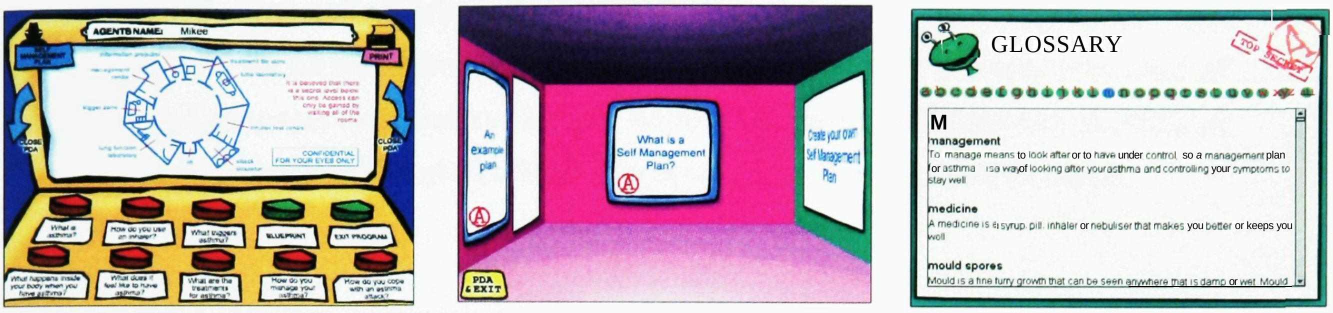
A sample plan was then used to demonstrate how to apply the instructions. It contained multiple choice questions at different points providing feedback on questions answered incorrectly (Figure 6.7). Children were given the opportunity to enter their best peak flow or calculate it (based on height, age and sex), which was then incorporated into a personalised self- management plan which could be printed out. The plan provides figures for 75% and 50% of best peak flow as well as the associated actions. Personal triggers entered in the Triggers room were also incorporated into the plan.



(a) **(b)** **(c)**

Figure ***6.7-*** (a) & (b) Different sections of the self- management plan are demonstrated separately, using examples and multiple choice questions. (c) Children enter their best peak flow (or calculate it) to be incorporated into a self- management plan.

All personal information, including rooms visited, was stored on a 'Personal Digital Assistant' accessed by their user name (Figure 6.8a). In response to feedback describing children's confusion with what they had and hadn't already visited, a system of 'thumbprints' had been introduced, whereby a symbol appeared next to areas already viewed (Figure 6.8b). This worked extremely well in pracfice and reduced confusion significanfly. A glossary of terms was also compiled which was accessible in every room (Figure 6.8c).



(a) (b) (c)

Figure 6.8- **(a)** The Personal Digital Assistant stores children's personal information and the sections already viewed. It also contain a 'blueprint' of the area to be explored. (b) 'Thumbprints' mark areas visited. (c) A glossary of terms is accessible in every room.

Months 11-12

Three more children used the program in the asthma clinic, and reported being aided by the improvements in navigation. Fears of cognitively overioading younger children (Gollis, 1991) prompted simplification of the treatment file section as it contained a great deal of text. However, users were able to access slightly more complex text if required and thus the program provided text for different reading abilities and a wider range of age groups (see Figure 6.2b above).

As an incentive to explore the whole range of information, users were told that there was a 'secret level', accessible only if all other sections had been viewed. This contained games and quizzes which reinforced key messages from the program in a fun and interacfive format. Readers are encouraged to investigate this section themselves.

In total, 28 children and young people were involved in the pilofing of the program; fifteen children used it on one occasion, ten used it twice and three used it three times. All contributed valuable comments which greafly enhanced the program and ensured its acceptability to users.

Months 13- 14

The final version of the script was produced and checked for errors and inconsistencies by the whole group before professional sound recording took place. The self- management plan to be printed out by the program was agreed by all members of the team. The CD-ROM was officially launched at the European Respiratory Society Annual Congress in Stockholm in 2002. A copy of the completed CD-ROM can be found in the back of this thesis.

6.4.2 Written information

An information booklet was given to all participants in the study. It took the form of a simple 15- page, A5 booklet entitled 'Asthma at Home'. This had been written in 1999 by the asthma nurse specialists at Nottingham City Hospital and Derby Children's Hospital and is still used widely in both clinics. Topics covered were:

- *What happens in asthma?*
- *Common symptoms*
- *Asthma triggers*
- *Asthma treatment*
- *Medicines taken by mouth*
- *Inhalers*
- *Peak flow meters*
- *Coping with an asthma attack & what to do*
- *Self- management plan.*

It also provided space to write down contact details of the local hospital and appropriate health care professionals, as well as the child's usual treatment. A copy of the booklet can be found in Appendix 21.

6.5 Procedure

6.5.1 Recruitment (Time 1)

Clinic lists were obtained from hospital information systems a week in advance. For each person listed, age and hospital number was provided, and addresses were either printed out on labels or copied down by hand from the computer system. Pafients in the appropriate age range were identified from the clinic lists and a check made to see if they had previously i) taken part; ii) refused to take part; iii) taken part in the pilot phase (rendering them ineligible for participation) or iv) been contacted and found not to meet inclusion criteria. Appropriate children were then sent an information pack containing a letter to their parent(s) and a letter for the child, emphasising that participation was voluntary (Appendix 9).

When the child and parent attended the clinic appointment, they were approached and inifially screened for entry to the study using the above inclusion criteria. Written parental consent and the child's assent were obtained- obtaining both was mandatory for entry to the study (see Appendix 10).

Having been weighed and measured as part of clinic routine and whilst waiting to see the consultant, the child and their parents were taken to a quiet side room and made comfortable. A parent was asked to complete the Parent Demographic and Knowledge Questionnaire and the Asthma Control Quesfionnaire whilst the child was being interviewed.

The child was interviewed by the author who completed the first part of the Asthma Knowledge Assessment (the AKQ1) using the child's answers. Older children then typically completed the True/ False section (the AKQ2) and the Asthma Locus of Control (ALOG) scale by themselves. Younger children were given assistance with reading if necessary, but encouraged to participate by ficking the appropriate box after they had made their decision. A measure of the child's verbal ability was taken using the standardised British Picture Vocabulary Scale (BPVS), which took between approximately

5- 15 minutes to administer. Finally, the child's lung funcfion was assessed and noted at the top of the questionnaire.

Parents and children were thanked and informed that they would be contacted in approximately one month's fime, either by post (with the booklet) or telephone call to arrange a suitable fime for a computer visit. They then saw the respiratory consultant as usual.

6.5.2 Randomisation

Having completed recruitment measures, a pre- prepared, sealed envelope containing a random number was opened: if it was an even number, the child was allocated to the intervenfion (computer) arm of the study. An odd number signaled allocation to the control (booklet) arm.

One month after recruitment, participants in the control group were sent the informafion booklet accompanied by a short note asking them to look through it. At the same time, those in the computer group were contacted by telephone to arrange a suitable fime to be visited at home.

6.5.3 Intervention

During a visit to a child at home, a laptop computer was set up on a table and computer program started. After the introductory sequence, the researcher gave brief navigational instructions to the child and they were then invited to use the computer program in any way they wished, for as long as they wished. During the computer session, the researcher was available to answer queries, but otherwise allowed the child to use the program without interference. Children typically used the program for approximately an hour and a half, although there were no minimum or maximum fime limits imposed.

When the child finished using the program, they were asked about the program's acceptability and ease of use (see Appendix 15 for evaluafion schedule used). They were given a copy of the CD-ROM to keep and, if requested, this was installed on their personal computer. They were also left a copy of the same information booklet given to the control group.

Part of the computer program's strength is that users can enter their details and produce a personalised self- management plan. However, because a laptop computer was used to show the CD-ROM to the children for its portability, there was not the opportunity for the children to print out a plan as intended. Therefore, a batch of colour copies were printed with space to write personal peak flow scores (best, 75% and 50%). One of these self-management plans was completed by the researcher whilst the child was using the computer program using his or her best peak flow score, and this was also left with the child (Appendix 20).

6.5.4 Follow- up (Time 2)

One month after the booklet had been sent (control group) or child visited at home (computer group), unless they had an imminent appointment at the asthma clinic, a date was arranged to visit the child at home for a follow- up assessment. At this visit, their lung function was assessed as before using the spirometer and peak flow meter. The same parent that had completed the questionnaires at Time 1 was asked to complete the follow-up versions.

Children were asked if they had found chance to look at the booklet and, for the computer group, whether they had used the computer program again since the initial visit. Those who had looked at the booklet were asked to indicate which parts they found useful. Following this, the AKA was completed as before, along with the ALOG.

Children and parents were sent a letter of thanks shortly after their follow-up visit.

6.5.5 Recruitment difficulties

A few weeks after recruitment had commenced, it was clear that the high percentage of each clinic list failing to attend their clinic appointment was having a significant impact on recruitment rates. To remedy this, all children who had been invited to take part but not attended their appointment were written to with an offer of home recruitment. This yielded a further 11 participants. Parents could also request not to be contacted again if they were not interested in taking part.

6.5.6 Six month follow-up (Time 3)

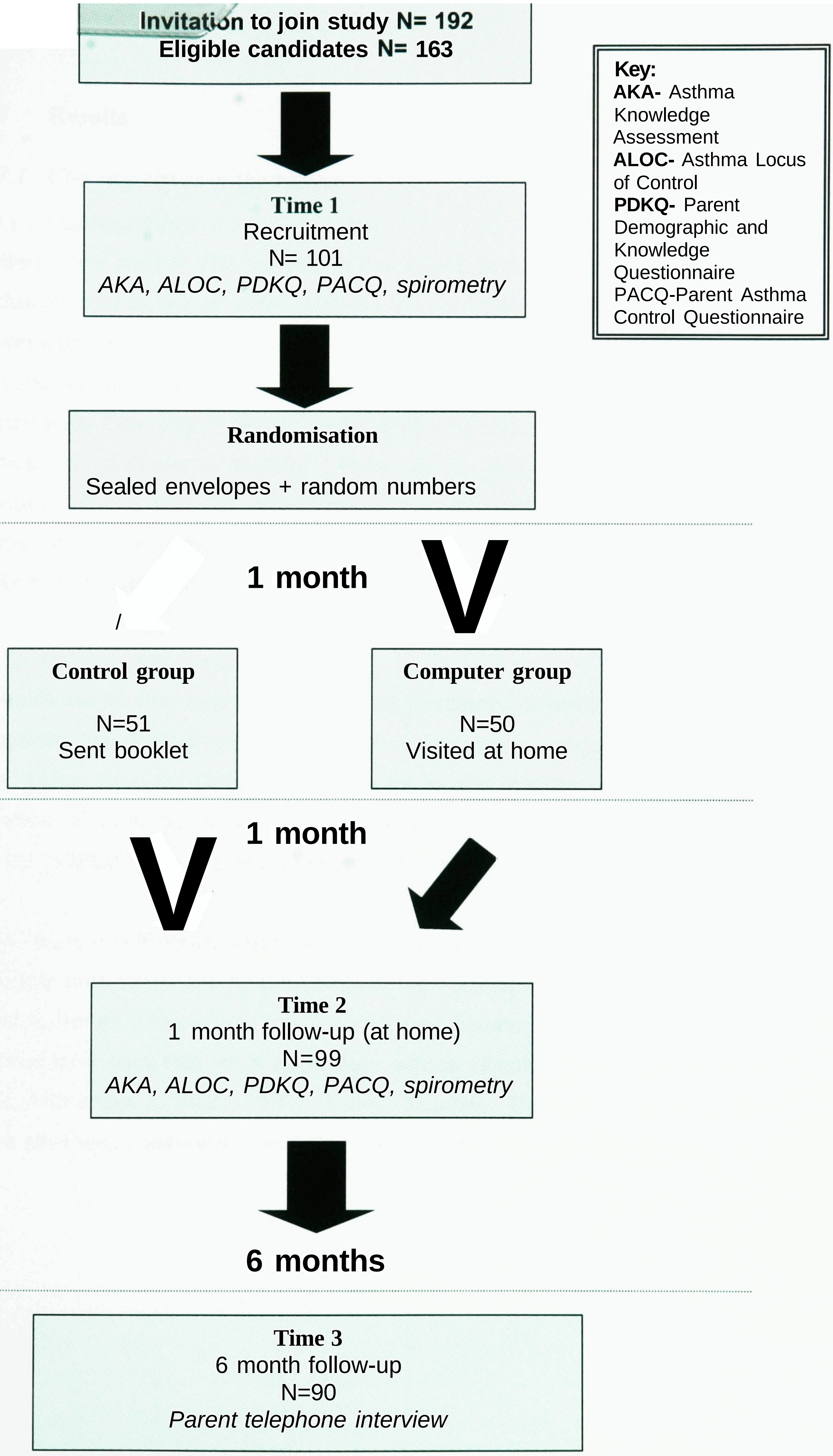
Six months after receiving the booklet or computer program, parents were telephoned and briefly interviewed about their child's asthma. Major events, such as a hospital admission were recorded as well as the number of school absences due to asthma their child had taken in the previous six months (see full descripfion of questionnaire in 'Measures').

The study schedule is pictured in Figure 6.9.

6.5.7 Analysis

Data were analysed using SPSS 11.0. Normality was tested using One-Sample Kolmogorov- Smirnof test. Parametric tests were used with normally distributed data, including Pearson's correlafion, t- test and ANOVA. Non-parametric tests were used on non- normally distributed data, including Spearman's correlation, Mann- Whitney- U and Kruskall Wallis- H tests. Repeated measures ANOVA was used to look at differences between Time 1 and Time 2. Linear regression was used to investigate predictive variables whilst controlling for other, potentially confounding variables. A level of $p < 0.05$ was set.

Figure 6.9- Study schedule



6.7 Results

6.7.1 Characteristics of the sample

6.7.1.1 RESPONSE RATES

Letters were sent to 192 children in the appropriate age range. 163 met the inclusion criteria out of which 101 (61.9%) children took part in the study. Twenty-one (12.9%) children did not attend their appointment, 19 (11.6%) refused to take part and 17 (10.4%) children were missed due to time constraints. Fifty- eight were recruited at Nottingham City Hospital outpatient clinics, 34 at Queen's Medical Centre clinics and 9 at Derby Children's Hospital. Those that did not attend or cancelled their appointment ('non-responders'), were missed or who refused to take part- did not significantly differ from those who participated on age or gender.

6.7.1.2 DIFFERENCES BETWEEN CLINICS

As participants had been recruited from paediatric clinics in three different hospitals, the demographic and baseline data were compared by hospital site. There were no statistical differences in age, gender, response rates, duration of asthma, verbal ability or socioeconomic status between the clinics. Mothers' age and education level also did not differ across the clinics.

There were no differences between the clinics at baseline on any of the study outcome measures: the Asthma Knowledge Assessment, Asthma Locus of Control, Parent Knowledge Questionnaire and Asthma Control Questionnaire all produced data that were equivalent across clinics. There were also no clinic differences in FEV_1, PEF or school absence. Therefore, data from the three sites was combined. See Table 6.1 for details for individual clinics.

Table 6.1- Characteristics of sample by clinic

	N'ham City Hospital n=58	QMC n=34	Derby n=9	Whole group n=101	Statistical diff between clinics
Gender: Number male (% site sample)	29 (50%)	22 (64.7%)	3 (33.3%)	54%	**NS**
Median age in years (range)	9 (7-14)	10.5 (7-14)	9 (7-13)	10 (7-14)	**NS**
Mean BPVS (sd)	103.8 (16.31)	99.7 (14.04)	100.1 13.97)	102.4 (15.40)	**NS**
Mean asthma duration in years (sd)	6.7 (3.07)	7.2 (3.80)	5.4 (3.61)	7 (3.37)	**NS**
Response rates	61.7%	58.6%	81.8%	61.9%	**NS**

6.7.1.3 AGE & GENDER

The 101 children that took part across all clinics had a median age of 10 years (range 6-14 years)[1] and 53.5% of the total number of participants were male. The mean length of fime since being diagnosed with asthma across all clinics was 7 years (sd= 3.4) (Table 6.1).

6.7.1.4 ETHNICITY

Eighty nine (88.1%) parents described their child's ethnicity as white; five (5%) and 6 (5.9%) participants were mixed race and Asian, respectively and one participant was black British. The sample is broadly representative of Nottingham as a whole, which had a white populafion of 89.2% in the 1991 census (Office of Nafional Stafisfics, 1991).

[1] As in Oh. 5, one rising 7 year old girl was mistakenly included in the sample, although her data are included in the analysis as her verbal age was equivalent to 8 years and 8 months and she did not appear to demonstrate any more difficulties than the seven year olds in the sample.

6.7.1.5 VERBAL ABILITY

The mean standardised verbal IQ score for the sample was 102.1 (sd= 15.40) which formed a gaussian distribution.

6.7.1.6 SOCIOECONOMIC STATUS

Socioeconomic status was derived from information provided by the parents on their occupations and categorised using Standard Occupational Classification 2000 manual (Office of National Statistics, 2000). They were then banded into three groups: band one (managerial and professional) was the most common (60.6%), followed by band three (roufine and manual- 24.5%) and then band 2 (intermediate occupations- 14.9%). The distribufion is shown in Figure 6.10.

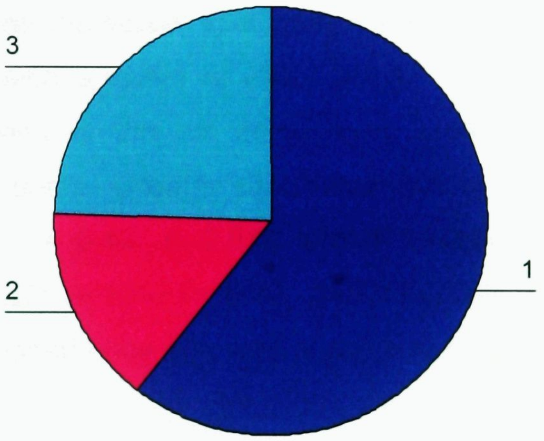


Figure 6.10- Socioeconomic status of sample (n=94)

6.7.1.7 ASTHMA CONTROL QUESTIONNAIRE (ACQ)

The ACQ score was not normally distributed. It was associated with lung function, both FEV_1 and PEF, which are objective measures of asthma severity. The FEV_1 score and PEF score, expressed as percentages of the child's predicted score, were significantly negatively correlated with ACQ score (FEV_1: n=95, r= -0.36, p< 0.001; PEF: n= 94, r= -0.54, p<0.001) demonstrating that parents of children with poor lung function perceived their asthma to be more pooriy controlled. The median ACQ score for the entire group was 8 (range 0-31). ACQ score was related to socioeconomic status, F (2, 92)= 3.6, p=0.03. Post- hoc analysis revealed that parents who were categorised as having 'professional/ managerial' occupafions perceived their child to be less severe than those classed as having 'roufine/ manual' occupations.

6.7.1.8 RESPONSIBILITY FOR MANAGEMENT OF ASTHMA

Quesfion 25 on the parent knowledge questionnaire (See Appendix 13) requires the parents to indicate the extent of responsibility their child habitually takes for aspects of asthma management. The parent was provided with a five point rating scale to indicate responsibility, which spanned from 'Parent/ adult mostly responsible', to 'child mostly responsible' with degrees of shared responsibility in between. These ratings were transformed into scores (-2 to 2) so that the more responsibility the child took, the higher the score. The 'parent and child share responsibility equally' rafing was given a score of zero, as did 'not applicable' responses. The scores on each of the six items were then summed to provide a total responsibility score. Greater child responsibility was associated with age of child (n=101, r= 0.46, p<0.01), and knowledge (AKQ1: n=101, r= 0.34, p=0.001; AKQ2: n=101, r= 0.40, p<0.001), although the associations with knowledge ceased once age was accounted for in a regression model .

6.7.1.9 CLINICAL FEATURES

Lungfunction

The percentages of predicted FEV_1 ranged from 44% - 138%, the mean being 94.5% (sd= 19.93). Peak flow scores at baseline ranged from 36.52% to 147.59% of predicted score with a mean of 98.63% (sd= 21.58). Lung function scores were negatively correlated with age (FEV_1: n= 97, r= -0.28, p<0.01; PEF: n= 96, r= -0.21, p<0.05).

School absence

34 (34%) of children had missed at least one day of school in the previous month due to their asthma. Out of those who reported school absence, the median number of days absent was 5 (range 1-20).

Inhalers

All children were being prescribed some form of inhaled medication. Bronchodilator (reliever) inhaler was prescribed for all but one child (99%), 78.2% children were prescribed a corticosteroid (preventer) inhaler and 51.5% a long- acting bronchodilator (long- acfing reliever) inhaler. A combined preventer and long acfing reliever inhaler was prescribed to a further 10.9% children.

6.7.2 AIM I. TO INVESTIGATE KNOWLEDGE LEVELS IN CHILDREN WITHASTHMA

6.7.2.1 ASTHMA KNOWLEDGE QUESTIONNAIRE PART 1 (AKQ1)

Knowledge levels about the basic physiology of asthma and triggers for asthma were low. Out of a possible score of 22, the scores for the entire sample ranged from 2 to 12, with a median of 6. There were no differences in knowledge scores between giris and boys.

Ninety three children (92.1%) knew that the lungs and/or chest were affected by asthma, although only 6 (5.9%) stated that airways (or 'pipes'/ 'tubes') were affected. Roughly half the sample recalled that breathlessness (47.5%) was a symptom of asthma, whereas wheezing was only mentioned by 40 (39.6%) children and 61 (60.4%) named coughing. However, 93 (92.1%) were able to list at least one of the above symptoms.

Children were asked whether they could explain what was happening in their body to cause their symptoms. Correct possible answers were:

- Airways fighten
- Inside layer of airways swells
- Mucus is produced
- Breathing is difficult because ain/vays become smaller.

Very few children could answer this correcfiy: the majority of those able to answer this question described the airways fightening (22.8%). Overall, 30 children (29.7%) mentioned any of the possible answers. However, knowledge increased when children were asked to describe how they knew when their asthma was becoming worse. Correct answers were:

- Symptoms increase
- Inhaler is needed more often than usual
- Peak flow reduced
- Medication does not last 4 hours

Ninety- two children (91.1%) were able to provide some explanation for this question, mostly stating that symptoms would worsen i.e. they would wheeze or cough more. Few described the other scenarios.

When asked to list as many triggers as possible, the median number named was 2 (range 0-5). Activity was the most cited trigger (62.4% children), followed by animal fur (31.7% children). See Figure 6.11.

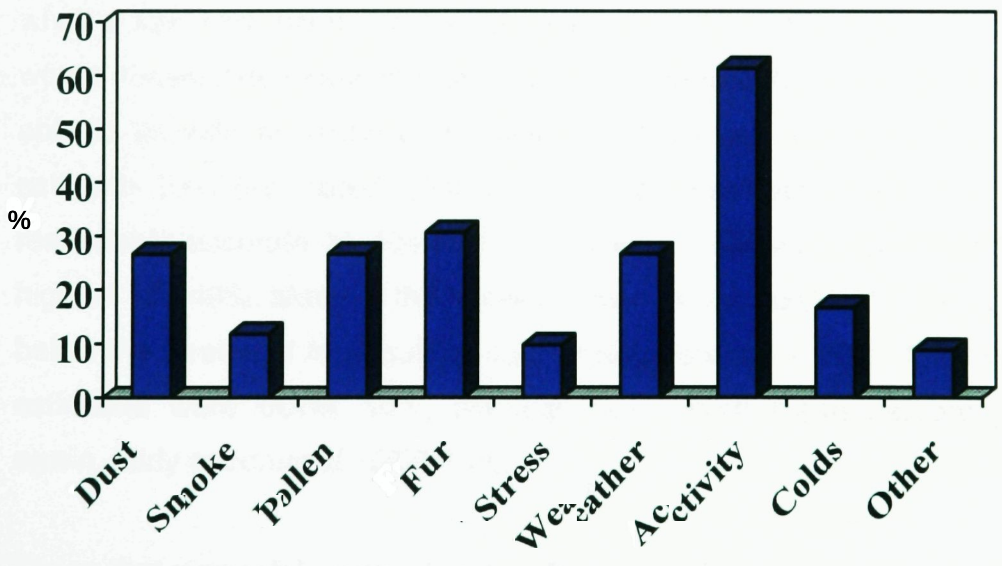


Figure 6.11- Percentage of children reporting triggers

Despite neariy all children being prescribed reliever medicafion, when asked if they knew how it worked inside their body, only 31 (30.6%) were able to give any explanafion i.e. that it stopped wheezing, it relaxed muscles around the airways or that it worked rapidly. Seventy eight children (77.2%) were being prescribed inhaled corticosteroid (preventer) medication through a single inhaler, although only 16 (15.8%) offered an explanation about its acfion: either that it was preventative, took longer to work than reliever medication or reduced inflammation in the airways. Approximately half of the sample (51.5%) were prescribed a separate long- acting reliever medication but very few knew anything about it; six children (11.5%) knew that it lasted longer than their other 'reliever' medication, but had no other knowledge about its physiological action. When asked about missing doses in the previous week, there was a positive significant correlation between the number of times the children reported missing a dose of preventer and age, such that older children reported forgetting a dose more often ($n=79$, $r=0.26$, $p=0.02$)

The majority of children (88%) reported owning a peak flow meter and all children were asked what they thought their best peak flow should be (i.e. their predicted PEF for their age & height or their personal best score) and what a 'low' PEF would be (i.e. approximately 50% of predicted PEF which would necessitate immediate attention). Approximately, three- quarters were able to provide an answer for these quesfions and the mean percentage esfimate (i.e. {estimated best PEF/ actual predicted PEF} x 100) was reasonably accurate at 104.25%. The lowest esfimation was 66.52%, the highest 184.49%. Many of the answers given for the 'low' PEF were seriously below the threshold for requiring immediate attenfion- a third of the sample's estimates were below 40%, although the overall mean percentage was again, fairly accurate at 103.60%.

Those that accurately esfimated their best peak flow (those whose estimates were above 85% of their predicted PEF) had a median age of 10 years and were evenly spilt between the sexes.

6.7.2.2 ASTHMA KNOWLEDGE QUESTIONNAIRE PART 2 (AKQ2)

The median score on the AKQ2 for the whole sample was 12, out of a possible 15 points (range of 7-15). The quesfions most commonly answered correctly were:

Q4. Smoking is good for people with asthma (false) (99%)
Q8. A peak flow meter can help to tell you when your asthma is getting bad (true) (97%)
Q13. Steroids used for asthma will make you big and hairy (false) (95%)
Q15. Your house only needs to be vacuumed once a month (false) (93.1%).

The questions answered most pooriy were:

02. Exercise is good for people with asthma (true) (60.4%)
09. Preventers are blue inhalers (false) (39.6%)
014. Anfi- leukotrienes are a type of reliever (false) (34.5%).

6 7.3 AIM 2. TO INVESTIGATE FACTORS ASSOCIATED WITH HIGHER KNOWLEDGE LEVELS AND SUCCESSFUL SELF- MANAGEMENT.

6.7.3.1 HYPOTHESIS 1. GREATER KNOWLEDGE WILL BE ASSOCIATED WITH OLDER AGE, HIGHER VERBAL IQ AND LONGER DURATION OF ASTHMA

Spearman's correlations were performed with **AKQ1** scores and age, BPVS score and asthma duration. It was found that higher **AKQ1** scores were associated with older age (**n=101,** r = 0.60, p=0.000), higher verbal IQ (**n=101,** r= 0.29, p< 0.01) and with longer duration since diagnosis of asthma (n=101, **r** = 0.20, **p<** 0.05).

Since duration of illness was likely to be confounded by age, stepwise linear regression was carried out with **AKQ1** score as the dependent variable and age, verbal IQ and durafion as independent variables. Age (p = 0.59, t= 7.88, p<0.001) and verbal **IQ** (p=0.32, t=4.20, p<0.001) entered into the regression indicafing that children with higher knowledge scores for Part 1 were older and had better verbal ability (total adjusted r^2= 0.46). Once these two variables had been accounted for, duration of asthma no longer contributed to knowledge.

Spearman's correlations were also performed using AKQ2 scores. Higher scores for the true/false quesfions were correlated with older age (n=101, r= 0.52, p<0.001), longer duration of asthma (n=101, r=0.24, p=0.02) and verbal ability (n=99, r= 0.28, p=0.01). As above, step-wise regression was carried out with the AKQ2 score as the DV, which showed that age (p = 0.52, t=6.27, p<0.001) and verbal IQ (p= 0.26, t= 3.15, p= 0.002) both contributed to knowledge score but again, duration of asthma did not (p= 0.07, t= 0.70, p=0.49). Children with higher true/false scores were older and had higher verbal IQ but not a longer history of asthma (total adjusted r^2 = 0.33).

6.7.3.2 HYPOTHESIS 2. THOSE WITH A MORE INTERNAL LOCUS OF CONTROL WILL HAVE HIGHER KNOWLEDGE LEVELS

The median score on the ALOG was 7 (range 2-10). Children with more internal locus of control were older (r= 0.68, n=100, p<0.001), had higher BPVS scores (r= 0.23, n=99, p<0.05) as well as a longer durafion of illness (r=0.21, n=100, p<0.05). Locus of control was not affected by socioeconomic status. In a regression analysis with ALOC scores as the dependent variable, once age and BPVS had been accounted for, duration of asthma no longer contributed to ALOC Score (p=- 0.06, t= - 0.65, p= 0.52). The total variance of ALOG scores explained by age and verbal ability was 45.5%.

Asthma locus of control scores were associated with knowledge using both AKQ1 (n= 100, r= 0.56, p=0.000) and AKQ2 (n=100, r= 0.48, p=0.000) scores, indicating that those with greater knowledge would be expected to have a more internal locus of control. As age and verbal ability were both associated with knowledge, stepwise linear regression was carried out with ALOG score as the dependent variable and age, BPVS scores and knowledge score (AKQ1 & AKQ2) as the independent variables. This showed that knowledge scores no longer contributed to the ALOG score after age and verbal ability were accounted for (AKQ1: p= 0.16, t= 1.55, p=0.12; AKQ2: p= 0.18, t= 1.67, p= 0.10). Therefore, asthma knowledge is not an independent predictor of locus of control.

6.7.3.3 HYPOTHESIS 3. THOSE WITH A MORE INTERNAL LOCUS OF CONTROL WILL HAVE BETTER CONTROL OF THEIR ASTHMA.

ALOC scores were entered into a correlation calculation with parent- rated Asthma Control Quesfionnaire scores to ascertain whether parents' percepfion of their children's control of asthma was associated with the level of control the children felt they had over their asthma. Pearson's correlation indicated that there was no association between these two scores (n=98, r= 0.05, p= 0.63).

There was no association between ALOC score and lung function when using FEV_1 percent predicted scores (n= 96, r= -0.18, p= 0.081) or PEF percent predicted scores (n= 95, r= -0.14, p= 0.16), although the scores were the inverse of what might be expected i.e. as lung function declined, ALOG scores became more internal. (Figure 6.12).

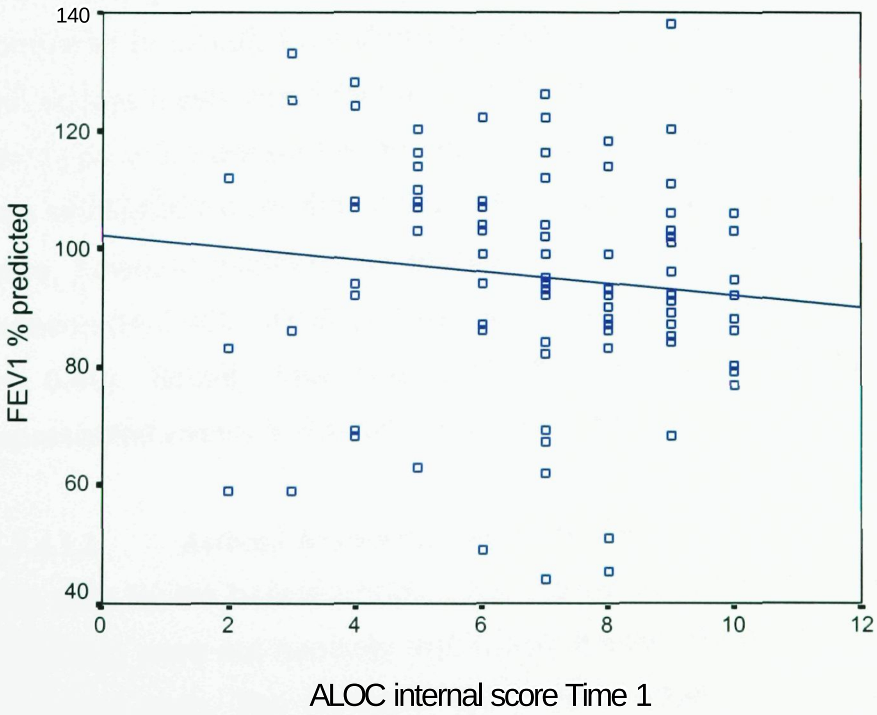


Figure 6.12- Correlation between ALOC scores and FEV_1 at baseline (n=96).

A proxy measure of asthma control used in this study was school absence, with the assumption that more days off school would indicate more pooriy controlled asthma. Approximately, 34% of the participants had taken at least one day off school in the month prior to recruitment, although this factor did not affect their ALOC score ($t= -0.67$, $df= 97$, $p= 0.51$) and the number of days taken were not associated with their ALOG score ($r= 0.04$, $n= 99$, $p= 0.71$).

It appears that older children and those with better verbal ability have a more internal locus of control, although this is not associated with subjective measures of asthma control (the ACQ). More objecfive measures of control (FEV_1 and days off school) were also unrelated to ALOG scores.

6.7.4 *AIM 3. TO INVESTIGATE THE IMPACT OF AN EDUCATIONAL CD-ROM AND WRITTEN INFORMATION ON KNOWLEDGE LEVELS, LOCUS OF CONTROL AND CLINICAL OUTCOMES OF CHILDREN WITHASTHMA.*

6.7.4.1 CHARACTERISTICS BY GROUP AT BASELINE

The book group and computer group were considered separately and compared to identify their characteristics at Time 1. Using Yates's corrected chi- square it was noted that there were no differences in gender ($\chi^2 = 0.79$, $df= 1$, $p= 0.37$) across the groups at baseline although the computer group was significantly older than the booklet group ($Z= 2.79$, $p=0.000$). The groups were, however, matched on ethnicity ($\chi^2 = 0.000$, $df=1$, $p=1$) and asthma durafion ($t=-0.403$, $df=99$, $p=0.69$), as well as verbal ability ($t= -0.696$, $df=97$, $p= 0.49$). Social class was equivalent and each of the clinics were represented evenly in the two groups (see table 6.2).

6.7.4.1.1 Asthma Knowledge Questionnaire

The data for the baseline knowledge scores on both Part 1 (AKQ1) and Part 2 (AKQ2) were not normally distributed, indicafing the use of nonparametric statistical tests. The computer group had higher scores than the booklet group for both AKQ1 (6.5 Vs 6) and AKQ2 (12.5 Vs 12). As knowledge was confounded by age, with older children being more knowledgeable (AKQ1: r=0.60, n=101, p=0.000; AKQ2: r= 0.52, n= 101, p= 0.000), it was necessary to control for age when comparing the groups' baseline knowledge scores. AKQ1 and AKQ2 knowledge scores were log transformed which resulted in data with a normal distribufion. These scores were then included as the dependent variable in a univariate general linear model with intervenfion group as the fixed factor and age as a covariate. The covariate was significant for AKQ1 (F= 47.8, df= 1, p=0.000) and AKQ2 (F= 31.3, df= 1, p= 0.000). After adjusfing for age, the two groups no longer differed at baseline on either AKQ1 or AKQ2 knowledge scores (Part 1: F= 0.63, df=1, p=0.43; Part 2: F= 0.02, df=1, p=0.903). See Table 6.3.

Table 6.2- Sample demographics by intervention group

	Book group n=51	**Computer group n=50**	**Statistical significance**
Age (median) **(mode)**	9 years 7 years	11 years* 8 years	**Z**= -2.80, **p=0.000**
Gender (males)	24(47.1%)	30 (60%)	NS
White ethnicity	44 (86.3%)	45 (90%)	NS
Mean duration of asthma (sd, range)	6.64 years (3.12, 1-14 years)	6.91 (3.65, 3 months-13 years)	NS
Mean BPVS (sd)	101.0 (14.64)	103.12 (16.23)	NS
Mean maternal age (sd)	36.6 years (5.85)	37.96 years (5.99)	NS
Mother's educational level *GCSE & below* *A level & above*	 35(71.4%) 14 (28.6%)	 39 (83.0%) 8(17.0%)	NS
Family member with asthma	38 (74.5%)	36 (72%)	NS
Socioeconomic status: *Managerial & professional* *Intermediate* *Routine & manual*	 28 (58.3%) 7 (14.6%) 13 (27.1%)	 29 (63.0%) 7(15.2%) 10(21.7%)	NS

NS- Not significant; * significant at the 0.001 level

6.7.4.1.2 Parental knowledge

All 101 parents completed the Parent Knowledge Questionnaire (PKQ) at baseline which had a maximum possible score of 14. The median score obtained by parents in both booklet and computer groups was 12 and, apart from one outlier in the computer group who scored 3 out of 14, the range was 7-14 in both groups; therefore no significant differences were found between groups (Z=-1.32, p=0.19). Scores on the 'responsibility' secfion of the parents quesfionnaire did not differ between the two groups at Time 1 (t= -0.58, df= 99, p= 0.56).

6.7.4.1.3 Asthma Control Questionnaire (ACQ)

The mean ACQ score for the enfire group was 8.86 (sd= 7.35). However, the booklet group had higher scores on the ACQ with a mean score of 10.86 (sd= 7.33), representing more poorly controlled asthma in comparison with the computer group, who had a mean score of 6.81 (sd= 6.84). Therefore, parents in the book group rated their children's asthma as more severe than parents in the computer group, which showed a statistical difference (t= 2.83, df= 97, p <0.01). These differences were not related to clinical outcomes, however, as there was no difference between the groups on lung funcfion.

Because the computer group was older than the book group and asthma can reduce in severity with age, a correlation was performed between the ACQ score and age; but there was no associafion between the two variables (n=99, r= 0.04, p=0.68). Mother's age was, however, associated with AGO score, such that younger mothers tended to assess their child's asthma as more poorly controlled than older mothers (n=99, r= -0.23, p= 0.03). Mother's age did not differ between groups so does not account for the differences in ACQ between the booklet and computer groups.

6.7.4.1.4 Asthma Locus of Control

The scores from the ALOG were normally distributed so parametric tests were used. The overall mean score was 6.9 (sd= 2.13), the mean score for the book group was 6.69 (sd= 1.91) and the computer group had a mean score of 7.1 (sd= 2.32). There were no statistical differences between the two groups.

6.7.4.1.5 Clinical features (including proxy measures)

Lungfunction

The computer group had a slightly higher mean FEV_1 than the book group (97.22 *Vs* 92.53) although this was not significanfly different (t= -1.17, df= 95, p= 0.25). There were no differences on PEF between the two groups with the book group having a mean PEF of 99.5% predicted and the computer group 97.7% (t= 0.403, df= 86.60, p= 0.69).

School absence

There was no statistical difference between the control group (39.2%) and the computer group (28.6%) for school absence at Time 1. Nor was there a difference in number of absent days reported.

Medication

There were no differences between the groups on medication prescribed (see Table 6.3).

Table 6.3- Baseline scores on outcome measures by intervention group

	Book Group n=51	**Computer group n=50**	**Statistical significance**
Part 1 Median asthma knowledge score (range)	6(2-11)	6.5 (2-13)	**NS"**
Part 2 Median asthma knowledge score (range)	12(7-15)	12.5(7-15)	**NS"**
Median parent knowledge score (range)	12 (7-14)	12 (3-14)	**NS**
Mean parent rated asthma control score (sd)	10.86 (7.33)*	6.81 (6.84)	**t= 2.8, df=** 97, **p=0.006**
Mean asthma locus of control score (sd)	6.68(1.91)	7.10(2.32)	NS
Clinical:			
Mean FEV_1 % predicted (sd)	92.5% (20.8)	97.2% (18.6)	NS
Mean PEF % predicted (sd)	99.5% (24.6)	97.7% (18.2)	NS
Median no. days off school (mode, range)	0 (0, 0-20)	0 (0, 0-20)	NS
Inhalers:			
Reliever	50 (98%)	50(100%)	NS
Preventer	42 (82.4%)	37 (74%)	NS
Long Acting Reliever	31 (60.8%)	21 (42%)	NS
Combination Prev. & LAR	3 (5.9%)	8 (16%)	NS

NS- Not significant

* Significant at the 0.01 level

\# Calculated using log- transformed scores

6.7.4.2 HYPOTHESIS 1. CHILDREN USING THE CD-ROM WILL HAVE GREATER KNOWLEDGE INCREASES THAN THOSE VIEWING ONLY THE BOOKLET.

Repeated measures ANOVA was performed to investigate whether the change in knowledge scores over time was different between the two groups. AKQ1 scores at Time 1 and Time 2 demonstrated homogeneity of variance (Mauchly's W=1, $p< 0.001$) and covariance (Box's M= 6.56, $p=0.093$), thus satisfying assumptions for use in a repeated measures ANOVA, despite Time 1 scores not having a normal distribution (Grimm and Yarnold, 2000). It was particularly appropriate for this sample as each child would act as a 'control' for him or herself, thus minimising the effect of the disparity of ages between the two groups. Age was also entered as a covariate in the analysis.

Using a repeated measures ANOVA, there was no overall effect of time on knowledge scores: $F(1, 96)= 0.74$, $p=0.39$; however, the analysis showed an interaction between fime and group: $F (1, 96)= 13.55$, $p< 0.001$. There were no differences between groups on knowledge at baseline but examination of the two groups' means showed a greater increase in the computer group- mean change of 3.03 Vs 1.09 in the control group. It can also be seen from Figure 6.13 (on the next page) that whilst the confidence intervals overiap at baseline (indicating no differences), there is no overiap at Time 2. Therefore, knowledge levels of children in the computer group increased significantly more than those of children in the control group.

Repeated Measures ANOVA was also performed on the total knowledge (AKQ1 + AKQ2) scores at Time 1 and Time 2, covarying for age. Again, the data met sphericity assumptions (W=1, $p<0.001$; M= 0.61, $p=0.90$). The interaction was significant for group over time for total knowledge scores: $F(1, 96)= 10.27$, $p<0.01$. Mean change was greater for the computer group (3.83) than the control group (1.63) which is demonstrated in Figure 6.14 on the next page.

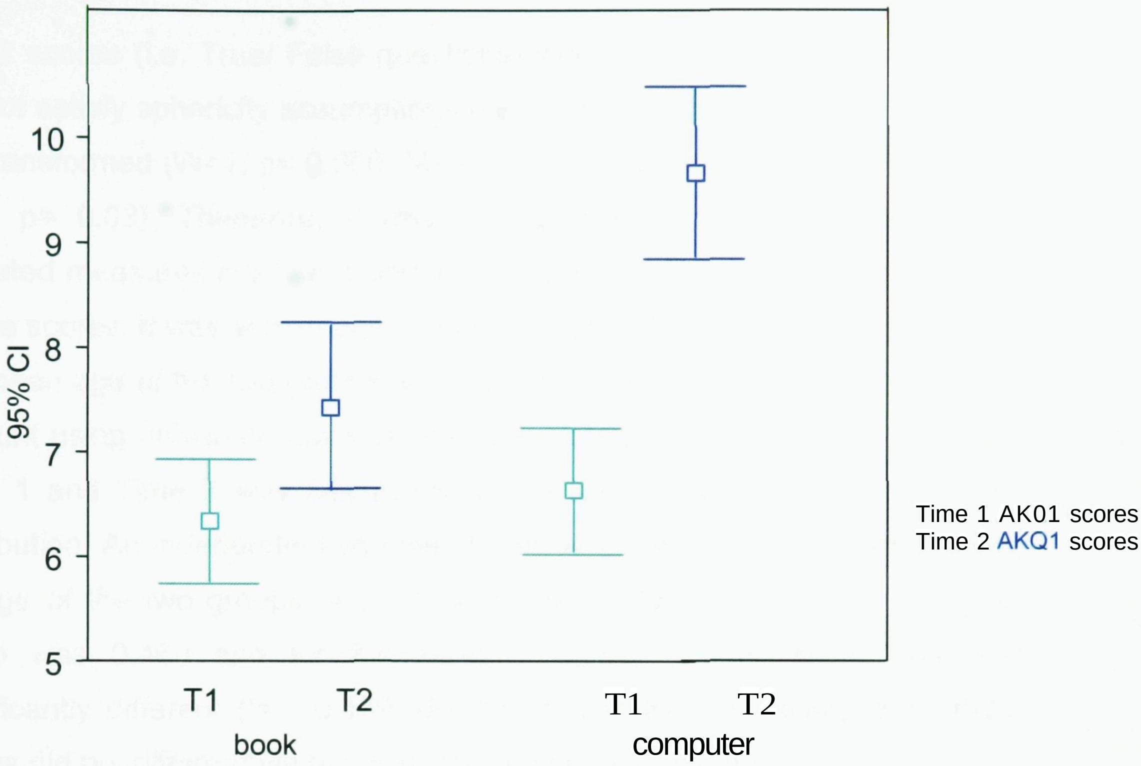


Figure 6.13- Mean increase in AKQl (semi -structured) knowledge scores

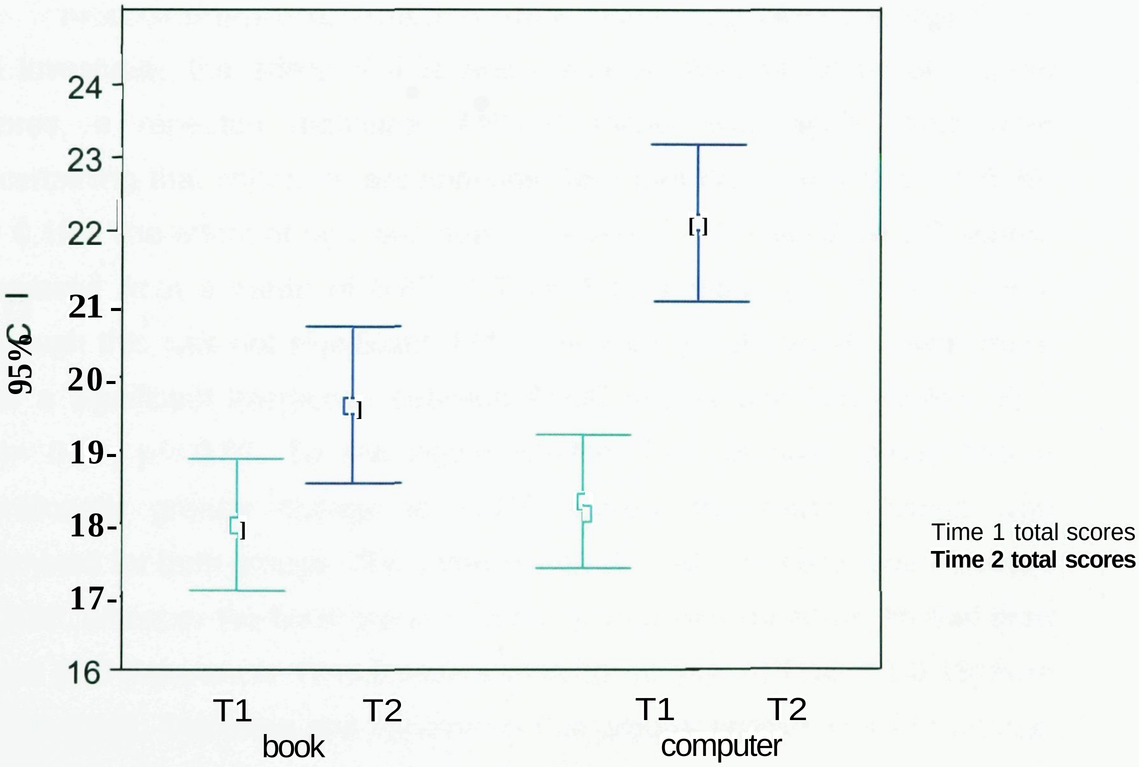


Figure 6.14- Mean increase in total (open questions & T/F summed) knowledge scores

AKQ2 scores (i.e. True/ False quesfions) were not normally distributed and did not safisfy sphericity assumptions (W= 1, p=0.000, M= 0.046) even when log transformed (W=1, p= 0.000, M= 0.024) or squared (W= 1, p= 0.000, M= 8.85, p= 0.03). Therefore, it was not appropriate to include them in a repeated measures ANOVA model to test the effect of time and intervention on the scores. It was also inappropriate to conduct Mann Whitney analysis as the mean age of the two groups was different, which would not be taken into account using univariate analysis. Instead, change in AKQ2 scores between Time 1 and Time 2 was calculated, which resulted in data with a normal distribufion. An independent samples t- test was used to compare the mean change of the two groups; the mean change in AKQ2 scores for the book group was 0.460 and for the computer group 0.510, which was not significantly different (t= - 0.159, df= 86.14, p=0.87), indicafing that AKQ2 scores did not differentiate between the two groups over time.

6.7.4.3 HYPOTHESIS 2. CHILDREN VIEWING THE CD-ROM WILL SHOW A GREATER INCREASE IN INTERNAL LOCUS OF CONTROL THAN THOSE VIEWING THE BOOKLET.

To investigate the effect of time and group on Asthma Locus of Control scores, a repeated measures ANOVA model was again used after ascertaining that sphericity assumptions were met (W=1, p=0.000, M=5.39, p= 0.15). The effect of age was again co- varied out. Overall ALOG scores increased from a mean of 6.85 at Time 1 to a mean of 7.11 at Time 2 although this was not significant: F(1, 94)= 2.06, p< 0.154. However, there was a significant interacfion between ALOG scores and intervenfion: F(1, 94)= 8.71, p< 0.01. To investigate whether the computer group had a significantly greater change in ALOC scores, the mean change was examined for both groups. The computer group had a positive mean change of 0.90, whereas the book group's mean change was negative, so that their mean ALOG scores at Time 2 were slightly lower than at Time 1 (-0.18) (see Figure 6.15). Therefore, the hypothesis that greater change in internal locus of control would be seen in the computer book was accepted.

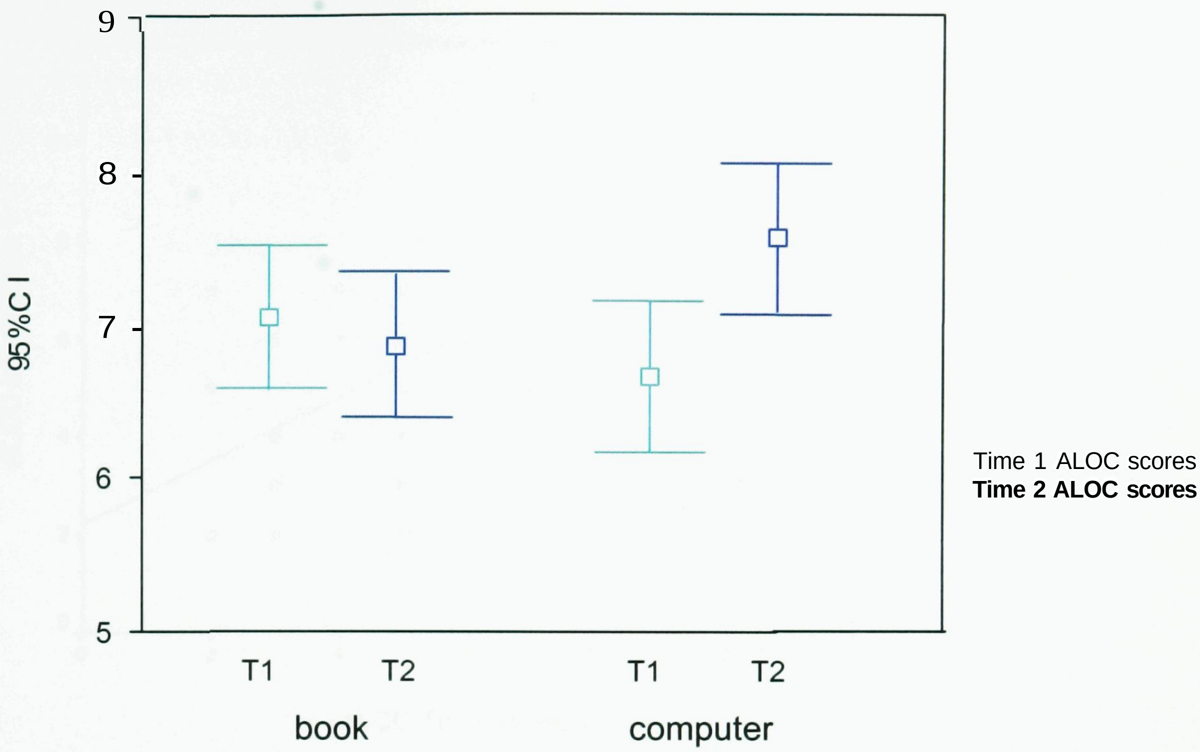


Figure 6.15- Asthma Locus Of Control scores at Time 1 and Time 2

To invesfigate whether the increase in locus of control scores were mediated by knowledge, correlations and linear regression were performed. Asthma locus of control scores at Time 2 were highly correlated with ALOG Time 1 scores (n=97, r= 0.64, p<0.01; see Figure 6.16). To invesfigate the influence of knowledge on AL0G2 scores, a stepwise regression was carried out with ALOG Time 2 scores as the dependent variable and AL0G1, age and knowledge as the independent variables. In order to avoid any complicating effect of 'group', it was not included in the regression model. The regression showed that AL0G1 scores (p= 0.33, t= 3.33, p=0.001) age (p= 0.30, t= 3.0, p<0.01) and knowledge measured by AKQ1 scores at Time 2 ((3= 0.22, t= 2.41, p=0.018) all contributed toward the variance in AL0G2 scores with a total adjusted R^2 of 0.50. Knowledge measured by the AKQ2 scores at Time 2 did not contribute to the variance in ALOC2 scores when included in the regression model.

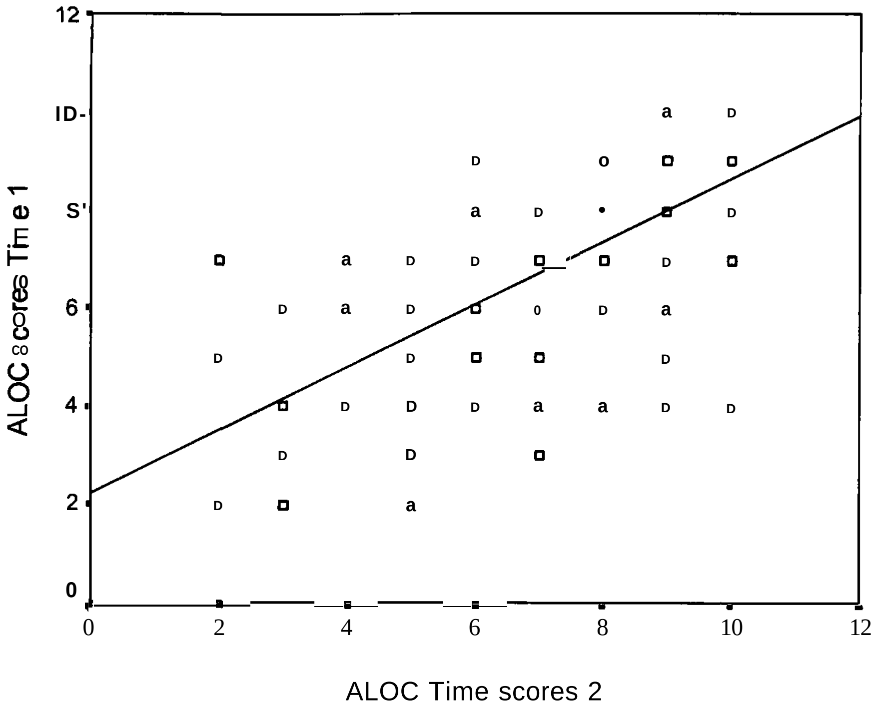


Figure 6.16- Correlation between Asthma Locus of Control scores at Time 1 and Time 2.

It can be concluded, then, that the primary predictive factor in ALOC scores at Time 2 is scores at Time 1, but that age also accounts for a significant amount of the variance. Knowledge also had a mediating effect on ALOC scores.

6.7.4.4 HYPOTHESIS 3. CHILDREN VIEWING THE CD-ROM WILL DEMONSTRATE A GREATER INCREASE IN RESPONSIBILITY FOR MONITORING AND RESPONDING TO ASTHMA SYMPTOMS THAN THOSE VIEWING THE BOOKLET.

In order to investigate change in responsibility between Time 1 and Time 2, responses to Question 25 in the parental questionnaire (see Appendix 13) were used.

The data were normally distributed and met sphericity assumptions so repeated measures ANOVA was used to investigate change in the scores between the two fime-points. Although there was a significant effect of time, whereby mean scores increased from -4.60 to - 3.58 (with higher scores representing child taking greater responsibility), the interacfion between intervenfion and fime was not significant i.e. the increase was not markedly different between the groups: F (1, 95)= 1.59, p= 0.210 (See Figure 6.17)

Individual aspects of self- management were considered separately for evidence of change, but only 'responsibility for reliever medication' showed any significanfly different change between Time 1 and 2, and it was seen for the book group (Z= -2.03, p=0.04) (See Figures 6.18 & 6.19).

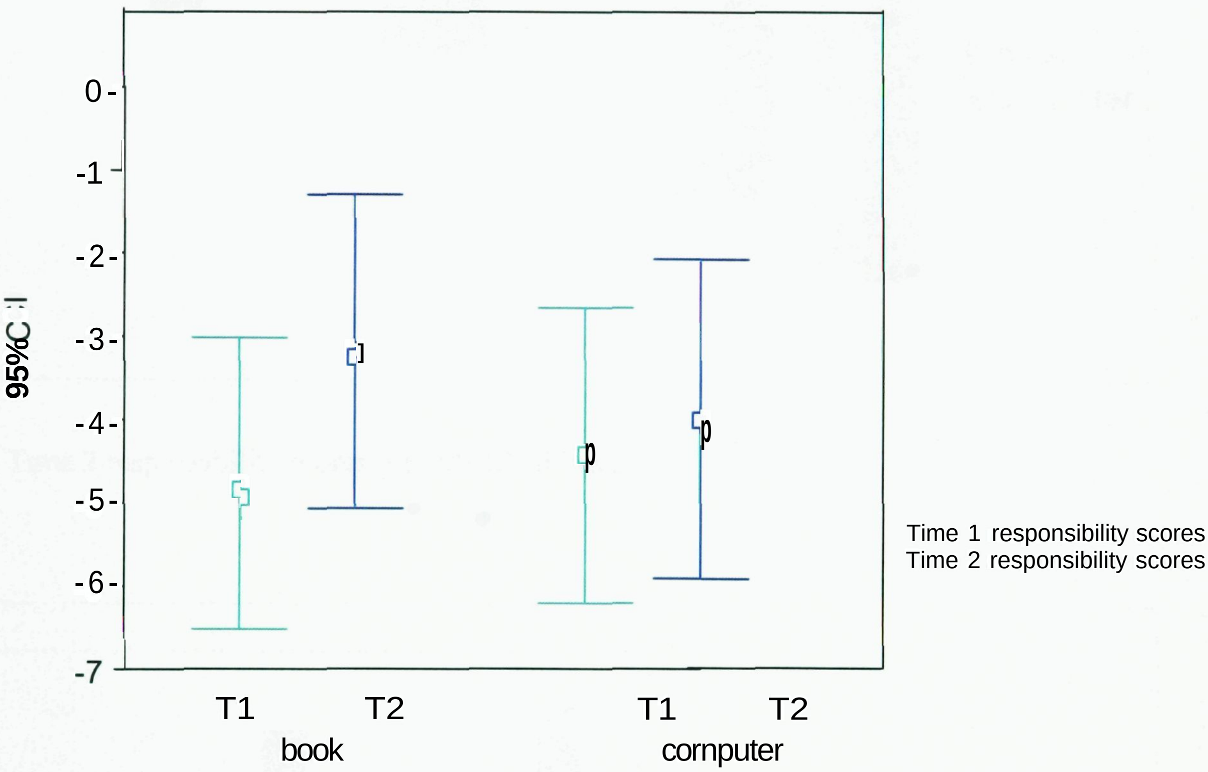


Figure 6.17- Responsibility scores at Time 1 and Time 2

The responses of those children who had shown positive change in any responsibility items were examined for an intervention effect, but there were no significant differences between the two groups.

In addition to questioning the parents about responsibility over asthma behaviour, children were also asked who (if anyone) reminded them to take their medications and/or perform PEF measurements. Their responses at Time 1 and Time 2 were compared but there were no differences between the groups in change in responsibility in these two variables overall. Twenty-one children took greater responsibility for taking their inhalers and twenty-five for performing their PEF measurements between the two time- points, although again, this was not significantly different between groups.

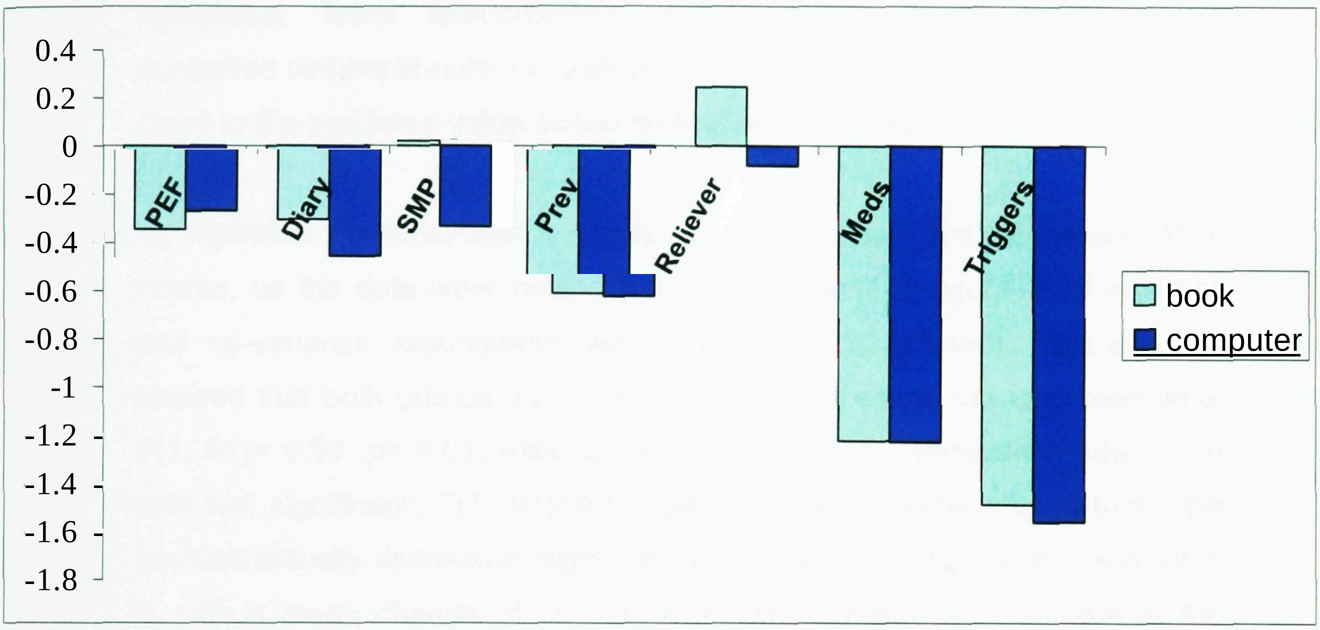


Figure 6.18- Time 2 responsibility scores for individual items

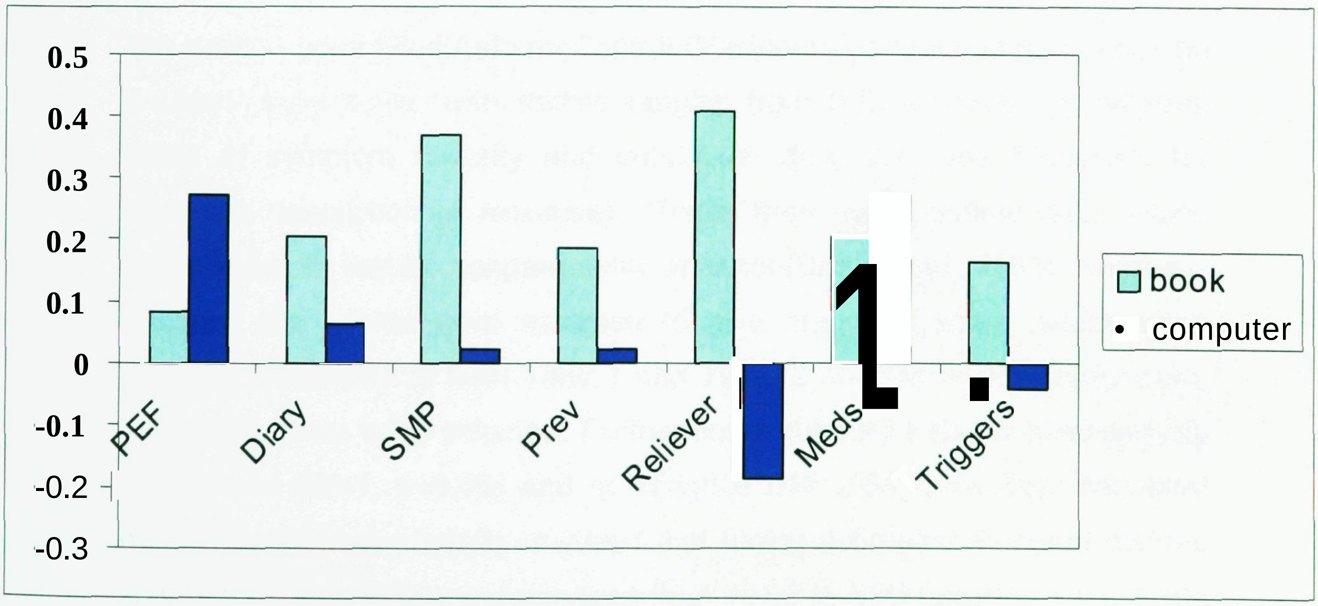


Figure 6.19- Change in responsibility scores for individual items

6.7.4.5 HYPOTHESIS 4. CHILDREN VIEWING THE CD-ROM WILL DEMONSTRATE A GREATER INCREASE IN CONTROL OVER THEIR ASTHMA THAN THOSE VIEWING THE BOOKLET.

The most basic outcome measure of asthma control employed was lung funcfion, a proxy outcome measure for self- management behaviour. As the literature shows, 'good' self- management should result in reduced asthma symptoms, fewer exacerbations and minimum limitations; thus, well controlled asthma should, in most cases, result in FEV_1 and/ or PEF readings close to the predicted value based on the individual's details.

A repeated measures ANOVA model was used with both FEV_1 and PEF scores, as the data were normally distributed and homogeneity of variance and co-variance assumpfions were safisfied in both cases. The analysis showed that both groups' FEV_1 percent predicted score changed over time: $F(1, 91)= 6.53$, $p= 0.01$, although the lung function- intervenfion interaction was not significant: $F(1, 91)=0.11$, $p=0.74$. The analysis shows that lung function actually decreased slightly in both groups between Time 1 and Time 2, with a mean change of -3.14% in the book group and -4.08% in the computer group, although this difference wasn't significant: $F(1, 91)= 1.03$, $p= 0.31$. PEF scores did not change over fime in either group but remained high at around 98- 99% at Time 2.

The parent- completed Asthma Control Quesfionnaire required responses on a Likert- style scale, with scores ranging from 0-6, represenfing different levels of symptom severity and impact on daily life (See Measures for complete description of measure). These, then, were ordinal data, which would normally require nonparametric analysis (Brace *et al.*,2003). However, because the scores were summed to give one final score, which were normally distributed at both Time 1 and Time 2 and had a meaningful zero, parametric tests were selected. Furthermore, the data showed homogeneity of variance ($W=1$, $p=0.00$) and co-variance ($M= 2.84$, $p= 0.43$). Repeated measures ANOVA analysis revealed that (using esfimated marginal means) scores for the book group decreased from 10.62 to 9.06 between Time 1 and 2, indicafing an improvement in symptoms, although the computer group's scores had increased marginally, from 6.24 to 6.98, indicafing that symptoms had worsened. The effect of time within the two groups was not significant, although the effect of intervention group was statistically significant: F(1, 91)= 6.059, p=0.02. The ACQ- fime interaction was just short of significance at F(1, 91)= 3.79, p= 0.055. Despite the small increase of ACQ scores in the computer group, this was not significant (t= -0.82, df= 45, p= 0.42). See Figure 6.20

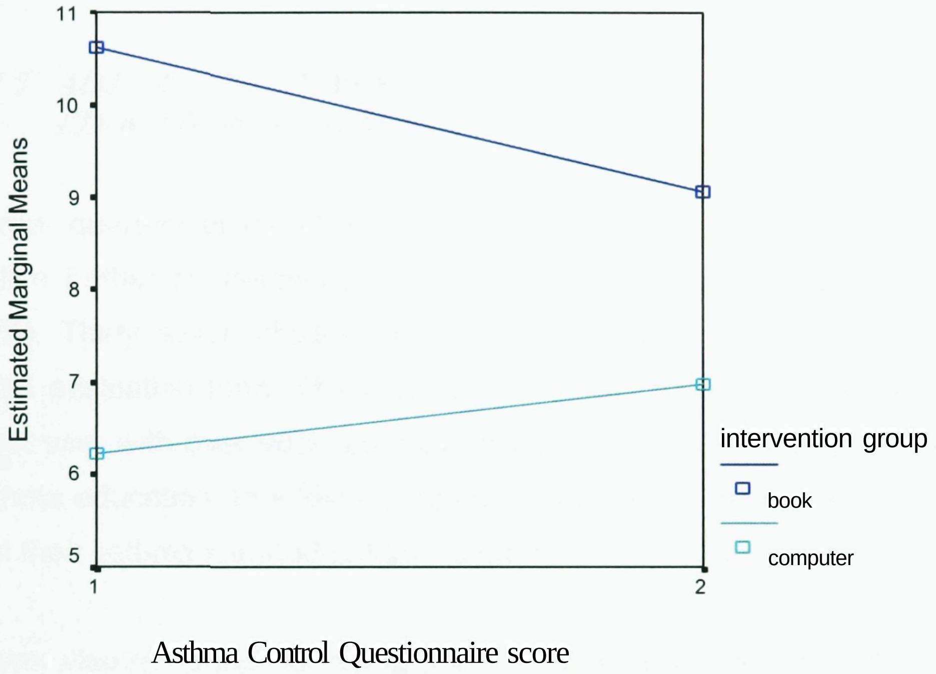


Figure 6.20- ACQ estimated marginal means at Time 1 and Time 2 by group

Other indicators of asthma control were whether the child had required oral steroids since Time 1 and whether medications had been increased or decreased, which were obtained through parent report at Time 2. Ghi-squared calculations showed no difference between the book and computer group on these variables. None of the children had been admitted to hospital during the course of the study, and equal numbers in each group had made unscheduled visits to their GP or attended Accident and Emergency since the baseline interview.

In Part 1 of the AKQ, children were asked which inhalers they were currenfly taking, as well as the dose (how many puffs) and frequency. Children self-report correlated significantly with parental report (reliever medicafion: r=

0.32, n= 89, p= 0.002). These answers were used to calculate whether they were taking more medication at Time 2, the same or less. These simplified scores for reliever and preventer medication were then compared separately across groups using chi- square calculafions, which revealed that there were no differences in self- reported change in levels of either reliever or preventer medication between the computer and book groups.

6.7.5 AIM 4- TO INVESTIGATE THE ACCEPTABILITY OF AN EDUCATIONAL CD-ROM IN USERS WITH ASTHMA

Three- quarters of the children in the computer group owned a computer, with a further six percent purporting to have access to a computer (total= 82%). Thirty seven children from the computer group completed the CD-ROM evaluation form. The program was rated by the children as being of great use, with over 90% reporting that they had found it a good method of asthma education. In addifion, the majority felt that it had been effective and that their asthma knowledge had increased through using the program.

It was also important to investigate how easy the children had found it to navigate round the program. Approximately 30% of the children appeared to have experienced some difficulties; they reported that they would like to have received more help finding 'hidden' parts of the program and that it was somefimes unclear how to exit different sections. Older children found the navigation easier than younger children (Z= -2.56, p< 0.01). Overall, however, most children (83.3%) found navigafion relatively simple. Three quarters of the children perceived the program as 'fun' which was unaffected by age (z= -0.13, p= 0.91). Table 6.4 summarises the responses to the CD-ROM evaluafion quesfions.

Table 6.4- Responses to CD-ROM evaluation form

Item	**Agree** (%)	**Disagree** (%)
It was easy to find my way round	31 (83.8)	6 (16.2)
I learned a lot looking at the program	31 (86.1)	5(13.9)
The Asthma Files was boring	3(8.1)	34(91.9)
There should be more interactive bits	13(35.1)	24 (64.9)
The Asthma Files is a good way to learn about asthma	35 (94.6)	2 (5.4)
The pictures helped me understand what happens inside my body	32 (86.5)	5(13.5)
The Asthma Files was a waste of time	2(5.6)	34 (94.4)
I know more about my asthma having looked at The Asthma Files	31 (83.8)	6(16.2)
I always knew how to get out of a room	25 (69.4)	11 (30.6)
The Asthma Files was fun	27 (75)	9(25)
The voices were good	29 (78.4)	8(21.6)
There should be more help finding the secret level	11 (29.7) yes	26 (70.3)
I would tell other people to use The Asthma Files	33 (89.2)	4(10.8)

The findings on the evaluation form were confirmed by the qualitafive responses children gave;

- "I liked the whole program, I thought it was brill!" (Charlotte, 14 years)
- "I liked it all, especially the interactive bits where you do things for yourself (Andrew, 14 years)
- "The secret games level was good" (Gary, 10 years)
- "I liked the top secret file, it was cool!" (Shannon, 12 years)
- "I liked the games and interactive things" (Emily, 13 years)
- "I liked all of the games, especially the asthma triggers. All of the information is really interesting and the quizzes are very good." (John, 8 years)
- "I liked the interactive things that you could click on" (Jenny, 14 years)
- "I liked it because you could learn things about asthma that you didn't know" (Nick, 13 years)
- "I liked finding out about my asthma" (Sarah, 12 years)

Over half of the children (57.1%) reported using the computer program again after the initial visit. On average, they had used it twice more, although some children reported using it up to ten fimes. Beyond having access to a computer, there did not appear to be any variables that predicted whether or not a child used the computer program again: those who used the program again did not differ from those who had not looked at it again on age, gender, ALOG or knowledge scores at Time 1. There were no items on the CD-ROM evaluation form which were indicative of continued use. However, those who had used the computer again had significantly higher knowledge scores (AKQ1) at Time 2 than others in the computer group who had not used the package again ($t= -2.67$, $df= 47$, $p=0.01$).

6.7.6 Six month follow- up results

Incidences of hospital admission, unscheduled visits to the hospital or GP, use of oral steroids and days off school were collected at the six- month follow- up telephone interview with parents. Out of 101 enrolled participants, 90 participated in the 6 month follow- up interview (89.1%). Two children (1.98%) had dropped out between Time 1 and Time 2, one in each group: one parent cited current personal difficulties and the other did not give a reason. The remaining nine (8.9%) children were untraceable. Those who were lost to follow- up at six months did not differ from the rest of the sample on any baseline measure or Time 2 measures, except from AKQ1 scores at Time 2, which were higher for responders (median= 9.5) than non-responders (median= 5), ($Z= -2.01$, $p=0.04$).

Chi- square statistics were used to compare the two groups on the 6 month outcome measures. One child in each group had been admitted to hospital and slightly higher proportions of the book group than the computer group had paid an unscheduled visit to their GP (33% Vs 18%) although this wasn't significantly different. Only 13% of the computer group required oral steroid medicafion in the six months post intervenfion, compared with 31.8% of the book group ($\chi^2= 4.14$, $df=1$, $p= 0.04$, one- tailed; Figure 6.21). At baseline, there were no differences between the groups on the number taking time off school due to their asthma, but at follow-up, significantly greater numbers of the book group (57.8%) had taken fime off school for their asthma than the computer group (36.4%) (χ^2= 4.094, df=1, p= 0.035, one- tailed). The book group had also taken significanfly more days in total (median= 2 days) than the computer group (median = 0), (Z= -2.12, p= 0.03).

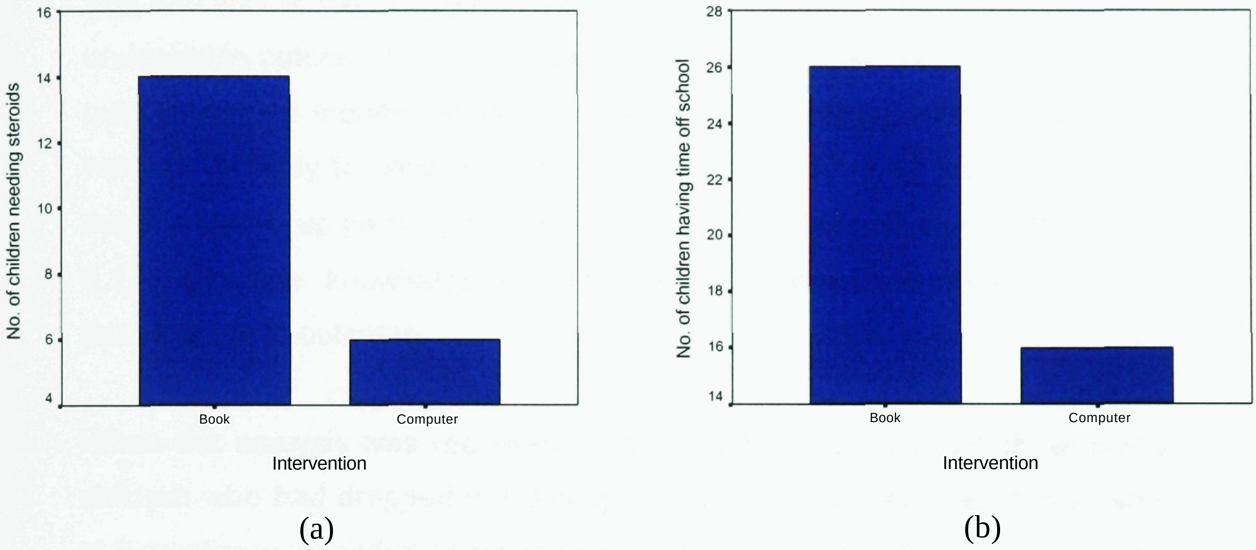


Figure 6.21a & b- Use of oral steroids (a) and days off school (b) in six months post-intervention for whole sample (n=88)

When the children were considered in age bands (7-10 & 11-14 years) differences between the groups were also found. Amongst the younger children, the book group were significantly more likely to have required oral steroids than the computer group (Z= -2.95, p< 0.01), although there were no differences in those taking fime off school. Unsurprisingly, given that medication had been required, the younger book group were also more likely to have had an unscheduled visit to their GP than the computer group in the younger age range. There were no differences between the groups when the data for the older children were examined.

The number of days taken off school in the month prior to enrolling in the project were compared with school absences in the six- month follow-up (adjusted to represent one month). In a linear regression model, only the number of days reported at Time 1 predicted the extent of school absence at

6 month follow- up (β=0.38, t=3.74, p=0.00); knowledge, intervenfion or ALOC did not contribute.

A dichotomous variable was created which represented those who had reported either taking oral steroids during the six month follow-up period and/ or taking time off school versus neither requiring steroids nor time off school. The aim was to identify characteristics which could be used to predict these undesirable outcomes. Logistic regression revealed that intervention affected outcome at six months on this variable, such that those in the book group were more likely to have required steroids and/ or time off school in the six months follow- up period (χ^2= 4.61, df= 1, p= 0.03; Odds Rafio= 0.40, 95% CI 0.17-0.93). Age, knowledge or ALOG scores at Time 2 did not contribute to the variance in outcome.

When the analysis was repeated on an 'intenfion- to- treat' basis, whereby children who had dropped out during the study or had not been contactable at 6 months were coded as having an 'adverse outcome', the computer group still had more favourable outcomes than the control group (χ^2= 4.40, df= 1, p=0.036; Odds Ratio= 2.33, 95% GI 1.05- 5.20).

6.8 Discussion

This study comprised a randomised, controlled trial evaluafing the effectiveness of an educafional CD-ROM for children with asthma. In addition, information needs of the children were investigated, along with factors contributing to higher knowledge levels and successful self-management. Effecfiveness of the computer program was assessed by looking at changes in knowledge, locus of control and control of asthma symptoms. Acceptability of the program was established through child feedback.

6.8.1 Knowledge levels and information needs

For the group as a whole, knowledge levels at baseline were low, which concurs with previous research (Gleeson, 1995; Gibson *et al,* 1995) although higher scores were achieved when using the true/ false scale rather than semi- structured questions. This is unsurprising given that true- false questions are less cognitively demanding, requiring only recognition of the information rather than free recall; thus a knowledge test based solely on true/false questions may not reveal the true extent of the child's information needs.

The majority of the children knew that asthma affected their lungs but very few mentioned involvement of the airways (or colloquial terms such as 'pipes' or 'tubes'). Perhaps it does not matter whether children know and can recall such medical facts and terminology? It could be argued that as long as children know what to do when they have an asthma exacerbafion, it is not vital that they have a good working knowledge of the part(s) of the body responsible. However, inflammation in the ain/vays is considered to be the primary agent in asthma exacerbations (Ho *et al,* 2003) and prevention of this inflammation is key to good asthma management (McQuaid *et al.,*2003). Regular use of prophylactic medication, i.e. inhaled corticosteroids, can prevent inflammation, which many of the children were prescribed. Only around 15% could explain their preventer inhaler's acfion, which is lower than previously reported (Gleeson, 1995) so it appears that few understood the fundamental role inflammafion prevention plays in their asthma management. Without some appreciation of the reason for taking medication, adherence to treatment may be less likely (Eiser, 1988); in the early years, parental knowledge may compensate for lack of child knowledge to ensure adherence, but as children get older and become more responsible for their managing their own illness, it is important that they know the main elements of asthma management, including the primary purpose of taking their medications. Therefore, it would seem important that children have some knowledge of the basic physiology of asthma given that it is directly applicable to management of the illness.

In addition to asthma knowledge, however, there may be areas that are important to patients which weren't addressed in this intervention. Quality of life was only touched on briefly in relafion to daily funcfioning, but is an important aspect of assessing the impact of any chronic illness (Drummond, 2000; Eiser & Morse, 2001). Tasks and events that may affect children and young people on a daily basis, such as taking medicafion at school and explaining asthma to peers were addressed in the program using a range of techniques, including modelling positive behaviour which is an important element of Social Learning Theory (Smith, *et al,* 2003). However, the participants' experience of such matters and the level of importance it held for them was not investigated in this current study and it could be that concerns such as these impact upon health- related behaviour in a more fundamental manner, regardless of knowledge levels.

Eariy symptom perception is another critical component of asthma management (Male *et al,* 2000; J0rgensen ef *al,* 2003), but less than half of the sample named either breathlessness or wheezing as signs of asthma exacerbafion, even though research suggests that they are the symptoms most commonly experienced (Kanabar, 2000; Helms, 2001).

The other main component of good asthma control is avoidance of allergens or irritants which are known to 'trigger' an exacerbation of asthma symptoms. Children showed only a moderate awareness of factors which could potentially aggravate their symptoms. Interestingly, the trigger most commonly named was exercise/ activity, although other research has demonstrated dust mite allergy to be the most common trigger (Rees and Price, 1995), which only approximately a quarter of the children in this study named. Estimates of the extent of exercise- induced asthma varies between studies, from 45% (Sano ef *al,* 1998) to 90% (Milgrom and Taussig, 1999) but it is possible that children with asthma are inappropriately avoiding exercising when guidelines suggest that most children with asthma can exercise safely if taking appropriate medication (Cypcar and Lemanske, 1994). Previous research has found that more children simply avoid exercise than prevent attacks with pre- exercise medication (Eiser ef *al,* 1988), although this may not solely be due to a lack of knowledge; it may also reflect the reluctance of children to take medication in front of peers as well as anxiety teachers may have when including children with asthma in exercise classes. However, this lack of exercise may put children at risk of obesity which has been linked with poor asthma control (von Mufius *et al,* 2001; Chinn and Rona, 2001; Li *et al,* 2003; Ho *et al,* 2003). Information about possible trigger factors and addressing them appropriately evidently requires particular attention in any educational programme.

The majority of children owned a peak flow meter, although not all of them could estimate what their predicted (or best) score would be, nor what reading would necessitate urgent action. On average, those who did answer provided reasonably accurate figures; however, some esfimated much lower than predicted for their age and height for both 'best' and 'low' peak flows. Overesfimating or underesfimafing PEF obviously has implicafions for successful management of asthma symptoms, as medication may be taken unnecessarily or dangerously late. It is clear from this that even children who own a PEF meter may not know how to use it to aid their asthma management. Doctors of those with mild asthma may not feel that it is necessary for them to measure their peak flow regulariy, although it is common for children to be encouraged to assess their lung funcfion if symptoms exacerbate. Indeed, it has been shown that self- management programmes based on peak flow (as opposed to simply symptoms) are more likely to improve lung funcfion and reduce morbidity (Guevara et al, 2003; Wolf et al, 2003), therefore it is still important for children to have knowledge of their predicted, or 'best' score, even if approximately.

6.8.2 Factors affecting knowledge levels and/or self- management

Children who scored higher on both parts of the knowledge quesfionnaire were older and had a higher verbal IQ. However, the duration of the child's asthma did not affect their knowledge scores which adds to the confused picture of the relationship beh/veen illness experience and knowledge. Perhaps this is an example of how chronic illness may 'retard' the development of illness- related knowledge (Eiser *et al,* 1988), even about new illness concepts (Krishnan *et al,* 1998). It is possible that after a certain length of fime suffering from a chronic illness, children no longer absorb any further information, so special efforts are needed to cater to children who may still have information needs unmet by traditional health education despite having a long-standing illness.

It was hypothesised that children with higher knowledge would feel more in control of their asthma (as measured by the ALOC) but this was not the case once age and verbal IQ had been accounted for. This would suggest that older children who have a more sophisticated level of knowledge about asthma do not necessarily feel more in control of their asthma and its treatment than older children with less knowledge. Alternatively, it may simply reflect the fact that verbal IQ and knowledge were very strongly associated.

6.8.3 Impact of computer program

Despite children in both groups receiving some form of information, knowledge levels did not significantly increase overall once age had been taken into account, although there was a small increase. The knowledge scores of children in the computer group increased significantly more than the children in the booklet group when comparing scores on Part 1 of the AKA and the total scores (AKQ1 + AKQ2), suggesting that computer delivery was superior. Furthermore, those who had subsequenfiy used the computer program after the researcher's visit demonstrated higher knowledge levels (AKQ1) after one month than those who had only used it once. However, the change in true/ false scores did not differentiate between the groups. This may be because the mean at baseline was reasonably high at 12/15 and thus there was not scope to show large improvements i.e. a 'ceiling effect' (Goolican, 1996).

Asthma control (as perceived by the parent) improved in the booklet group between Time 1 or Time 2, although the computer group scored slightly but not significantly worse. It is likely that this effect was a result of the disparity in ages between the groups.

Children in the computer group demonstrated significantly more internal locus of control at Time 2 compared with the control group, who became slighfiy more externally orientated. This is a particularly pertinent finding, given the links between feelings of control over illness and improved illness outcomes (Dupen *et al,* 1996; Tieffenberg *et al,* 2000). The computer package is cleariy adept at promoting children's feelings of control which is further support for multimedia's ability to work effectively within a social learning theory framework.

It has been suggested that solely providing information without any opportunity to practise skills and receive positive reinforcement is unhelpful (Bandura, 1986; van der Palen *et al,* 2001). Furthermore, researchers have previously warned of the dangers of providing informafion without appropriate support (Allen *et al,* 1984). In this current study, children in the computer group were given the opportunity to become more proficient in skills through pracfice, albeit virtually, whereas the children receiving the booklet had no such opportunities. Children were also supported when undertaking tasks on the computer and given feedback so that mistakes were used as a learning experience and correct behaviour was reinforced.

There were no time limits set for using the computer program, although it typically took 1- ½ hours to complete the whole thing. In comparison, it is unlikely that the children looked at the booklet for anywhere near that long. Therefore, it could be argued that it was the extent and intensity of the information received via the computer program that enhanced knowledge levels rather than the program *per se.* However, this is one of the great strengths of multimedia education for children: by making it entertaining and providing a competitive element, children will engage with the program to become proficient at it, whilst learning the information entrenched in it (Lieberman, 1997). Of course, if a health professional went through printed material with a child for an extended period of time, this may well also result in improved knowledge. However, given the resources that would require, if nurse fime and the computer package are equivalent, a computer program would be more cost- effective. Research directly comparing the two would be useful future work.

ALOG scores were mediated by knowledge scores when free- recall (AKQ1) scores were included in a regression model, which agrees with previous research reporting links between the two variables (Taggart *et al,* 1991; Tieffenberg ef *al,* 2000). Age, along with baseline ALOG scores, accounted for a large part of the variance in ALOC scores, however.

It was hypothesised that the computer program would increase the level of responsibility taken by children over their asthma management, for example, by measuring their peak flow or avoiding 'triggers' on their own inifiative with less support from their parents. These are vital components of asthma management about which children need to be both competent and confident if they are to control their asthma successfully as they grow older. The computer program was designed to instil this confidence in them, both through the teaching of basic skills and provision of positive reinforcement. Although there was a small increase in responsibility across the sample, there was not a marked increase in either group on the pooled score (across all six facets) or on individual items. The exception was an increase of responsibility in taking reliever medication which was demonstrated by the book group. It is possible that better asthma control in children in the computer group meant that they needed their reliever inhaler less so making the control group's rates appear increased, although self- reported medication use did not change. Alternatively, this finding may be a type I error because of the large number of comparisons made. A true shift in responsibility would necessitate a significant change in parental behaviour, given that only 17% children reported that they always remembered to take their inhalers at the start of the study. Tieffenberg and colleagues successfully showed an increase in child responsibility for avoiding triggers and measuring peak flow after their educafional intervenfion (Tieffenberg, 2000); however, this was after intensive work with parents by professionals with a view to changing this specific behaviour in both child and parent. Our study did not target parents specifically, although many reported having previously seen a copy of the booklet, which may possibly have influenced their behaviour. In comparison, the computer program was very much targeted at children and parents may have been reluctant to use it on their own.

The primary clinical outcome measures was lung funcfion, which showed no significant difference on PEF and a slight decrease in FEV_1 across both groups over time. An increase in lung funcfion is dependent upon enhanced knowledge influencing self- management to such an extent that airway inflammafion reduces, which was perhaps a little opfimisfic in one month. Furthermore, there was unavoidable variafion in fime of spirometry assessment throughout the day; many of the participants were recruited at a morning clinic and the majority of one- month follow-up visits took place after school. Normally, the lowest lung funcfion occurs in the morning, rising to its peak later in the afternoon (Vianna *et al,* 2002) which is the opposite of our findings. However, it is possible that children were particulariy careful to take their medicafion before coming to the asthma clinic which may have increased their morning lung funcfion; long- acfing β_2- agonists in particular have been found to increase lung function in the morning (Reddel *et al,* 1999). In addifion, school activities and journeying home may have impacted on their lung function scores at the afternoon follow- up visits; research has shown that exercise- induced bronchospasm is greater in the evening than the morning (Vianna *et al,* 2002). Measures of lung funcfion such as FEV_1 and PEF are also susceptible to difficulties with technique; to get three technically correct manoeuvres from which to select the highest score may take many attempts, which can distress some children and even induce asthma symptoms. It may also have been beneficial to assess inhaler technique as this can have significant implications for medicafion adherence (Gleeson, 1995): improving self- management behaviour will not be effecfive if fundamental skills are erroneous. However, children in both groups had their inhaler technique assessed and corrected if necessary at each clinic visit so it would be unlikely to count as a major factor.

After one month, no differences between groups on steroid use were apparent and none of the sample were admitted to hospital during the course of the study. However, one month was probably insufficient time to assess this properiy, especially since people seeking help from hospitals often report having already experienced symptoms for extended period of time (Male et al, 2000). Equivalent numbers in each group had made unscheduled visits to the hospital or their doctor due to an exacerbation of asthma symptoms and there was no change in inhaled medication between groups. Again, is likely that the interval was insufficient to capture any true differences

It was encouraging that increased knowledge and locus of control scores were demonstrated by the computer group at one- month follow-up but the two groups were broadly equivalent on the other outcome measures. However, the differences behA/een the groups on 'proxy' clinical outcomes were much more apparent after six months. Significantly more children in the book group reported school absence than in the computer group and the total number of days taken was also significantly higher in the book group. Attending school allows children to develop both socially and educationally and school absence is commonly used as an outcome measure, given its power as a marker of funcfioning in children with chronic illness. It is a non-specific indicator, however, and can reflect not only health status such as the severity of the illness, but also the ability of the child and family to cope with the condition, their health beliefs and the effectiveness of current illness management (Weitzman, 1986). Even small increases in school attendance can reflect significant improvements In funcfioning. One of the goals of the computer program was to provide the children with the skills to manage their asthma effecfively whilst minimising disruption to their everyday life and so attempted to target both physical and psychosocial needs. Using school attendance as an outcome in this study was therefore particulariy appropriate because of its ability to reflect the child's functioning on a number of levels. However, this study relied on parental report, which may be unreliable and open to recall bias. Obtaining the data directly from school records is a more rigorous approach, although presents several problems of its own: obtaining school attendance rates for individuals is very fime- consuming and schools can be reluctant to share the information. Informed consent should be sought for this information to be gathered, which can make parents unwilling to participate in research. Knowing that this informafion will be recorded may also influence children's attendance, which may confound the effect of an intervenfion.

It is possible that there was recall bias when reporting days off school at the six- month follow-up interview. It could be argued, however, that school absence would be particulariy noted by parents of children in the computer group due to having received the intervention. Parents of children in the booklet group who had minimal contact with the researcher may be less likely to note days off school, thereby biasing recall in the 'wrong' direction. To show fewer days school absence in the computer group should be regarded as a robust finding in these circumstances.

As school absence is an indirect measure of asthma severity, it is possible that the differences at six months were due to the baseline differences in asthma control, such that the control group had higher ACQ scores (i.e. more poorly controlled asthma) than the computer group, despite little variafion in lung function. However, there were no differences in school absence between the groups at Time 1, suggesfing that the differences subsequently seen at 6 months were a function of the intervention.

Oral steroid use was also more common in the book group at six months follow-up. Steroid use prior to the study was not recorded; this information may have helped investigate the impact of the intervention on clinical outcomes further.

The likelihood of having an overall 'adverse outcome' i.e. requiring steroids or time off school, was 2 ½ times less likely for children in the computer group regardless of age, knowledge or locus of control scores. Even when the data were analysed on an 'intention to treat' basis, which is a conservafive approach, the computer group still came out as having better outcomes at six months.

It was reassuring that parents correctly perceived when their child's asthma control was worsening, although the parental perception and the child's feelings of control didn't appear to be associated. Parental and child reports have often been found to disagree, especially on symptom reporting (Usherwood *et al,* 1990) and quality of life (Milnes and Gallery, 2003). This gives cause for concern given that many of the parents will be acting as a 'proxy' for the child, both in interactions with medical professionals and when following a self- management plan. Thus, self- management for children is complicated by the involvement of such 'proxy' figures, whereby 'self could feasibly refer to three or more people. The self- management plan referred to in The Asthma Files (and that can be printed out) addressed the child directly (i.e. if *you* feel fine, confinue with *your* usual treatment [emphasis added]), thus involving children directly in their management, which has been suggested to be an important feature for plans to be efficacious (Milnes and Gallery, 2003).

In a study by McQuaid and colleagues, it was found that objective preventative medication adherence (as measured by an inhaler monitor device) was worse in older children, even though they had higher knowledge levels and a greater conceptual grasp of asthma (McQuaid *et al,* 2003). Similarly, older children in our study reported missing more preventer medicafion doses than younger children which was supported by a negative correlation between age and FEV_1 and PEF scores at baseline, demonstrafing that older children had significantly worse lung function. However, older age was also associated with higher knowledge and ALOG scores. If older children have the knowledge about how to look after their asthma and also feel more in control of their asthma, why isn't that translafing into positive behaviour? Rubin *et al.* suggest that there is a knowledge 'threshold'; they posit that increasing knowledge in children with low levels can be beneficial, although if children have reasonably high scores already, increasing them is not going to make any difference to behaviour (Rubin *et al,* 1989). This is certainly applicable to the sample in this study who demonstrated low levels of asthma knowledge regardless of how long they'd had asthma, although this was quite specific medical knowledge of asthma. It would seem advantageous, to direct the computer program toward those with low knowledge levels such as in our study, who could be screened using the true/ false scale which is quick and simple to use and score- using it with children with low levels of knowledge would obviate the suspected 'ceiling' effect.

The computer program that was used in this study- The Asthma Files- was very popular with participants across the whole age range. The year- long development and piloting phase played a vital role in its success; several aspects of the program changed as a result of children's comments in the early stages so that the version used in the RCT was as accessible and user-friendly as possible. Having used it with the fifty addifional children during the trial, aspects of the program have subsequently been updated; specifically, one of the interactions on the 'secret level' was replaced with a more interactive game for the final version. All 101 children enrolled in the study will shortly be receiving a copy of the latest version of The Asthma Files; those without access to a computer will be offered the opportunity to use it on the laptop computer at a home visit.

6.8.4 Study strengths and weaknesses

There are several methodological issues associated with this study which should be addressed. Firstly, the sample was fairly heterogeneous, indicated by the wide range of lung function at baseline (FEV_1 range 44- 138%), although it was broadly representative of clinic attenders. Assessing asthma severity was problematic given that the Asthma Control Questionnaire was subjectively rated by the parents. ACQ scores were associated with measures of lung function, however, although both may reflect the child's self- management skills rather than the true severity of their asthma. It was not practicable for reversibility or exercise tests to be incorporated into the inclusion criteria, but since all participants were recruited from specialist respiratory outpatients clinics, a moderate level of severity was assumed.

The self- management plan used as part of the study was based on advice given roufinely to children attending the clinics involved. This advocates doubling the dose of inhaled corticosteroids when peak flow falls below 50% of best peak flow and there is little response to inhaled short- acting bronchodilator medicafion. The most recent guidelines published by the British Thoracic Society state that evidence for this is not proven (BTS, 2003). However, a recent evidence- based review of key components of successful self- management (or 'action') plans found that both increasing the dose of inhaled steroids and inifiafing oral steroid medicafion demonstrated consistent benefits (Gibson & Powell, 2004).

The baseline measures were conducted prior to randomisation which took the form of random numbers in opaque envelopes taken unsystematically from a box. Using a randomisation procedure such as this is considered to be the 'gold standard' in research, given that every member of a populafion has an equal chance of being selected (Fletcher *et al.*,1988). This then increases the chance that the study results are generalisable to a wider population and that possible confounding factors are distributed equally across the groups. (Polgar and Thomas, 1995). Unfortunately, despite this rigorous randomisation, there were a number of differences between the two groups: there were more boys (although not statistically significantly so) in the computer group. Given that there were no differences between giris and boys in knowledge scores either at Time 1 or Time 2, nor in the *change* in knowledge scores, it seems unlikely that this would have affected the results. More significantly, the computer group was significantly older than the booklet group and the booklet group had significantly higher ACQ scores indicating poorer asthma control. There were no differences in lung function however, which is curious given that Time 1 ACQ scores for the whole sample correlated significantly negatively with objecfive measures of lung function. It would, perhaps, have been wiser to stratify according to age, to ensure that both groups were balanced, although to do this correctly, the characteristics (i.e. age) of all participants would need to be known in advance (Polgar and Thomas, 1995) which was not the case. The disparity in ages between the groups was controlled for in the analysis, however, by entering age as a covariate in a general linear model to compare groups at baseline and then using repeated measures co- varying for age, to examine change in scores between the groups at different time- points. Although less than ideal, the difference in ages between the groups does not invalidate the findings.

Lack of researcher blinding to group was an issue because the same researcher was responsible for sending the booklet or showing the computer program and then conducting the follow- up visit one month later. It would, of course, have been ideal if a different person had conducted the follow- up interviews but this was not possible; however, measures of lung funcfion were objective and the AKQ Part 2 (True/ False) and ALOG scales provided scope little for biased results. Inter- rater reliability on AKQ Part 1 (semi-structured questions) showed a high level of agreement.

This study differs from previous work with multimedia education packages because it did not require children to own a computer for study eligibility, nor necessitate special trips into a hospital or school. However, the high rate of computer ownership in the sample suggests that this may not be such a limiting factor as maybe it once was. But, a substantial proportion of the sample were from high socioeconomic groups, so there is the possibility that the sample was biased. Nevertheless, verbal ability, which is a good indicator of socioeconomic status (Sternberg , Grigorenko & Bundy, 2001), showed no bias towards higher scores and were comparable to norm values, suggesting that our sample was reasonably representative. In the past, children from lower socioeconomic groups have reportedly found it harder to use computers (Fasick, 1992), but over a decade later, computer and informafion technology skills are a core part of the school curriculum and children are familiar with such technology from an increasingly younger age. There was no set time period the child was required to use the program for, and this was deliberate, to fit in with the ethos of catering to the individual's information needs. All children in the computer group were left with a copy of the CD-ROM and encouraged to use it at home, at school or on a friend's computer. Often, technical problems prevented this so more efforts to simplify installation and offer technical assistance between visits may be helpful.

Recruifing in outpafient clinics can also bring methodological difficulties. Due to the busy nature of the asthma clinics, children's testing sessions were occasionally interrupted and some parents declined to participate because of fime constraints. The study deliberately did not have complex inclusion criteria in order to be as inclusive as possible. All children in the appropriate age- range were invited to participate but recruitment was hampered by high proportions of non-attenders. Offering home recruitment to those not attending their appointment may have contributed further to the heterogeneity of the sample but ensured that children who may possibly have different characterisfics to regular attendees (Woodward, **1998)** were represented in the research. It was also notable that the attrition and follow- up rates are more favourable in this study than reported in previous studies of this kind (Homer *et al,* 2000; Tieffenberg *et al,* 2000; Redsell ef *al,* 2003).

This study made strenuous attempts to validate the instruments used as outcome measures. Despite the moderate sample recruited in the ALOC validafion study, reliability and validity were largely confirmed. The AKA also performed well and reliably distinguished between those with high and low knowledge levels. The reliability of the measure was demonstrated by a reasonable Gronbach's Alpha co-efficient and high inter- rater scoring (see Chapter 5. However, although statistically significant, the difference in knowledge scores between the two groups was reasonably small. This is likely to have been because the knowledge levels of children with asthma were so low. Further work regarding the clinical significance of these differences is advisable.

A longer inifial follow- up period may have allowed for changes in hospital admission and medicafion to be detected between the groups and possibly changes in the extent of asthma responsibility taken by the child. However, there is the risk of greater attrition when long intervals are left behA/een contacts and the nature of paediatric asthma is such that symptoms can vary considerably over time, which may have masked differences related to the study.

CHAPTER 7: DISCUSSION

This thesis sought to develop a greater understanding of children with asthma and their needs. To do this, two instruments- the Asthma Knowledge Assessment and Asthma Locus of Control- were designed and validity and reliability established. These were then employed to evaluate the efficacy of a mulfimedia educafional program aimed at children behA/een 7 and 14 years. Positive outcomes on a number of variables were demonstrated in addition to some unexpected findings. These are discussed below with reference to relevant literature. Implications for further research are also examined.

The information needs of adults with asthma (Caress *et al,* 2002) and parents (Morgenstern and Evans, 1997; Ho ef *al,* 2003), have been investigated but, despite being the most common childhood illness, reasonably little is known about the information needs of children with asthma. The studies described in this thesis revealed fairiy low levels of asthma knowledge. Children did not roufinely know basic information regarding symptoms, triggers and treatments, which are fundamental to asthma self- management.

To educate children with asthma about self- management in this study, an interacfive multimedia **program**, The Asthma Files, was developed. This method of education has several advantages over more traditional formats; it is economically advantageous due to the reduction in staffing requirements, it is child centred and accessible and can therefore be used over several sessions to suit the child's pace of learning in addition to providing long-term support. Pictorial representafions are particulariy effecfive for children, who may not be confident readers. It is also interactive, popular and engaging.

The authors of the recent Cochrane systematic review of educational interventions for children with asthma suggest that "To be successful, programs must be based on a sound theoretical understanding of behaviour change..." (Wolf *et al,* 2003; p2). To guide the educational process and expedite learning in our educafional package, it was underpinned by a Vygotskian approach to learning, which provides support for the child whilst they learn, in order to extend their knowledge beyond the level that they would achieve alone. Its emphasis on learning from experts to enable development beyond natural limits sits well with mulfimedia educafion for children; the program provided 'scaffolding', which enabled the child to problem solve without the aid of a parent, teacher or other 'expert'. It then removed assistance little by little until the child was capable of managing the task themselves but maintained the learner's interest in the interim (Standen and Low, 1996; Wood, 1998; Neitzel and Dopkins- Stright, 2003). Whether they were then able to carry out the task for themselves was the ultimate outcome of the study- had they learned enough to improve their self-management skills?

A behaviourist paradigm was incorporated into the program where expert skills and behaviour were broken down into parts which were then modelled, established in the child's mind by repetition and practice and reinforced by providing feedback in tesfing sessions (Atkins, 1993). Figure 7.1 is a simplified illustration of how the theoretical basis of the program translates into the 'mechanics' of the computer program, but it underiines how readily mulfimedia lends itself to educafion with a strong basis in learning theory.

The Vygotskian approach is inherently child- centred, given that individual strengths and weaknesses are assessed in order to tailor information. This approach makes group education problematic because it is difficult to assess individuals' Zone of Proximal Development 'en masse' (Wood, 1998). Mulfimedia can obviate these problems by assessing each child's abilities and adjusting the informafion accordingly. The Asthma Files contained different 'levels' of informafion for children of various abilities, enabling the child to select as much or little detail as they wished. This was primarily provided in areas which were more text- based, so that children with lower reading levels would not be penalised. It had originally been planned to have more sections incorporating different levels of informafion, but it was found that the majority of the information was well suited to interactions and modelling which were fairiy basic but clear and understandable; sections focussed on the physiological aspects of asthma lent themselves naturally to be depicted in this way which children rated as helpful when learning more about what happened in their bodies.

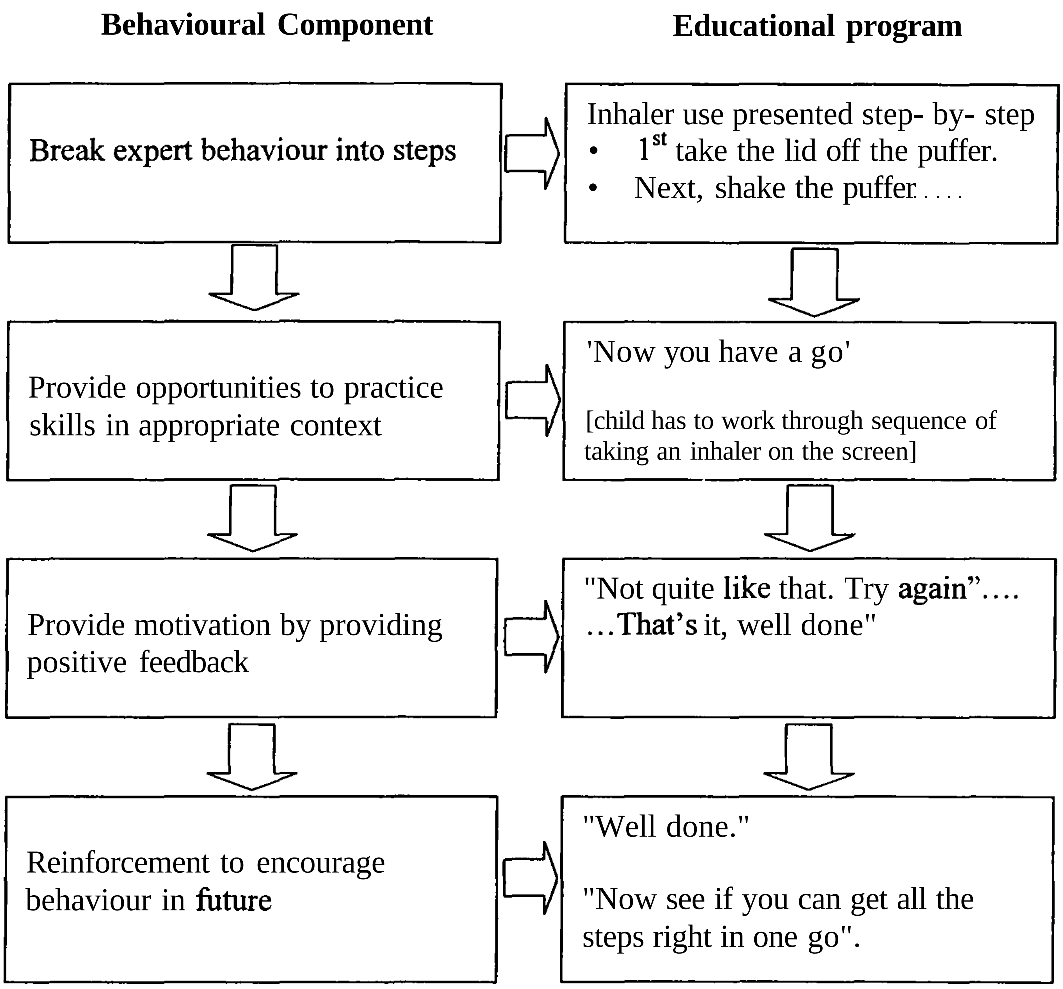


***Figure** 7.1*- Behavioural components of learning a new task with corresponding examples from The Asthma Files

Information in both the computer program and the booklet provided the opportunity to be personalised, which has previously been shown to be of benefit (Madge *et al,* 1997); the booklet provided space to write medication and doses and contact telephone numbers although The Asthma Files was more detailed, incorporating the child's information into a self- management plan with guidance on peak flow. It is likely that the combination of interacfion with personalisation was one of the primary advantages gained by the children in the computer group.

However, the link behA/een knowledge and behaviour is not straight fonA/ard (Ho *et al,* 2003; Bender ef *al,* 1998). One factor that appears to mediate the transfer of knowledge into behaviour is locus of control (Rubin *et al,* 1989; Tieffenberg *et al,* 2000). Although a child may be technically competent in a skill, they may not actually put it into practice unless they feel confident that they have a reasonable chance of success. It is likely that children with asthma have certain traits which have been developed as a result of their illness- certainly, past behaviour and perception of their self- efficacy will have contributed to their current feelings of control over their illness. The literature review eariier described the rationale behind an asthma- specific measure of locus of control and the resulting instrument- the Asthma Locus of Control- performed well in both the validation study and the main study. The computer program was designed to reinforce that effective asthma management was under the control of the child for the majority of the time. It also highlighted that there may possibly be fimes when an acute exacerbation of asthma will require emergency intervention, despite the child's best endeavours. Although vital information, these 'attack strategies' were not the main emphasis of the educafional package, focussing much more on preventative measures. At one month follow- up, the computer group demonstrated significantly higher ALOC scores than the booklet group; this is promising but it is only conjecture how long those advantages would be retained. It is hoped that the feelings of control lead to better management with fewer symptoms, which in turn will reinforce the feelings of success and promote efficacious long-term management. Furthermore, previous work suggests that once shaped by experience, LOG is reasonably resilient (Lau, 1982). Repeafing the ALOG at one year post- intervenfion may provide useful information on whether the 'experience' provided in programs such as ours is sufficient and on the longevity of programs such as ours in promoting a more internal orientation.

Despite encouraging increases in knowledge and LOG, there was no improvement in lung function in our study, which would have indicated better adherence to the self- management plan. Other studies have also noted the lack of association behA/een knowledge and adherence (as measured by an electronic inhaler monitor), and with asthma outcomes such as health service ufilisation, school absence and functional severity (McQuaid *et al,* 2003; Ho *et al,* 2003). Other cognitive variables also need to be considered as determinants of compliance, for example, children's attitudes. Negative or problematic attitudes may be a form of coping strategy in children with chronic illnesses (Hazzard & Angert, 1986). A study by van Es and colleagues described how attitudes were one part of a multi- factorial model they used to explain self- reported medication adherence in teenagers with asthma. Both posifive and negative attitudes towards taking medication and the consequences of not adhering played a large part in predicting adherence to medication over the period of one year (van Es *et al,* 2002). These attitudes, when combined with the adolescents' expectations or feelings of control, were a powerful indicator of the *intention* to adhere, which corresponded with later behaviour change. By improving knowledge in this study, we were hoping to promote positive attitudes towards self-management and remove barriers to asthma control. However, a more complex model may provide greater predicfive power.

Other factors which may affect the 'transfer' of knowledge into behaviour, include family funcfioning, personality, parental attitudes, anxiety levels and socioeconomic status. Factors such as these could potenfially have a considerable effect on the success of asthma educafion although aren't always readily quantifiable. It should be noted, however, that behavioural 'outcomes' such as lung function, service usage and school attendance are not direct measures of behaviour and are in fact 'proxy' measures for behaviour change. This makes it even harder to assess the factors which link knowledge and behaviour.

In the last chapter, we saw how the differences in proxy measures of self-management, such as use of oral steroids and school absence, were quite striking at the six- month follow-up point. Of course, we were reliant on parental report, which is not always accurate, although the findings fit with the conclusions of the recent systematic review of educational programs which demonstrated greatest outcomes at 7-12 months post- intervention (Wolf *et al,* 2003). This augurs well for our study, which has a further strength in that the computer program is readily available for 'refresher sessions' at any fime, which have shown to be valuable in maintaining asthma knowledge and positive health outcomes (Gebert *et al.*,1998).

Implications for future research

Longer term follow- ups would be a useful addition to the body of work presented here and have considerable implications for future educational programs. The role of mulfimedia in education is growing exponenfially and innovative ways of using it are being invesfigated. For example, using computers in collaborative learning is an exciting area of research; invesfigafing how children use mulfimedia within a social context as a tool for exploration areas can open opportunifies for peer tutoring whilst remaining essentially child- centred (Standen ef *al,* 1998; Smith *et al,* 2003). Work on collaborafion of children with parents or other adults may also be fruitful. Both Homer and Bender highlight the importance of involving parents in asthma educafion (Bender *et al,* 1998; Homer *et al,* 2000) who were not formally included in this educafional component of the current study. Anecdotally, many parents reported learning new informafion incidentally whilst overhearing their child use the package and many were drawn to the program's appealing graphics and interactive nature. Invesfigafing ways of enhancing the learning process through collaborafion is likely to be worthwhile.

The use of peak flow meters in self- management for childhood asthma is not automatic (Milnes and Gallery, 2003), despite reports that self- management plans based around peak flow are superior to those just based on symptoms (Wolf *et al.,* 2003). The results of the main study presented here strongly suggest that a large proportion of children do not know how to interpret peak flow readings, making it unlikely that they will incorporate them into their asthma self- management effectively. Regular education on correct usage of peak flow meters and interpretation of results is necessary; research on ways of conveying this information would be beneficial.

The worth of asthma self- management programmes for children and adolescents is now widely accepted. It is vital for the successful implementafion of such programmes that young people are provided with the tools to enable them to make informed healthcare decisions. Mulfimedia has the potenfial to play a significant supportive role in this process by developing the child's understanding of asthma and by reinforcing a sense of mastery over the condition.

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Appendix 1

National Asthma Campaign self- management materials.

WHAT ELSE IS IMPORTANT TO KEEP YOUR ASTHMA WELL CONTROLLED?

AVOID TRIGGERS

It is likely that there will be many different things that trigger your asthma so you probably won't be able to avoid them all. The main ones are:

- Colds and viral infections
- House dust mite
- Tobacco smoke
- Pets
- Pollen

If anything in particular seems to make your asthma worse, make a note on your chart and talk to your doctor or nurse.

KEEP ACTIVE

Exercise is the best way to keep your body in tip top condition. It is fun and leaves you feeling good about yourself. However, exercise is also a common asthma trigger. But that doesn't mean you should stop! Exercise is good for everyone, including people with asthma.

STOP SMOKING

If you have asthma and smoke, you will be damaging your airways and are increasing the risk of an asthma attack. Within a few weeks of giving up you should notice a huge difference. See your doctor or nurse for advice or ring quitline on:

0800 00 2200 (in England)
0800 848 484 (in Scotland)
0345 697 500 (in Wales)

FINDING OUT MORE

There are lots of ways to find out more about your asthma, your treatment and ways you can help yourself to be in control. Ask your doctor or nurse for leaflets.

Contact the National Asthma Campaign Asthma Helpline – 0845 7 01 02 03 – for advice that's right for you Monday to Friday 9 to 7pm
(charged at local rates)

Look at the National Asthma Campaign's website **www.asthma.org.uk** for up-to-date asthma information 24 hours a day.

HOW TO USE YOUR PEAK FLOW METER

1 Push the number pointer on the peak flow meter back to zero
2 Take good breath in
3 Seal your lips around the mouthpiece
4 Blows hard and fast as you can
5 Write down the number score next to the number pointer
6 Do steps 1-5 again two more times
7 Mark down your highest number score with a dot or a cross on the peak flow graph on the other side of this card

IS IT AN EMERGENCY?

AN EMERGENCY IS WHEN ANY OF THE FOLLOWING HAPPENS:

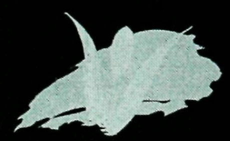
1 Your reliever (blue) inhaler does not help
2 Your symptoms get worse (cough, breathless, wheeze, tight chest)
3 You're too breathless to speak

WHAT TO DO:

1 Continue to take your reliever (blue) inhaler
2 Call your doctor or an ambulance if no better after five minutes

SURGERY CONTACT NUMBER:

NATIONAL **ASTHMA** CAMPAIGN
conquering asthma



Be in control

Name:

YOUR PERSONAL ASTHMA DIARY AND ACTION PLAN

CONTENTS

NATIONAL **ASTHMA** CAMPAIGN
conquering asthma

ACTION PLAN

Be in control

Symptoms are:	Peak Flow is:	Action is:
No symptoms		Normal - continue your treatment or talk to your doctor/nurse about taking less treatment
Getting a cold, symptoms during daytime and/ or nightime		Take .... of ....(times aday) and blue inhaler for relief of symptoms
Out of breath Blue inhaler does not help		Continue as a above and start steroid tablets ....ings \ .... and contact ....
Too breathless to speak		This needs emergency action straight away. See back page

	Your treatment is:	How much to use:	When to use:
PREVENTER			
RELIEVER			
OTHER			

IS IT AN EMERGENCY?

An emergency is when <u>any</u> of the following happen:

1. Your reliever (blue) inhaler does not help
2. Your symptoms get worse (cough, breathless, wheeze, tight chest)
3. You're too breathless to speak

What to do:

1. Continue to take your reliever (blue) inhaler
2. Call your doctor or an ambulance if no better after five minutes

SURGERY CONTACT NUMBER:

Be in control

Name: ______ **ASTHMA PLAN**

- Have you had difficulty sleeping because of your asthma symptoms (including coughing)?
- Have you had your usual asthma symptoms during the day (cough, wheeze, tight chest or feeling breathless)?
- Has your asthma interfered with your usual activities (eg housework, work or school, etc)?

If "yes" to one or more of the above, or if you haven't been for twelve months or more, arrange to see your doctor/nurse for a review.

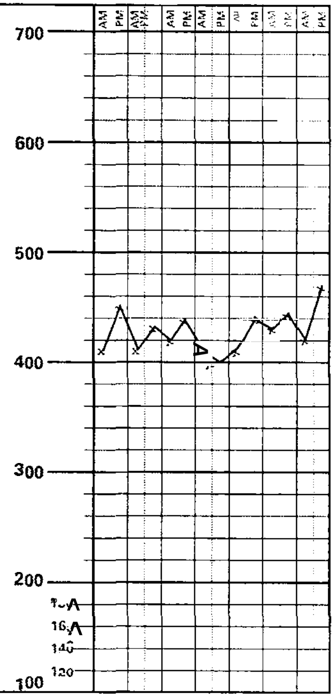
if "yes" to all three of the above - is this an emergency? (See back page)

Your personal asthma plan folds to the size of a credit card.

Date you started this diary		8/11	9/11	10/11	11/11	12/11	13/11	14/11
1 Have you had difficulty sleeping because of your asthma symptoms (including coughing)	Circle Y for Yes or N for No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
2 Have you had your usual asthma symptoms during the day (cough, wheeze, tight chest or breathlessness)		Y/N	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
3 Did your asthma interfere with your usual activities (eg housework, work or school)		Y/N	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N

Blow your peak flow first thing in the morning and in the evening before your treatment.

When you blow your peak flow do it 3 times and write down the best one, mark a cross or a dot on the chart opposite.



What to use on an every day basis	How Much?	When?	Write down the total number of times you took your treatment each day
1			
2			
3			

Appendix 2

McPherson, A, Glazebrook, C, and Smyth, A (2001). Double-click for health: the role of multimedia in asthma education. *Archives of Disease in Childhood*, 85 , 447- 449.

Leading articles

Double click for health: the role of multimedia in asthma education

Asthma is now the **most** common chronic childhood illness in Britain and the prevalence is increasing.' Currently 1.5 million children (aged **2–15** years) in the UK are estimated to have asthma, giving the country one of the highest prevalences in the **world,**[2] with estimated costs of **£100–150m.**[3] Asthma also has a significant social impact, including school absence' and poorer psychological health.'

Educational programmes for children with asthma have been around since the **1940s,** albeit in varying guises, utilising leaflets, group work, individualised training, home visits, and specialised **camps.**[6–9] The goal behind them has always been to improve the child's physical and/or psychological management of their asthma.'° More recently, anention has focused on the potential contribution of multimedia computer programs to paediatric health education." Multimedia software delivers information to a laptop or desktop computer screen using a range of visual and auditory forms, including animation, video, voice over, and sound effect. The interactive capabilities of such programs and their potential to store users' responses can be harnessed to provided personalised information in engaging forms such as games or quizzes. Computer technology has altered the way children spend their free time, and has become increasingly integrated into education, possibly because of expectations that all leaming must be **"fun".**[12] Educadonal software developers have been quick to catch up with this demand for "edutainment", and packages have been developed for a variety of illnesses, including asthma." " Arguably, they are suited to paediatric education because they combine familiar technology with interesting graphics that hold children's attention." " " Voice-overs and graphical demonstrations can enhance comprehension of complicated concepts that might otherwise be hampered by the child's level of literacy. Such technologies can also reduce demands on parents and medical staff in terms of information provision." Furthermore, Dorman highlights the potential benefits of allowing children to "role play" asthma management in a safe environment, before transferring those skills to the real **world.**[12]

This review will explore the rationale behind educational programmes for children with asthma and explore the role of multimedia in meeting children's information needs.

Why do children with asthma need health education?

Expansion in the provision of health education for children with asthma has been driven, at least in part, by a growing acceptance that children with chronic conditions should be actively involved in the management of their illness and in decisions about treatment.' Proposed benefits of health education for children with chronic disorders include reduced distress during treatment" and decreased morbidity." Giving children information about their illness helps to promote a sense of control and "mastery" over their health.' Sense of control has been found to improve compliance in asthma," which fits well with the ethos that children with asthma should take more responsibility, for example, by carrying their own medications.' As attitudes towards health related behaviours can persist beyond **childhood,**[20] education may also influence health outcomes in adulthood.

Effective management of asthma depends primarily on early recognition of asthma symptoms. Children with acute asthma, who have a poor perception of breathlessness, may present late, leading to a greater degree of **hypoxia.**[21] Paediatricians often rely on parents' assessment of symptoms to guide **diagnosis;** however, evidence fi-om pain research suggests that parents underestimate intensity of symptoms and that even very young children are capable of observing and assessing their *own* symptoms." Picture based rating scales facilitate this process and have been found to correlate well with physiological **measures.**[21]

Self determination, or the **ability** to make decisions, exercise choice and take control, is influenced by knowledge and skills as well as by environmental factors." It can therefore be enhanced, both by education and by reducing the demands of the decision making **task.**[23] Interactive multimedia has much to offer in this respect, as it can present information about treatment alternatives in an accessible format and allows children to make choices in a safe "virtual" environment. Furthermore, there is evidence firom studies with children and young people with leaming disabilities that skills learnt through a desktop virtual environment do generalise to real world **situations.**[24]

How do we educate children about asthma?

Group based teaching for children and parents has been the traditional model for asthma education, using talks, videos, role playing, and outings to educate about asthma symptoms, physiology, triggers, and medication. This has been effective in improving knowledge,'' reported self management behaviours,' and health locus of control'; the methodology has also been successfully adapted to target specific vulnerable groups, such as low income **families**[25] and Hispanic families in the United **States.**[26] However, -such improvements may not be maintained over time and **"refresher** courses" may be necessary to maintain a high level of competence in asthma behaviour.'

Although traditional educational programmes can be effective, they can be costly in terms of time and resources. They also "... teach the same skills regardless of the characteristics of the child and of **his/her** asthma"." To **circum**vent these difficulties, a number of researchers have •employed computer technology to impart information for a range of illnesses, including diabetes," nocturnal enuresis," as well as asthma."""

An important aspect of these multimedia packages is that they can be individualised to the user, and can easily store personal information such as triggers, medication, and peak flow. An interactive asthma education computer program which is currently being evaluated has utilised the internet, so that gaps in the child's and their carers' knowledge are identified by the program and the education customised accordingly. This feedback, including personal medication and symptoms, can then be reported back to their health centre so that these aspects can be addressed at the next visit. Preliminary findings reported at a recent asthma conference suggest increased knowledge in carers of children (aged 0-6 and 7-17 years) and increased knowledge in the children themselves in the 7-17 year age group. Asthma health outcomes were also improved: emergency room visits, days of asthma symptoms, and doses of inhaled corticosteroid were all reduced in the intervention (computer) group." More traditional individualised education programmes, using a tailored management plan and constant access to an asthma nurse, have already been shown to reduce hospitalisations in children over 2 years of age[28]; hence it appears that taking individuals' characteristics into consideration when planning their education is paramount.

Computerised education programs can also provide "support", albeit in a more limited fashion than a dedicated asthma nurse. Adults using computer assisted instructions about asthma management and practical techniques (such as using a peak flow meter) felt that it was useful for validating what they already knew about asthma.[29] In addition, computerised programs can provide cognitive support by presenting complicated tasks in a simplified manner, for example, breaking down into simple steps how to use an inhaler. It has been hypothesised that children are able to extend beyond their existing knowledge to a more sophisticated level of understanding if given appropriate guidance and instruction (termed "scaffolding")." Thus, a computer program which provides an appropriate degree of support, such as simplifying instructions and providing simulations of complex physiological processes, could help children understand more complex aspects of their asthma management. Furthermore, the appealing, interactive nature of many computer programs can encourage the user to engage with the task long enough for them to absorb more information for themselves.

Residential camps for children with asthma, such as Camp SUPERTEEN" have been used to develop asthma management skills in a supervised environment, thus promoting confidence managing real life crises. Multimedia health education could potentially complement this approach by allowing the user to "experiment" safely in ways that they never could in the real world. For example, Brown *et al* developed an educational computer game for children with diabetes to monitor a character's blood glucose, take the right amount of insulin, plan meals, and engage in other appropriate self care behaviours." Children using the program could learn the consequences of those actions without putting their own health in danger.

However, it is still vital that computerised programs are pitched at an appropriate stage of the child's development. Bartholomew and colleagues developed an interactive computer program called "Watch, Discover, Think & Act", where children were assigned a character whose asthma they managed by avoiding triggers, taking medication, and monitoring symptoms." When compared with children who hadn't seen the program, the intervention group had a lower rate of hospitalisation and greater functional status; however, despite having screened for reading ability prior to the study, the authors found that asthma knowledge increased only in older children and those with better baseline knowledge. They felt the results indicated that it was too complex for younger and less able children.

Evaluations of multimedia are growing and early indications are that they can be of benefit in educating children about asthma management. However, it is unlikely that they will prove to be superior to individualised teaching fi-om an expert. Homer *et al* showed in their randomised, controlled trial that their program for children, "Asthma Control", was effective in increasing knowledge, reducing emergency visits, and improving child behaviour and self reported symptom severity." However, the comparison group, who had returned to the hospital to review an asthma booklet with a researcher and play on a non-educational computer game, also had improved outcomes. Knowledge about asthma was the only outcome that was significantly different in the computer group children. In practical terms, if both approaches are broadly equivalent in producing positive behavioural change, a computer program could be far more cost effective in the long term.

Conclusions

Health education for children is important in order to set positive attitudes to take into later life. This is especially important for children with asthma, who need to be able to recognise symptoms and respond appropriately in order for them to manage their asthma effectively. Educational programmes for asthma are now widespread and have been shown to produce positive outcomes; stress, self efficacy, and coping strategies can all be improved through education, which can reduce medical resource usage. Transmission of knowledge and reinforcement of positive beliefs and behaviours are central to this process.

Innovative means have been sought to make health education more appealing to children and improve compliance. Interactive group work and tailor made, child focused education programmes have been popular, but have significant time and resource implications. Computer programs have many advantages for paediatric education by presenting information in an engaging manner and using technology that most children are familiar with these days. Multimedia technology can provide an "expert" role, and thus help children understand information or concepts which they might not understand alone. Multimedia is flexible and sensitive, so that programs can be tailored to suit a wide range of information needs, for example by providing different "levels" of text for varying reading abilities. Pressure on staff and parental time is somewhat ameliorated by using computer programs in asthma education, and may offer a feasible option for "booster session" work. Furthermore, observing the way children use computer programs may lead to more effective education, for example, by encouraging collaborative leaming and peer tutoring."

The emergence of multimedia in paediatric education offers exciting possibilities, and by supplementing, rather than replacing more traditional educational methods, it can be seen as an additional tool to help educate children with asthma and encourage self management. There clearly needs to be more research evaluating the effectiveness of multimedia, and identifying those children who will benefit most from such programs. To this end, our group is currently undertaking a randomised, controlled trial of an innovative multimedia package which aims to educate children about asthma and promote self management skills. We are investigating whether, by augmenting existing care through multimedia, we can enhance children's understanding of asthma and improve clinical outcomes. In this technological generation, we hope to make fiirther discoveries as to whether multimedia holds the key to asthma education of the future.

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STAMPS IN PAEDIATRICS

Dr Henryk Goldszmit (Janusz Korczak) 1878–1942

The stamp, issued in Poland in 1992, depicts a statue marking the 50th anniversary of the murder of Dr Henryk Goldszmit in the Treblinka camp,' along with the children from his orphanage and many thousands of other victims. Henryk (known throughout Europe under his pen name Janusz Korczak) holds a small child in his arms, and is followed by others, as described by those who witnessed their departure for the trains. The statue is in the Jewish Cemetery[2] near the former Warsaw Ghetto, where he lived with the orphans. Henryk was a Polish-Jewish paediatrician,' writer, broadcaster, and vigorous advocate for the rights of the child. His children's stories are known in 20 languages, but few of his writings, until recently, have been available in. English.* His ideas were important in the development of the UN Convention on the Rights of the Child.[5]

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1 http://fcit.coedu.usf.edu/holocaust/resource/VR/TRE3S.htm
2 http://warsawghetto.epixtech.co.uk/Korczak.htm
3 http://korczak. com/
4 http://www.korczak.org.uk/
5 http://www.ibe.unesco.org/International/Publications/Thinkers/ThinkersPdf/korczake.pdf

Appendix 3

Asthma Locus of Control scale (ALOC).

Date ....

Children's Asthma Locus of Control

Please read the statements below *and* put *a circle around the* 4 if you agree and round the 6 if you disagree with the statement

PRACTICE:

- Children with asthma *can* get wheezy

If you agree with this, put a circle around.................................. ✓

If you disagree, put a circle around X

- Children never get asthma

If you agree with this, put a circle around .... ✓

If you disagree, put a circle around..X

	Yes I agree	No I disagree
1. There are many things I can do to keep from getting wheezy	✓	X
2. People with asthma who are never wheezy are just plain lucky	✓	X
3. When my asthma is bad, I can do things to get better	✓	X
4. Only a doctor or nurse stops me getting wheezy	✓	X
5. I can do many things to fight asthma	✓	X
6. If I have *an* asthma attack, it's just bad luck	✓	X
7. I *can* choose how to look after my asthma	✓	X
8. There are things I *can* do to control my asthma	✓	X
9. Other people must tell me what to do when I have an asthma attack	✓	X
10. I can do many things to prevent an asthma attack	✓	X

Appendix 4

Children's Health Locus of Control scale (CHLOC)
(Parcel & Meyer, 1978).

CHILDREN'S HEALTH LOCUS OF CONTROL SCALE

NFER NELSON

Name:..

Date:...**Record Number:**..

We would like to learn about different ways children look at their health. Here are some statements about health or illness (sickness). Some of them you will think are true and so you will circle the YES. Some of them you will think are **not** true and so you will circle the NO. Even if it is very hard to decide, be sure to circle YES or NO for **every** statement. **Never** circle both YES and NO for one statement. There are no right or wrong answers. Be sure **to** answer the way **you** really feel and **not** the way other people might feel.

PRACTICE: Try the statement below.

a. Children can get sick.
If you think this is true, circle...YES
If you think this is not true, circle..NO

b. Children never get sick.
If you think this is true, circle...YES
If you think this is not true, circle..NO

Try one more statement for practice.

c. When I am not sick, I am healthy..YES NO

NOW DO THE REST OF THE STATEMENTS THE SAME WAY YOU PRACTISED.

1. Good health comes from being healthy...	YES	NO
2. I can do things to keep from getting sick..	YES	NO
3. Bad luck makes people sick..	YES	NO
4. I can only do what the doctor tells me to do..	YES	NO
5. If I get sick, it is because getting sick just happens.............................	YES	NO
6. People who never get sick are just plain lucky......................................	YES	NO
7. My mother must tell me how to keep **from** getting sick.........................	YES	NO
8. Only a doctor or a nurse keeps me from getting sick..............................	YES	NO
9. When I am sick, I can do things to get better.......................................	YES	NO
10. If I get hurt it is because accidents just happen..............................	YES	NO
11. I can do many things to fight illness..	YES	NO
12. Only the dentist can take care of my teeth...	YES	NO
13. Other people must tell me how to stay healthy..................................	YES	NO
14. I always go to the nurse right away if I get hurt at school......................	YES	NO
15. The teacher must tell me how to keep from having accidents at school .	YES	NO
16. I can make many choices about my health..	YES	NO
17. Other people must tell me what to do when I feel sick...........................	YES	NO
18. Whenever I feel sick I go to see the school nurse right away..................	YES	NO
19. There are things I can do to have healthy teeth..................................	YES	NO
20. I can do many things to prevent accidents..	YES	NO

Appendix 5

Asthma Control Questionnaire

Adapted from Juniper *et al.* (1999).

Asthma Control Questionnaire

>leasc answer the following questions by putting a circle round the response that best describes ıow your child has been during the *PAST* WEEK

rf the past week has NOT been typical please complete for a TYPICAL WEEK

.. **On average,** during the post **week,** how often was your child woken by his/her asthma during the night?	0	Never
	1	Hardly ever
	2	A few **minutes**
	3	Several times
	4	Many times
	5	A great many times
	6	Unable to **sleep** because of asthma.
:. 2. *On* average, during the past week, how bad was your child's asthma symptoms when they woke up In the morning?	0	No symptoms
	1	Very mild symptoms
	2	Mild symptoms
	3	Moderate symptoms
	4	Quite severe symptoms
	5	Severe symptoms
	6	Very *severe* symptoms
. 3. In general, during the past week, how limited was your child in their activities because of their asthma?	0	Not limited at oil
	1	Very slightly limited
	2	Slightly limited
	3	Moderately limited
	4	Very limited
	5	Extremely limited
	6	Totally limited
. 4. In general, during the past week, how much shortness of breath did your child experience because of his/her asthma?	0	None
	1	A very little
	2	A little
	3	A moderate amount
	4	Quite a lot
	5	A great deal
	6	A very great deal
. 5. In general, during the past week, how much of the time did your child **wheeze?**	0	Not at all
	1	Hardly any of the time
	2	A little of the time
	3	A moderate amount of time
	4	A lot of the time
	5	A great deal
	6	A very great deal
. 6. *On* average, during the past week, how many **puffs** of short-acting bronchodilator (reliever i.e. Ventolin) did your child use each day?	0	None
	1	1-2 **puffs** most days
	2	3-4 **puffs** most days
	3	5-8 **puffs** most days
	4	9-12 **puffs** most days
	5	13-16 puffs most days
	6	More than 16 **puffs** most days

Thank you for completing this questionnaire.
Your answers will remain confidential at all times.

Appendix 6

Asthma Knowledge Assessment (clinic version) with scoring protocol.

Child's n[redacted]ght .... .cm FEV1 .... %pred

Hospital no: .... Clinic .... FVC .... %pred

Study number .... Date:__/__/__ PEF (spir) .... PF(man) ....

Asthmmanagement and toomlfed^qfiMSi onaire (child)

1. What port of your body is *affected* by asthma?
Lungs or chest [I mark]; Airways [1 mark] *(max. 2 marks).*

2. Can you name any symptoms of asthma
Wheezing, breathlessness, cough, tight chest, sore tummy, other i.e. lack of energy [1 mark each] *(max. 6 marks).*

Prompt: How does asthma feel inside your body?
It was **noted** if the child required prompting.

3. Do you know what is happening in your body to make you feel like that?
Airways tighten, inside layer swells, mucous produced, breathing becomes difficult because airways become smaller [1 mark each] *(max 4 marks).*

4. How *can* you tell if your asthma is getting bad?
Symptoms increase, inhaler required, peak flow reduced, medication doesn't last as long as usual [1 mark each] *(max 4 marks).*

'5. What are your triggers?
6. Can you name anything that might trigger someone's asthma off, not just your own?
Dust, exercise, animal dander, cigarette smoke, weather, cold/ virus, excitement/ stress, other [1 mark each] *(max 6 marks).*

	Blue	**Brown/ orange**	**Green**	**Purple**
7. What colour arc your inhalers?	•	•	•	•
8. Do you know how they work?	• Stops wheezing • Works quickly • Relaxes muscles round airways. [1 mark each]	• Stops getting wheezy in 1st place • Takes longer to work • Stops swelling in airways. [1 mark each]	• Lasts longer than normal relievers • Take every day • Stops nighttime and/ or exercise symptoms. [1 mark each]	• Combines preventer & LAR • Lasts 12 hours [1 mark each]
9. How often do you take them?	**No. of puffs**....,... **Times per day**.......	**No. of puffs**........ **Times per day**.......	**No. of puffs**....... **Times per day**.......	**No. of puffs**........ **Times per day**.......
10. In the past week, how many times have you forgotten them?				

11. Who reminds you to use your inhalers?

- I usually remember
- ❑ sometimes remember
- ❑ My Mum or bad usually has to remind me

12. do you have a peak flow meter at home? YES/ NO

13. When do you use your peak flow meter

- Never/ hardly ever
- When I'm ill
- ❑ Once a week
- Most days
- Every day
- Twice a day

14. Who reminds you to use your peak flow meter?

- ❑ I usually remember
- ❑ I sometimes remember
- ❑ My Mum or bad usually has to remind me

15. Do you know what your peak flow reading should be?..................................

16. What would be a low peak flow reading? ....

17. What would you do?

....

....

Prompt- Would you make any changes to your medicine? YES/NO

....

Prompt- Would your Mum or Dad make any changes to your medicine? YES/NO

....

18. Does your asthma stop you doing anything you'd like to do?

....

....

True/false questions

1	You can catch asthma from other people	☐True	0False
2	Exercise is good for people with asthma	☑ True	☐ False
3	Lots of people have asthma	☑True	☐ False
4	Smoking is good for people with asthma	☐True	☑ False
5	Some people's asthma goes away when they get older	☑True	D False
6	Using *a spacer* with *a* puffer helps get medicine into your lungs	☑True	D False
7	Everyone's asthma is exactly the same	☐True	☑ False
8	A peak flow meter *can* help to tell you when your asthma is getting bad	☑True	D False
9	Preventers *are* blue inhalers	☐True	☑ False
10	You should take your reliever *before* doing sport if it is one of your triggers	☑True	D False
11	Children with asthma have sensitive airways	☑True	☐False
12	During an asthma attack, the wheeze may be because your airways *are* getting bigger	☐ True	0 False
13	Steroids used for asthma will make you big and hairy	☐True	0 False
14	Anti-leukotrienes are a type of reliever	☐True	0 False
15	Your house only *needs* to be vacuumed once *a* month	☐True	☑ False

Appendix 7

Asthma Knowledge Assessment (school version).

Child's name..DOB _/_/_ Date of testing _/_/__

School...Class...............................Study No...............................

Child reports asthma? ☐ Yes ☐ No

Asthma knowledge questionnaire

1. What parts of the body are **affected** by asthma?

....

....

2. Can you name any symptoms of asthma?

....

....

Prompt 1: How does asthma feel inside the body?

....

....

Prompt **2**: What does asthma make you/people do?

....

....

3. Do you know what is happening inside the body to make them feel like that?

....

....

4. How can people tell if their asthma is getting bad?

....

....

5. Can you name anything that might trigger someone's asthma **off?**

....

....

True/false questions

You can catch asthma from other people	• True	• False
Exercise is good for people with asthma	• True	❑ False
Lots of people have asthma	• True	• False
Smoking is good for people with asthma	• True	• False
Some people's asthma goes away when they get older	• True	• False
Using *a spacer* with *a* puffer helps get medicine into your lungs	• True	• False
Everyone's asthma is exactly the same	• True	• False
A peak flow meter *can* help to tell you when your asthma is getting bad	• True	• False
Preventers *are* blue inhalers	• True	• False
You should take your reliever *before* doing sport if it is one of your triggers	• True	• False
Children with asthma have sensitive airways	• True	• False
During an asthma attack, the wheeze may be because your airways *are* getting bigger	• True	• False
Steroids used for asthma will make you big and hairy	• True	• False
Anti-leukotrienes *are a* type of reliever	• True	• False
Your house only needs to be vacuumed once *a* month	• True	• False

Appendix 8

British Picture Vocabulary Scale (BPVS): example plates, stimulus words, norms table and age equivalence table.

I De British Picture Vocabulary Scale Second Edition

Performance Record

NFER-NELSON

Name (last) ____________ (first) ____________ Sex: M F (Circle)

School ____________ Teacher ____________

Home Address ____________ Tel. ____________

Reason for Testing ____________

LANGUAGE OF THE HOME ☐ Standard English ☐ Other ____________ DISABILITY: ☐ None ☐ Suspected ☐ Confirmed

(Specify foreign language or type of English dialect spoken) Type (if any): ____________ (Specify: hearing/vision loss, speech defect etc)

Norms Table B

Conversion of Standardized Scores to Percentile Ranks

Standardized Score	Percentile Rank	Standardized Scott	Percentile Rank
139+	99+	99	48
138-133	99	98	45
132-130	98	97	42
129-128	97	96	40
127-126	96	95	17
125	95	94	34
124-123	94	01	32
122	93	92	30
121	91	91	28
110	91	90	26
119	90	89	14
118	89	88	11
117	•7	«7	10
116	86	86	11
115	84	85	1<
"4	•1	84	14
113	80	83	13
"1	7«	82	12
" 1	77	•1	11
>>0	74	no	9
109	71	79	1
108	70	78	7
107	68	77-76	«
IM	66	75	5
IM	63	74-73	4
104	CO	71.71	1
103	58	70-68	1
102	55	67-62	1
101	52	61	1
100	50		

Dates	Year	Month	Day
Date of Testing			
Date of Birth			
Age in years and completed months			

Record of Scores

		Confidence Bands		
		SS–6		SS+6
Raw Score				
Standardized Score	(From Norms Table A)		to	
Percentile Rank		(From Norms Table B)	to	
Age Equivalent		(From Norms Table C)	to	

Please see Testbook for details of Calculation and Interpretation (pages 10 to 18

Administering the Test Items

Caution: Before administering the actual test items, it is essential to begin the test session correctly, use the training plates appropriately, and only then introduce these test items. Instructions to carry out all three of these steps are found on the examiner's side of the training plates.

Where to start the Test

For a subject assumed to be of average ability, find the set corresponding with the person's age and begin the test with the first word in that set (otherwise consult the manual). Once you begin a set, always administer every item in it.

How to establish the Basal Set

If no more than one error is made in the Stan Set, a basal is established. If more than one error is made, test backwards by sets in reverse order until no more than one error is made in a set. This becomes the Basal Set

How to establish the Ceiling Set

Only after the Basal Set has been established, test forward by sets until eight or more responses are wrong in a set of 12 items. This is the Ceiling Set.

How to record the responses and errors

As illustrated below, record the subject's responses for each item administered and draw an oblique line through the circle (O) after the response if incorrect. If correct, leave the circle blank.

12 drum (3). 4 Ø

Upon completion of each set, record the number of wrong responses in the space provided.

Remember these Rules

- Once a set is started, always administer *all* 12 items in that set.
- The Basal Set rule is *one or no errors* in a set.
- Use the *lowest* Basal Set to obtain the raw score.
- If the subject has made more than one error in Set 1, item 1 becomes the Basal.
- The Ceiling Set rule is eight *or more errors* in a set.
- Use the lowest Ceiling Set to obtain the raw score.

Set 1	↓Start – Ages 2½-3	Response
1	hand	(1) ____ O
2	baby	(2) ____ O
3	cat	(2) ____ O
4	Jumping	(4) ____ O
5	bus	(4) ____ O
6	drinking	(3) ____ O
7	tractor	Ml ____ O
8	running	(1) ____ O
9	gate	(3) ____ O
10	reading	(2) ____ O
11	cow	(11 ____ O
12	drum	(3) ____ O

Set 2	↓Start – Ages 4-5	Response
13	ladder	(2) ____ O
14	plant	(1) ____ O
J5	circle	(4). ____ 0
16	candle	(2). ____ 0
17	wooden	(2). ____ 8
18	nest	(4). ____ O
19	dancing	(4). ____ 0
20	tortoise	(1) ____ 0
21	farmer	(3). ____ 8
22	cobweb	(3). ____ O
23	neck	(3). ____ O
24	penguin	(1) ____ O
		No. of errors

Set 3	↓Start - Ages 6-7	Response
25	wrapping	(4) ____ O
26	fruit	(1) ____ O
27	smelling	(3) ____ O
28	arrow	0). ____ O
29	teacher	(2) ____ O
30	full	(3) ____ O
31	panda	(4) ____ O
32	exercising	(4) ____ O
33	coin	(2) ____ O
34	claw	(n- ____ 8
35	measuring	(2) ____ 0
36	peeling	(3) ____ 0
		No. of errors 1

39	lock	(4)	0
40	telescope	(3)	O
41	dripping	(2)	O
42	huge	(3)	O
43	furry	(4)	O
44	nostril	(1)	O
45	roots	(1)	0
46	vegetable	(3)	0
47	diving	(2)	O
4S	liquid	(4)	O
		No. of errors	

Set 7	↓Start – Age 12	Response	
73	greeting	(4)	O
74	antlers	(1)	0
75	orbit	tn	O
76	collision	(1)	0
77	inflated	(41	O
78	applauded	(31	O
79	nutritious	(3)	0
80	adjustable	(11	0
81	scalp	(21	0
82	reptile	(21	
83	resuscitation	(31	8
84	Units	(41	0
		No. of errors	

Set 10		Response	
109	detonation	(2)	8
UO	summit	(41	
111	salutation	(11	0
112	agricultural	(41	0
113	geriatric	(11	0
114	talon	(3)	0
115	consuming	(3)	0
116	dwelling	(11	0
117	emaciated	(21	0
118	lubricating	(1)	0
119	descending	(21	0
120	spherical	(4)	0
		No. of errors	

Set 5	↓Start – Age 10	Response	
49	luggage	(3)	O
SO	dentist	(2)	O
51	weasel	(2)	0
52	tugging	(1)	O
33	hive	(1)	0
54	delighted	(41	0
33	globe	(3)	8
56	furious	(41	
57	swamp	(1)	8
58	waiter	(21	0
59	target	(2)	
60	eagle	(4)	8
		No. of e m s	

Sets	↓Start – Ages 13-15	Response	
85	arctic	(J)	O
86	glider	(2)	O
87	lecturing	(3)	
88	engraving	(1)	8
69	co-operation	(2)	0
90	Actional	(11	0
91	hoisting	(1)	8
92	isolation	(3)	8
93.	syringe	(4)	
94	composing	(4)	8
95	fern	(1)	
96	weary	(4)	8
		No. of errors	

Set 11		Response	
121	exterior	(11	O
122	trestle	(2)	8
123	perforated	(21	8
124	fowl	(31	O
125	cascade	(41	0
126	vagrant	(11	8
127	trajectory	(1)	
128	Inoculating	(21	8
129	arable	(3)	
130	beacon	(41	8
131	deciduous	(4)	0
132	submerging	(11	0
		No. of errors	

Set 6	↓Start – Age 11	Response	
61	pair	(2)	O
62	coming	(4)	O
63	tubular	(2)	O
64	interviewing	(1)	O
65	snarling	(1)	O
66	medication	(4)	O
67	pod	(1)	O
68	grain	(4)	O
69	pedal	(3)	O
70	predatory	(2)	O
71	balcony	(J)	0
72	polluting	(3)	O
		No. of errors	

Set 9	↓Start- Ages 16-21	Response	
97	panllel	(41	0
93	dilapidated	(11	O
99	departing	(2)	0
100	easel	(4)	0
101	embracing	(3)	
102	utensil	(21	0
103	quartet	(41	0
104	citrus	(3)	0
105	digit	(11	0
106	feline	(2)	0
107	pillar	(1)	
108	timer	(11	8
		No. of errors	

Set 12		Response	
133	physician	(11	O
134	attire	(41	0
135	converging	(21	O
136	receptacle	(1)	o
137	festoon	(3)	O
138	incarcerating	(11	G
139	Incline	(4)	0
140	encumbered	(3)	O
141	caster	(1)	0
142	equestrian	(21	0
143	convex	(41	O
144	culinary	(21	0
		No. of errors	

Set 13		Response	
145	munificence (mew-nif-i-sens)	(1)	O
146	nautical (naw-ti-kuhl)	(4)	O
147	incertitude (in-suhrt-uh-tude)	(2)	O
148	gaff (gaf)	(1)	O
149	terpsichorean (tuhrp-sik-uh-ree-uhn)	(2)	O
150	bovine (boh-viyn)	(3)	O
151	pedagogue (ped-uh-gog)	(4)	O
152	succulent (suhk-yuh-luhnt)	(3)	O
153	altercation (ol-ter-kay-shon)	(3)	O
154	copious (koh-pee-uhs)	(2)	O
155	objurgating (ob-juhr-gayt-ing)	(4)	O
156	cenotaph (sen-uh-taf)	(1)	O
		No. of errors	

Set 14		Response	
157	nidificating (nid-uf-fuh-kayt-ing)	(3)	O
158	perambulating (per-am-bew-layt-ing)	(2)	0
159	vitreous (vi-tree-uhs)	(3)	0
160	supine (soo-piyn)	(4)	0
161	osculating (os-kyuh-layt-ing)	(1)	0
162	laciniated (luh-sin-ee-ayt-ed)	(0	0
163	lugubrious (luu-goo-bree-uhs)	(2)	0
164	pachyderm (pak-i-duhrm)	(2)	0
165	imbibing (im-biyb-ing)	(4)	0
166	casement (kay-sment)	(3)	0
167	tonsorial (ton-sohr-ee-uhl)	(4)	0
168	calyx (kay-liks)	(1)	0
		No. of errors	

Pronunciation key

- ay - long a as in day
- ee - long e as in feet
- iy - long i as in vine
- oh - long o as in road
- oo - long u as in soup
- a - short a as in man
- e - short e as in leg
- i - short i as in bit
- o - short o as in dog
- u - short u as in bun
- j - short g as in jam
- g - hard g as in gas
- s - soft c as in sent
- k - hard c as in cat
- aw as in law
- uh as in shove
- uhr as in circle
- ah as in lamb
- ohr as in shore

Calculating the Raw Score

Record below the number of the Ceiling Item, which is the last item in the Ceiling Set. Subtract from it the total number of errors made by the subject from the Basal Set through to the Ceiling Set.
This is the Raw Score.

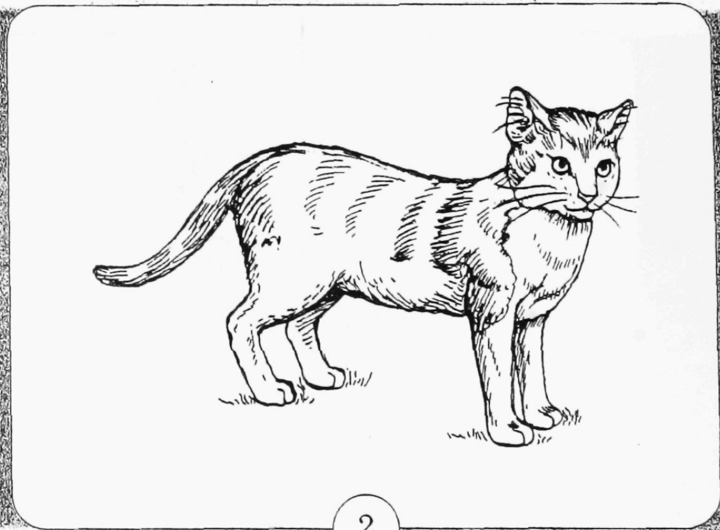
Ceiling Item ______

minus errors ______

Notes and Observations

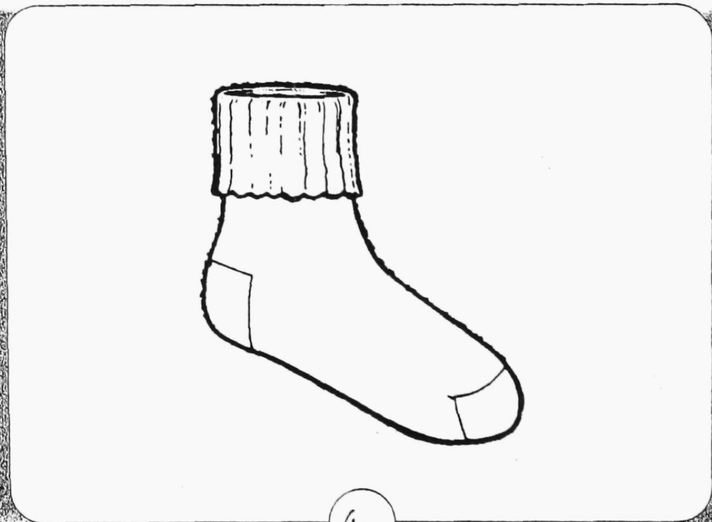
For example, briefly describe the subject's test behaviour, such as interest in the task, quickness of response, signs of perseveration, work habits, disabilities, etc.

1

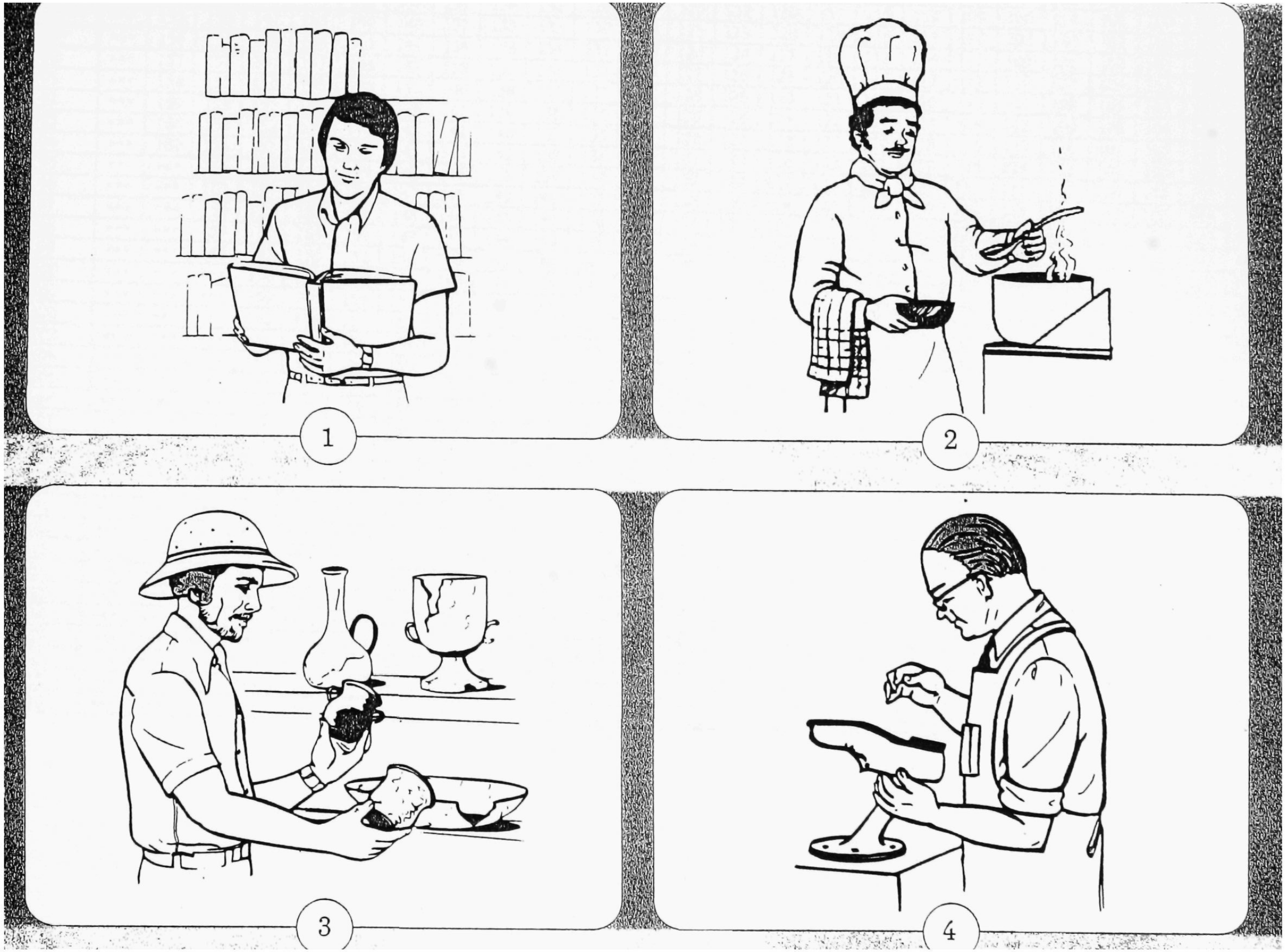


2

8



4


1
2
3
4

Age → / Score ↓	3:00-3:02	3:03-3:05	3:06-3:08	3:09-3:11	4:00-4:02	4:03-4:05	4:06-4:08	4:09-4:11	5:00-5:02	5:03-5:05	5:06-5:08	5:09-5:11	6:00-6:02	6:03-6:05	6:06-6:08	6:09-6:11	7:00-7:02	7:03-7:05	7:06-7:08	7:09-7:11	8:00-8:02	8:03-8:05	8:06-8:08	8:09-8:11	9:00-9:02	9:03-9:05
81	158	149	143	141	139	136	134	131	129	126	124	122	119	117	114	111	108	106	103	101	98	96	[illegible]	93	91	90
82	159	150	144	142	139	137	135	132	130	127	125	122	120	118	115	112	110	107	104	101	99	97	95	93	91	90
83	160	151	145	143	140	138	136	133	131	128	126	123	121	119	116	113	111	108	105	102	100	98	96	94	92	91
84	***	151	146	144	141	139	136	134	131	129	127	124	122	119	117	114	112	109	106	103	101	98	97	95	93	92
85	***	152	147	145	142	140	137	135	132	130	128	125	123	120	118	115	113	110	107	104	102	99	98	96	94	93
86	***	153	148	145	143	141	138	136	133	131	128	126	124	121	119	116	114	111	108	105	103	100	99	97	95	93
87	***	154	149	146	144	142	139	137	134	132	129	127	125	122	120	117	115	112	109	106	104	101	100	98	96	94
88	***	155	150	147	145	142	140	137	135	133	130	128	125	123	120	118	116	113	110	107	105	102	100	98	97	95
89	***	156	151	148	146	143	141	138	136	134	131	129	126	124	121	119	117	114	111	108	106	103	101	99	98	96
90	***	157	151	149	147	144	142	139	137	134	132	130	127	125	122	120	117	115	112	109	107	104	102	100	98	97
91	***	158	152	150	148	145	143	140	138	135	133	131	128	[illegible]	123	121	118	116	113	111	108	105	103	101	99	98
92	***	159	158	151	148	146	144	141	139	136	134	131	129	126	124	122	119	117	114	112	109	106	104	102	100	99
93	***	160	154	152	149	147	145	142	140	137	135	132	130	127	125	123	120	118	115	113	110	107	105	103	101	100
94	***	160	155	153	150	148	145	143	140	138	136	133	131	128	126	123	121	119	116	114	111	108	[illegible]	104	102	101
95	***	***	156	154	151	149	146	144	141	139	137	134	132	129	127	124	122	120	117	115	112	109	107	105	103	102
96	***	***	157	154	152	150	147	145	142	140	137	135	133	130	128	125	123	120	118	115	113	110	108	[illegible]	104	103
97	***	***	158	155	153	151	148	146	143	141	138	136	134	131	129	126	124	121	119	116	114	111	109	107	105	104
98	***	***	159	156	154	151	149	147	144	142	139	137	134	132	130	127	125	122	120	117	115	112	110	108	[illegible]	[illegible]
99	***	***	160	157	155	152	150	148	145	143	140	138	135	133	131	128	126	123	121	118	116	113	111	109	107	105
100	***	***	***	158	156	153	151	148	146	144	141	139	136	134	131	129	127	124	122	118	116	114	112	110	108	106
101	***	***	***	159	157	154	152	149	147	145	142	140	137	135	132	130	128	125	123	119	117	115	113	111	109	[illegible]
102	***	***	***	160	158	155	153	150	148	146	143	141	138	136	133	131	128	126	124	120	118	116	114	112	110	[illegible]
103	***	***	***	***	159	156	154	151	149	147	144	142	139	137	134	132	129	127	125	121	119	117	115	113	111	[illegible]
104	***	***	***	***	160	157	155	152	150	147	145	143	140	138	135	133	130	128	125	122	120	118	116	114	112	110
105	***	***	***	***	***	158	156	153	151	148	146	144	141	139	136	134	131	128	126	123	121	119	117	115	113	111
106	***	***	***	***	***	159	157	154	152	149	147	145	142	140	137	135	132	130	127	124	122	119	118	116	114	112
107	***	***	***	***	***	160	158	155	153	150	148	146	143	141	138	136	133	131	128	125	123	120	119	117	115	113
108	***	***	***	***	***	***	159	156	154	151	149	147	144	142	139	137	134	132	129	126	124	121	119	117	116	114
109	***	***	***	***	***	***	160	157	155	152	150	148	145	143	140	138	135	133	130	127	125	122	120	118	117	115
110	***	***	***	***	***	***	***	158	156	153	151	149	146	144	141	139	136	134	131	128	126	123	121	118	117	116
111	***	***	***	***	***	***	***	159	157	155	152	150	147	145	142	140	138	135	132	129	127	124	122	120	118	117
112	***	***	***	***	***	***	***	160	158	156	153	151	148	146	143	141	139	136	133	130	128	124	123	121	119	118
113	***	***	***	***	***	***	***	***	159	157	154	152	149	147	145	142	140	137	134	131	129	126	124	122	120	119
114	***	***	***	***	***	***	***	***	160	158	155	153	150	148	146	143	141	138	135	132	129	127	125	123	120	119
115	***	***	***	***	***	***	***	***	***	159	156	154	152	149	147	144	142	139	136	133	130	128	126	124	121	120
116	***	***	***	***	***	***	***	***	***	160	157	155	153	150	148	145	143	140	137	134	131	129	126	124	122	121
117	***	***	***	***	***	***	***	***	***	***	159	156	154	151	149	147	144	142	138	135	132	130	128	125	124	122
118	***	***	***	***	***	***	***	***	***	***	160	157	155	152	150	148	145	143	139	136	133	131	129	126	125	122
119	***	***	***	***	***	***	***	***	***	***	***	159	156	154	151	149	146	144	141	137	135	132	130	127	126	123
120	***	***	***	***	***	***	***	***	***	***	***	160	157	155	152	150	147	145	142	138	136	133	131	128	126	124

II BPVS II

Norms Table C: Age equivalents associated with each raw score together with 68 per cent confidence limits

Raw Score	Age Equivalent years:months	Lower Limit years:months	Upper Limit years:months
79	7:09	7:02	8:04
80	7:10	7:03	8:06
81	7:11	7:04	8:08
82	8:00	7:05	8:09
83	8:01	7:06	8:10
84	8:02	7:07	8:11
85	8:04	7:08	9:01
86	8:05	7:09	9:02
87	8:07	7:10	9:04
88	8:08	8:00	9:06
89	8:09	8:01	9:08
90	8:10	8:02	9:10
91	9:00	8:03	9:11
92	9:01	8:04	10:01
93	9:04	8:06	10:03
94	9:07	8:07	10:04
95	9:09	8:09	10:06
96	9:10	8:10	10:08
97	9:11	9:00	10:10
98	10:01	9:01	11:00
99	10:02	9:03	11:01
100	10:04	9:05	11:03
101	10:07	9:06	11:04
102	10:08	9:08	11:05
103	10:10	9:10	11:07
104	10:11	10:00	11:09
105	11:01	10:02	11:11
106	11:03	10:04	12:01
107	11:04	10:06	12:02
108	11:07	10:08	12:04
109	11:08	10:10	12:06

Raw Score	Age Equivalent years:months	Lower Limit years:months	Upper Limit years:months
110	11:10	11:00	12:08
111	12:00	11:02	12:10
112	12:01	11:05	13:00
113	12:04	11:06	13:02
114	12:05	11:07	13:04
115	12:07	11:09	13:06
116	12:10	11:11	13:08
117	13:00	12:01	13:10
118	13:01	12:03	14:00
119	13:04	12:05	14:02
120	13:06	12:07	14:04
121	13:08	12:10	14:06
122	13:10	13:00	14:08
123	14:01	13:02	14:10
124	14:03	13:04	15:02
125	14:05	13:07	15:04
126	14:07	13:08	15:06
127	14:10	13:11	15:09
128	15:00	14:02	15:11
129	15:02	14:04	16:01
130	15:04	14:06	16:03
131	15:06	14:09	16:06
132	15:08	15:00	16:08
133	15:10	15:03	16:10
134	16:00	15:05	17:00
135	16:02	15:07	17:02
136	16:04	15:09	17:04
137	16:06	15:11	17:06
138	16:09	16:01	17:08
139	16:10	16:03	17:10
140+	17:00	16:05	18:00

Appendix 9

Information letters sent to parents and children attending asthma clinics[1].

[1] Letters were sent on the headed paper of the appropriate hospital.

NOTTINGHAM City HOSPITAL

NHS TRUST

Hucknall Road
Nottingham
NG5 1PB
Telephone
0115 969 1169

Ext Fax No

NHS

Our Ref Your Ref Please ask for

Evaluation of Asthma Files: Health education program for children with asthma

Investigators: Dr Alan Smyth (Consultant in Paediatric Respiratory Medicine)
Dr Cris Glazebrook (Senior Lecturer in Behavioural Sciences)
Ms Amy McPherson (Researcher in Behavioural Sciences)

Dear Parent

Your child is being invited to take part in a study in a research study. Before you decide whether your child can take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask us if there is anything you are not clear about.

We have developed a computer program (CD-ROM) for children with asthma called The Asthma Files". It is an interactive program which uses a secret agent theme to give children information about symptoms, causes and management of asthma. It is important that children receive adequate information about asthma so that they are happier about treatment and better able to manage their own asthma. We are carrying out this study to see whether the program is effective in improving children's asthma knowledge and management skills.

Why has my child been chosen? We are contacting parents of all children aged 7-14 with appointments for Dr Smyth's Friday morning Asthma Clinic at the City Hospital. The research will take place at the Paediatric out-patient clinic whilst children are waiting to be seen by the doctor and by arranagement at the child's home.

What will happen to my child if we take part? When you arrive at the asthma clinic for your child's appointment our researcher, Ms Amy McPherson, will sit with your child and complete some questionnaires concerning your child's knowledge about asthma and the way that he or she manages asthma. This interview will be tape-recorded and the tapes will be stored securely and then wiped at the end of the study. Amy will also make an assessment of your child's verbal ability using a standard picture test. In addition, your child will be asked to blow into **a** tube to find out how well their lungs are functioning at that time. While your child is being interviewed you will be asked to complete a short questionnaire concerning your child's asthma management.

After completion of this 20-minute interview your child will be allocated to one of two groups. This will be done by chance by opening a sealed envelope.

Following the study, information from the 2 groups will be compared. Approximately one month after the clinic appointment children allocated to Group 1 will receive by post an infomnation booklet about asthma. Children in Group 2 will be visited at home by Amy who will give children in this group the opportunity *io* use the Asthma Files CD-ROM and also a copy of the CD-ROM to keep. One-month after this Amy will contact you to arrange a suitable twenty-minute slot to interview your child in his or her own home. She will ask your child about his or her current asthma management and knowledge about asthma. She will also ask you to complete a questionnaire concerning your child's asthma management. We would also like to obtain some information about your child's medical progress over the past few months from the medical notes. Children in Group 1 will be given the opportunity to use the Asthma Files program after the study has finished, including a copy of the program to keep.

Does my child have to take part? It is up to you to decide whether to allow your child to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. The standard of your child's care will not be affected in any way. All information will be confidential. If you have any questions about the study, please contact Dr. Cris Glazebrook or Ms. Amy McPherson on 0115 970 9338.

NOTTINGHAM City HOSPITAL NHS TRUST

NHS

Hucknall Road
Nottingham
NG5 1PB
Telephone
0115 969 1169

Ext Fax No

Our Ref Your Ref Please ask for

Health education program for children with asthma

Investigators:

Dr Alan Smyth (Consultant in Paediatric Respiratory Medicine)
Dr Cris Glazebrook (Senior Lecturer in Behavioural *5c\ences)*
Ms Amy McPherson (Researcher in Behavioural Sciences)

INFORMATION FOR CHILDREN

- Doctors *and nurses* at the City Hospital have designed *a* computer program "The Asthma Files" that tells children about asthma and the best ways to manage asthma
- We *are* carrying out some research to see if the program is useful in helping children to learn about asthma
- Our researcher, Amy McPherson, would like to ask you some questions about asthma and the way that you cope with your asthma at your next clinic visit.
- About 2 or 3 weeks after that she may come and see you at home to show you "The Asthma Files" program or you may be sent an information booklet about asthma by post.
- About 4 weeks later Amy will come to see you again at home to ask you some more questions about your asthma and how you cope with it.
- Remember that you *do* not need to take part in this *research* if you don't want to. Just tell your mum or dad or our researcher if you'd rather not.
- All children who take part in the study will get the opportunity to use "The Asthma Files" computer program eventually, if they would like to.

NOTTINGHAM City HOSPITAL
NHS TRUST

Hucknall Road
Nottingham
NG5 1PB
Telephone
0115 969 1169
Ext Fax No

NHS

Our Ref Your Ref Please ask for

Evaluation of Asthma Files: Health education program for children with asthma

Investigators:
Dr Alan Smyth (Consultant in Paediatric Respiratory Medicine)
Dr Cris Glazebrook (Senior Lecturer in Behavioural Sciences)
Ms Amy McPherson (Researcher in Behavioural Sciences)

Dear Parent,

Your child was recently invited to take part in a research study involving a computer program called "The Asthma Files". Unfortunately, our researcher, Amy McPherson, was not able to see you at your clinic appointment, but we would still like you and your child to be involved in the project.

Amy is happy to come out to your home if it would be more convenient for you. Otherwise, she can see your child at their next asthma clinic appointment. Please indicate on the enclosed slip your preference and post it back to the researcher (no stamp required).

If you do decide to take part you are still free to withdraw at any time and without giving a reason. The standard of your child's care will not be affected in any way. All information will be confidential. If you have any questions about the study, please contact Dr. Cris Glazebrook or Ms. Amy McPherson on 0115 970 9338.

Yours Sincerely,

Dr. Cris Glazebrook

NOTTINGHAM City HOSPITAL
NHS TRUST

NHS

Hucknall Road
Nottingham
NG5 IPB
Telephone
0115 969 1169
Ext Fax No

Our Ref | Your Ref | Please ask for

Health education program for children and young people with asthma

Investigators:

Dr Alan Smyth, Consultant in Paediatric Respiratory Medicine
Dr Cris Glazebrook, Senior Lecturer in Behavioural *Sciences*
Ms Amy McPherson, Researcher in Behavioural *Sciences*

You recently took part in our asthma education study, and wc would like to take this opportunity to thank you for all your time and help. All information provided during the course of the study has been extremely useful, but will, of course, be kept strictly confidential.

The study is ongoing, but we will send every person who has taken part in the study a free copy of "The Asthma Files" computer program *as soon as we* have updated it in the light of comments *received during* the study.

If you have any queries in the meantime, do not hesitate to contact one of the project investigators.

Many thanks and best wishes,

Amy

Appendix 10

Consent form for entry to study.

NOTTINGHAM City HOSPITAL
NHS TRUST

Hucknall Road
Nottingham
NG5 1PB
Telephone
0115 969 1169
Ext Fax No

NHS

Our Ref Your Ref Please ask for

CONSENT FORM

Title of project: **Evaluation of "Asthma Files": a multimedia health education programme for children with asthma**

Site Children's Out-Patients Clinic City Hospital Nottingham

Investigators Dr Alan Smyth (Consultant in Paediatric Respiratory Medicine)
Dr Cris Glazebrook (Senior Lecturer in Behavioural Sciences)
Ms Amy McPherson (Research Fellow in Behavioural Sciences)

The parent should complete the whole of this sheet himself/herself Cross out as necessary

- Have you read & understood the information sheet YES/NO
- Have you had opportunity to ask questions & discuss the study YES/NO
- Have all the questions been answered satisfactorily YES/NO
- Have you received enough information about the study YES/NO
- Who have you spoken to Dr/Mrs/Ms ,..........................
- Do you understand that you are free to withdraw from the study
  - at any time YES/NO
  - without having to give a reason YES/NO
  - without affecting your fiiture medical care YES/NO
- Do you agree to take part in the study YES/NO

I am happy for the researchers to contact my child's school YES/NO

Signature (Parent) Name (In block capitals) Date

____________ ____________ ________

I have explained the study to the above parent and he/she has indicated his/her willingness to participate.

Signature (Researcher) Name (In block capitals) Date

____________ ____________ ________

I am happy to take part in this study

Signature of child (optional)

____

Appendix 11

Information letters sent to parents and children in school sample.

Our reference

Your reference

Direct line/e-mail

School of Community Health Sciences
Division of Psychiatry

Behavioural Sciences
A Floor
South Block
Queen's Medical Centre
Nottingham
NG7 2UH
Tel: +44 (0) 115 970 9338
Fax:+44 (0) 115 970 9495
www.nottingham.ac.uk/psychiatry
www.nottingham.ac.uk/chs

9th October 2002.

Dear Parent/Guardian

Evaluating an Asthma Knowledge Questionnaire for Children

Your child is being invited to take part in a research study. Before you decide whether you wish your child to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask us if there is anything you are not clear about.

Why do a study on asthma? Asthma affects 1 in 8 children in the UK and an essential part of helping children to control their asthma is through education. This can help children to be more aware of their condition and happier about taking treatments. To teach children effectively we need to find out what they know already and we have developed a questionnaire to assess this. The questionnaire has already been used with lots of children with asthma and we now want to use it with children without asthma to compare the knowledge in the two groups. This study aims to make sure that the questionnaire we are using can distinguish between children who know a lot about asthma and children who know very little about asthma. Your child can still take part even if they do have asthma.

Who is carrying out the study? Children will be interviewed by a third year medical student, Ms Kate Miller, as part of her training. The project will be supervised by Dr Cris Glazebrook, Senior Lecturer in Behavioural Sciences, Ms Amy McPherson, Research Psychologist and Dr Alan Smyth, Consultant in Respiratory Paediatric Medicine. The study has been approved by the University of Nottingham Medical School Ethics Committee,

Why has my child been chosen? Four schools in Nottingham have been approached to take part in the study and we have written to the parents of all children between the ages of 7 and 14 years attending these schools. Approximately 5-6 children from each class will be randomly selected from the class register to take part and we aim to interview approximately 100 children altogether.

What does the study involve? If selected, your child will be asked a variety of questions about asthma which will be followed by a standard test of verbal ability. The interview will take place on the school premises and should last no more than 15 minutes. It will involve taking children out of a lesson for a short period of time, with the agreement of the school. Parents of children who take part will be asked to complete a brief form which will include a question on whether the child is, or has ever been, treated for asthma. A freepost envelope will be provided.

What happens **to** the **information collected?** The results of the study will be used to find out how much children know about asthma and to identify the best way of measuring children's knowledge about the condition. You will be given the opportunity to hear about the findings of the study at a later date. All information collected from you and your child will remain strictly confidential and you will not be identifiable in any documents or reports. Your child's questionnaires will be identified only by a number for the purposes of the study.

Does **my child have to take part?** It is up to you to decide whether your child to takes part in this study and you may withdraw your child at any point without giving a reason. If you are happy for your child to be considered to take part please sign the slip below and return it to the school via your child. Please keep this letter for your information.

Further Information. If you have any questions or comments regarding the study please feel free to contact Dr. Cris Glazebrook or Ms. Amy McPherson at the above address or telephone 0115 970 9338. Thank you for taking the time to read this letter.

Yours faithfully,

Dr Cris Glazebrook

Ms Amy McPherson

Ms Kate Miller

Dr A Smyth

Please detatch the slip and return to school office if you are happy for your child to be considered to take part in the study

✂...

I am happy for my child to take part in the study to assess children's knowledge of asthma.

Child's Name..

Year/Class:.............................. Tutor Group..........................

School: Chilwell Comprehensive

Parent's Name..

Signed.. Date.........................

Contact tel. No...

Information for Pupils

- I am a medical student researching how much children and young people know about asthma. We have designed a questionnaire to help us find out.

- To check that the questionnaire *is* working properly, we want to interview lots of children- both with and without asthma.

- *A few* people from each *class will* be randomly picked from the *class* register and asked to take part.

- If you *are one of* them, I *will ask* you *a* few questions about asthma and then ask you to do *a* short test with pictures to see how many words you know. It will only take about 15 minutes and you will have to come out of *one* of your lessons. It doesn't matter if you think you don't know much about asthma.

- You *can* take part whether you have asthma *or* not.

- If you don't want to take part, tell your parents, teacher *or* let me **know.**

- **Thank** you for your help.

Kate

Appendix 12

Approval letters from ethics commitees at University of Nottingham Medical School, Nottingham City Hospital, Queen's Medical Centre & Derby City General Hospital.

Please quote protocol ref no:

Direct line/e-mail
+44 (0) 115 970 9905380
Louise.Sabir@nottingham.ac.uk

06 September 2002

Faculty of Medicine
and Health Sciences

Medical School Ethics
Committee

Dean's Office
B Floor
The Medical School
Oueen's Medical Centre
Nottingham
NG7 2UH
Tel: +44(0) 115 970 9380
Fax: +44 (0) 115 970 9974

Dr Cns Glazebrook
Senior Lecturer
Behavioural Sciences
A Floor, South Block
Queen's Medical Centre

06 September 2002

Dear Dr Glazebrook

T/7/2002 - What do children know about asthma? Evaluating an asthma knowledge questionnaire.

Thank you for your letter dated 12th August 2002 in which you clarify the concerns raised by the Committee. These have been reviewed and are satisfactory and the study is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethic's Committee approval.

The Committee would expect to see a copy of the final questionnaire before it is used.

You promptly inform the Chairman of the Ethic's Committee of

(i) deviations fi^om or changes to the protocol which are made to eliminate immediate hazards to the research subjects.

(ii) Any changes that increase the risk to subjects and/or affect significantly the conduct of the research

(iii) All adverse drug reactions that are both serious and unexpected

(iv) New information that may affect adversely the safety of the subjects or the conduct of the study.

Please note that all correspondence and **queries** should be sent to my Ethics **CommitteeSecretary Louise Sabir**

ICH GCP Compliance

The University of Nottingham Medical Research Ethics Committee is fully compliant with "the International Committee on Harmonisation/Good Clinical Practice (ICH/GCP) Guidelines for the Conduct of Trials involving the Participation of Human Subjects" as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end, it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice adopted by the Commission of the European Union on 17 January 1997.

Yours sincerely

Professor R C Spiller
Chairman, Nottingham University Medical School Ethics Committee

Please note that all correspondence and queries should be sent to my
Ethics Committee Secretary Louise Sabir

NOTTINGHAM City HOSPITAL
NHS TRUST

Research Ethics Committee
Nottingham City Hospital
Hucknall Road
Nottingham
NG5 1PB

Tel. 0115-9691169 ext. 45860
Fax. 0115-962-7784

Chairman
Dr N Broderick

Honorary Secretary
Dr D Pearson

---

22 December 2000

Ms A McPherson
Researcher
Division of Psychiatry
Behavioural Sciences
A Floor
South Block
Queen's Medical Centre
NG7 2UH

Dear Ms McPherson

Re: A randomised controlled trial to investigate the effectiveness of "The Asthma **Files",** an interactive multimedia health education programme for children with asthma.

When replying please quote Ref: **EC00/187**

Thank you for your letter dated 7 December 2000 enclosing a revised patient information sheet and for answering the queries raised by the committee.

I can now give this study officer approval and this will be reported to the full committee at the next meeting to be held on 29 January 2001.

Approval is given on the following understanding:

- Approval is granted for 3 years fi-om the date of this letter. If you fail to start the research within this time you will have to re-apply for further approval.

- It is the responsibility of the investigator to notify the committee immediately of any information received by him/her or of which he/she becomes available, which would cast doubt upon or alter any information contained in the original application or a later amendment application, which would raise questions about the safety and/or continued conduct of the research.

- Patient information stored on computer must be handled in accordance with the Data Protection Act 1984 and local policies and procedures relating to the use of computer held data.

- All research must be conducted throughout according to good clinical research practice standards.

- All serious or unexpected adverse events and adverse drug reactions which may affect the conduct and the continuation of the study must be reviewed by the lead researcher and reported to the committee.

- All protocol amendments must be referred to the **committee** for further review and approved prior to implementation except where the welfare of the subject is paramount.

- All research which is discontinued temporarily or permanently should be reported to the committee.

- The committee requests the researcher to provide details of the progress of the research at least annually and details of its conclusion and outcome.

- The meeting of the committee which considered your application was quorate according to the **constitution** of the conmiittee.

- The membership of the committee is attached. It is against the policy of the committee to identify which members were present when your submission was approved.

Yours sincerely

Dr D Pearson
Honorary Secretary
<u>City Hospital Research Ethics Committee</u>

Southern Derbyshire
Acute Hospitals NHS Trust

RESEARCH AND DEVELOPMENT OFFICE

ac
Derby City General Hospita
Uttoxeter Roac
Derby
DE22 3N1
Tel: 0133234013
Fax: 01332 29055

TRUST APPROVAL LETTER

Dr Cris Glazebrook,
Senior Lecturer in Behavioural Sciences,
Division of Psychiatry,
School of Community Health Sciences,
A Floor, South Block,
QMC,
Nottingham,
NG7 2UH.
3rd April, 2002.

Dear Dr Glazebrook,

Re : A randomised, controlled trial to investigate the effectiveness of "The Asthma Files", an interactive multimedia health education program for children with asthma. (Ref. SD AH/2002/017)

Further to the Southern Derbyshire Local Research Ethics Committee approval for the above study, I am pleased to confirm Trust management approval for you to proceed in accordance with the agreed protocol, the Trust's financial procedures for research and development and the Research Governance Framework.

Please supply the following to Dr Teresa Grieve, R&D Manager :

- details of any publications arising from this research project.
- a final report and a report every six months if the study duration is greater than six months.
- notification of any adverse event or changes to the protocol or if the trial is abandoned.

Please note that approval for this study is dependent on full compliance with all of the above conditions.

I would like to take this opportunity to wish you every success with this study.

Yours sincerely,

Professor Richard Donnelly
Director of Research & Development.

CO. Dr Nigel Ruggins, Consultant Paediatrician, Derbyshire Children's Hospital.

Queen's Medical Centre
Nottingham

Research and Development Directorate

Please ask for: Janet Boothroyd, R&D Manager, Ext. 44307
Ruth Doyle, Data Manager, Ext. 44771
Linda Ellis, Administrative Assistant, Ext. 41049
Debbie Cocks, Secretary/Administrator Ext. 35117

Our Ref: CS010101

6* March 2001

Dr A Smyth
Division of Psychiatry
Behavioural Sciences
A Floor
South Block
UHN

Dear Dr Smyth

Re: **A Randomised Controlled Trial To Investigate The Effectiveness Of 'The Asthma Files', An Interactive Multimedia Health Education Program For Children With Asthma**

Thank you for submitting the above project for consideration by the Ethics Committee. The Ethics Committee met on 5* March 2001. Under the reciprocal arrangement the Committee is happy to approve the project subject to an information sheet being made available for QMC patients.

I should be grateful if you could let me have this as soon as possible.

On receipt of this information and it being considered satisfactory a full approval will be forwarded to you.

Kind regards

Yours sincerely

Dr I M Holland
Honorary Secretary
Ethics Committee

University Hospital
Nottingham NG7 2UH
Telephone (0115) 9249924
Direct Line (0115) 9709049
Fax External (0115 8493295) Internal 35295
Dr Ian Holland, Honorary Secretary. Ethics Committee
Queens Medical Centre, Nottingham, University Hospital NHS Trust

Southern Derbyshire
Acute Hospitals NHS Trust

RESEARCH AND DEVELOPMENT OFFICE

TRUST APPROVAL LETTER

Derby City General Hospital
Uttoxeter Road
Derby
DE22 3NE

Tel: 01332 340131
Fax: 01332 290559

Dr C Glazebrook,
Division of Psychiatry,
A Floor,
South Block,
Queen's Medical Centre,
Nottingham,
NG7 2UH.

29th October. 2001.

Dear Dr Glazebrook,

Re : Study to evaluate an Asthma Locus of Control Scale for children. (Ref. SDAH/2001/071).

Further to the Southern Derbyshire Local Research Ethics Committee approval for the above study, I am pleased to confirm Trust management approval for you to proceed in accordance with the agreed protocol, the Trust's financial procedures for research and development and the Research Governance Framework.

Please supply the following to Dr Teresa Grieve, R&D Manager :

- details of any publications arising from this research project.
- a final report and a report every six months if the study duration is greater than six months.
- notification of any adverse event or changes to the protocol or if the trial is abandoned.

Please note that approval for this study is dependent on full compliance with all of the above conditions.

I would like to take this opportunity to wish you every success with this study.

Yours sincerely,

Professor Richard Donnelly
Director of Research & Development.

Appendix 13

Parent Demographic and Knowledge Questionnaire (PDKQ).

rent's nan
ild's name...
ntact Tel number ....

Parent Asthma Management Questionnaire

Some information about your child

1. What is your child's date of birth? ___/___/___

2. How long has your child had asthma?..................

3. How old was he/she when diagnosed with having asthma?...........................

4. Does your child have any other allergies? *(e.g. eczema)* **YES/ NO/ Don't Know**..........................
(Please Specify)

5. In the last month, how many days off school have been due to your child's asthma?..........................

6. Please describe your child's ethnic background:..
Or
You *can tick one of* the following boxes if it is helpful:

- White
- ❑ Black Caribbean
- Black African
- Black British
- ❑ Mixed race
- ❑ Asian

Some information about you;

7. What relation *are* you to the child with asthma?

- Mother
- Father
- Grandparent
- Other.............................. *(Please specify)*

8. Is there anyone else in the family with asthma?

- Mother
- Father
- Grandparent
- Other.............................. *(Please specify)*

9. What educational level did you achieve?

- Left school before '0' levels/ *GCSEs*
- '0' levels/ *GCSEs*
- 'A' levels
- University
- Postgraduate qualification

10. What is your child's mother's occupation?..
or
Previous occupation (if not currently in paid employment)..
11. What is your child's father's occupation?..
or
Previous occupation (if not currently in paid employment) ....

12. The child's mother's age.............. yrs

13. The child's father's age..............yrs

Information about your child's asthma management

	Blue	Brown/ orange	Green	Purple
14. What colour are your child's inhalers?	●	●	❑	●
15. How often does your child take their inhalers in a typical week?	No. of puffs........ Times per day.......	No. of puffs....... Times per day.......	No. of puffs........ Times per day......	No of puffs...... Times per day..,
16. How often does your child miss a dose per week?				

17. Does anything trigger of your child's asthma? **Yes/ No/ Don't know**

18. If yes, please tick his/her triggers:

- Furry animals
- Dust
- Colds/ viruses
- Exercise
- Smoke
- Excitement/ stress
- Particular weather *(i.e. cold, foggy)*
- Pollen
- Other ....
  (please specify)

19. Do you take any measures to avoid triggering your child's asthma? *(i.e. special bedding, damp dusting etc)* ....

....

20. What is your child's best peak flow?..............................

21. What would be a low peak flow?..............................

22. What would you do?..

....

23. If your child was having an asthma attack, which of the following would make you call medical help: *(tick as many as appropriate)*

- First puff of reliever not helping
- Child has blue lips
- Peak flow remaining steady below best peak flow but above 75% but child still feeling unwell
- Peak flow falls to below 50% of child's best peak flow
- Child not able *io* talk
- Peak flow falls below 75% of best peak flow but returns above 75%

24.. Please indicate whether you think the following sentences are True or False

Children with asthma...

i. ...have exactly the same symptoms *as* all other children with asthma

- True
- False
- Don't know

ii. ...have airways which *are* sensitive to triggers

- True
- False
- Don't know

iii. ...have something wrong with their blood cells

- True
- False
- Don't know

iv. ...should *never do any exercise*

- True
- False
- Don't know

V. ...experience tightening of their airways during *an* asthma attack

- True
- False
- Don't know

vi. *...experience* widening of their airways during an asthma attack

- True
- False
- Don't know

vii. ...breathe very slowly taking long breaths during an asthma attack

- True
- False
- Don't know

viii. ...may find it hard to breathe because of the mucus in their airways

- True
- False
- Don't know

25. Who usually takes responsibility for your child's asthma management? Please circle the appropriate number (on the scale of 1-5) for each part:

	1 *Parent/adult mostly responsible*	**2** *Child occasionally remembers without reminder*	**3** *Parent/adult & child share responsibility equally*	**4** *Parent/ adult reminds child occasionally*	**5** *Child mostly responsible*	*Not applic able*
Measuring peak flow	**1**	**2**	**3**	**4**	**5**	**N/A**
Filling in peak flow diary	**1**	**2**	**3**	**4**	**5**	**N/A**
Taking daily preventer medicine	**1**	**2**	**3**	**4**	**5**	**N/A**
Taking reliever medicine	**1**	**2**	**3**	**4**	**5**	**N/A**
Following self-management plan	**1**	**2**	**3**	**4**	**5**	**N/A**
Changing medications if necessary	**1**	**2**	**3**	**4**	**5**	**N/A**
Reducing triggers in home environment	**1**	**2**	**3**	**4**	**5**	**N/A**

Appendix 14

Six- month follow- up schedule.

Child's name ______________________Tel no.____________________ bate__/__/__
Parent's name.______________________

6 month follow-up schedule

Clinic City QMV (V) QMC (T) QMC (5) Derby

Group Booklet/ Computer

Date of intervention __/__/__

- Has your child had any hospital admissions in the six months after the book/ computer? YES/ NO

If yes, how many? _____ total no. days ___

- Has your child seen the *GP for* their asthma, other than for a check up? YES/ NO

If Yes, how many times?______

- Has your child had to take oral steroids in the six months since the book/ computer? **YES/** NO

If yes, how many courses?_____

- How many days did your child have off school due to their asthma *in* the 6 months since book/ computer?

	Month	Year	No. days
	January		
	February		
	March		
	April		
	May		
	June		
	July		
	August		
	September		
	October		
	November		
	December		

Appendix 15

CD-ROM evaluation schedule.

Program evaluation

Please put a tick the box if you agree with the statement or a cross if you disagree

It was easy to find my way round the program	
I learned a lot looking at the programs	
The Asthma Files computer program was boring	
There should be more interactive bits in the program	
The Asthma Files is a good way to learn about asthma	
The pictures helped me to understand what happens inside my body	
Looking at The Asthma Files was a waste of time	
I know more about my asthma now I've looked at The Asthma Files	
I always knew how to get out of a room	
The Asthma files was fun	
The voices in the program were good.	
There should be more help finding the secret games level	
I would tell other people with asthma to look at The Aasthma Files	

I liked: ______________________________

____

____

I didn't like: ______________________________

____

____

Appendix 16

Letter of approval from Nottingham City Hospital for pilot study: "Evaluation of "The Asthma Files": a multimedia health education for children with asthma".

NOTTINGHAM City HOSPITAL
NHS TRUST

Research Ethics Committee
Nottingham City Hospital
Hucknall Road
Nottingham
NG5 1PB

Tel. 0115-9691169 ext. 45860
Fax. 0115-962-7784

Chairman
Dr N Broderick

Honorary Secretary
Dr D Pearson

20 June 2000

Dr A Smyth
Consultant
Papplewick Ward
Nottingham City Hospital

Dear Alan

Re: Evaluation of the "Asthma **Files":** a multimedia health **education** program for children with asthma. Ref: ECOO/67

Thank you for your letter dated 1 June 2000 enclosing a revised information sheet for parent and child and a revised consent form.

I can now give this study officer approval on the proviso you forward a copy of the assent form for parents and ensure the title on the consent form is the same as the title on the patient information sheet. We will need copies for our records.

Approval is given on the following understanding:

- Approval is granted for 3 years fi-om the date of this letter. If you fail to start the research within this time you will have to re-apply for further approval.

- It is the responsibility of the investigator to notify the committee immediately of any information received by him/her or of which he/she becomes available, which would cast doubt upon or alter any information contained in the original application or a later amendment application, which would raise questions about the safety and/or continued conduct of the research.

- Patient information stored on computer must be handled in accordance with the Data Protection Act 1984 and local policies and procedures relating to the use of computer held data.

- All research must be conducted throughout according to good clinical research practice standards.

- All serious or unexpected adverse events and adverse drug reactions which may affect the conduct and the continuation of the study must be reviewed by the lead researcher and reported to the committee.

- All protocol amendments must be referred to the committee for further review and approved prior to implementation except where the welfare of the subject is paramount.

- All research which is discontinued temporarily or permanently should be reported to the committee.

- The committee requests the researcher to provide details of the progress of the research at least annually and details of its conclusion and outcome.

- The meeting of the committee which considered your application was quorate according to the constitution of the committee.

- The membership of the committee is attached. It is against the policy of the committee to identify which members were present when your submission was approved.

Yours sincerely

Dr D Pearson
Honorary Secretary
City Hospital Research Ethics Committee

Appendix 17

Observation form used in pilot work with children using "The Asthma Files" computer program.

The Asthma Files

Observation rating scale

Participant ____________
N number ________
Date ________

Session ________
Section ________
Time ________

RESEARCHER BEHAVIOUR	FREQUENCY	COMMENTS
Instruction *i.e. Press the handle to start the machine*		
Suggestions/prompts *i.e. Have you tried all of the cabinets?*		
Pointing		
Physical guidance *i.e. helping to put triggers in box*		
Task specific comments i.e.		
Non task specific conversation		
Praise		

PARTICIPANT BEHAVIOUR	FREQUENCY	COMMENTS
Navigational errors		
Content related errors *i.e. trying to put wrong triggers in box*		
Task specific questions: Content *i.e. Is exercise a trigger?*		
Process *i.e. Where do I go now?*		
Non-task specific qus/conversation *i.e. I came on the bus today*		
Task related comments *i.e. I've got an inhaler like that!*		

General comments:

Appendix 18

Information letters sent to children and parents for pilot study

NOTTINGHAM City HOSPITAL

NHS TRUST

NHS

Hucknall Road
Nottingham
NG5 1PB
Telephone
0115 969 1169

Ext Fax No

Our Ref **Your Ref** **Please ask for**

Evaluation of "Asthma Files": A Health Education Computer Program for Children with Asthma

Dear Parent

Your child is being invited to take park in a research study. Before you decide whether your child can take part it is important for you to understand why the research is being done and -what it will involve. Please take time to read the following information carefully and ask us if there is anything that you are not clear about.

We are developing a computer program (CD-ROM) for children with asthma called "Asthma Files". It is an interactive program which uses a secret agent theme to give children information about the symptoms, causes and management of asthma . It is important that children receive adequate information about asthma so that they are happier about treatment and better able to manage their own asthma. We are carrying out this study to check that the different sections of the program are easily understood and enjoyed by children

Why have I been chosen?

We are contacting parents of all children aged 7 to 16 with appointments for Dr Smyth's Friday-morning Asthma Clinic at the City Hospital, between May and October. The research will take place at the Paediatric Out-patient Clinic whilst children are waiting to be seen by the doctor.

What will happen to my child if we **take part?**

Our researcher, Ms Amy McPherson, will sit with each child as he or she uses the program and the session will be video recorded so that we can check at a later date how well the program worked. Amy will also ask each child participant some questions about the content of the program and how they felt about using the program. The research session should take no more than 20 minutes. There will not be any direct medical benefit to your child, though we hope that he or she will enjoy using the program and also learn more about asthma.

Do I have to take part

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. The standard of your child's care will not be affected in any way. All information will be confidential.

Yours sincerely

NOTTINGHAM City HOSPITAL NHS TRUST

Hucknall Road
Nottingham
NG5 1PB
Telephone
0115 969 1169
Ext
Fax No

NHS

Our Ref

Your Ref

Please ask for

Health education program for children **with** asthma

Investigators:

Dr Alan Smyth (Consultant in Paediatric Respiratory Medicine)
Dr Cris Glazebrook (Senior Lecturer in Behavioural Sciences)
Ms Amy McPherson (Researcher in Behavioural Sciences)

INFORMATION FOR CHILDREN & YOUNG PEOPLE

- Doctors and nurses at the City Hospital have designed *a* computer program "The Asthma Files" that tells children about asthma and the best ways to manage it.
- *We are* carrying out some *research* to *see* if the program is useful in helping children to learn about asthma.
- Our *researcher.* Amy McPherson, would like to show you parts of the computer program the next time you come to the clinic and ask you a few questions.
- This is very useful for us because we want to make sure that children enjoy using the program and that it is as good as possible so it will help other children.
- Remember that you do not need to take part in this research if you don't want to. Just tell your mum or dad or our researcher if you'd rather not.
- Everyone who takes port in the project will be given a copy of 'The Asthma Files' computer program to keep when it is finished.

Appendix 19

McPherson, A, Forster, D, Glazebrook, C, and Smyth, A (2002)
The Asthma Files: Evaluation of a multimedia package for
children's asthma education. *Paediatric Nursing*, 14 (2), 32-35.

rhe Asthma Files:

:valuation of a multimedia package or children's asthma education

ABSTRACT

Children's knowledge of asthma triggers and the impact on children's knowledge of using The Asthma Files', an interactive, educational computer program, were evaluated in this pilot study. Thirty-one children aged between seven and 14 years and diagnosed with asthma were recruited to the study Ten boys participated in evaluating the triggers section and a questionnaire was used to determine their feelings about the program and retention of information. Children enjoyed using the package and knowledge about asthma triggers increased significantly The Asthma Files' shows promise as an additional tool to augment existing education.

ny McPherson BSc(Hons), searcher in Behavioural iences, Queen's Medical :ntre, Nottingham; ebra Forster RGN, RSCN, ic(Hons), Paediatric Respiratory urse, Nottingham City Hospital; lis Glazebrook PhD, BA (Hons), CN Senior Lecturer, Queen's ledical Centre, Nottingham; lan Smyth MA, MB BS, MRCP, ID, FRCPCH Consultant espiratory Paediatrician, ottingham Qty Hospita!

KEY WORDS

sthma
hildren
fcmputer-based leaming
itients: education

Asthma is now the most common chilcihood illness, affecting one in seven children aged two to 16 years (Kanabar 2000) which costs the UK an estimated £100-150 million a year (Lenney 1997). Childhood asthma also has an immense impact on school attendance and family life (Brook et cd 1991, National Asthma Campaign 1999).

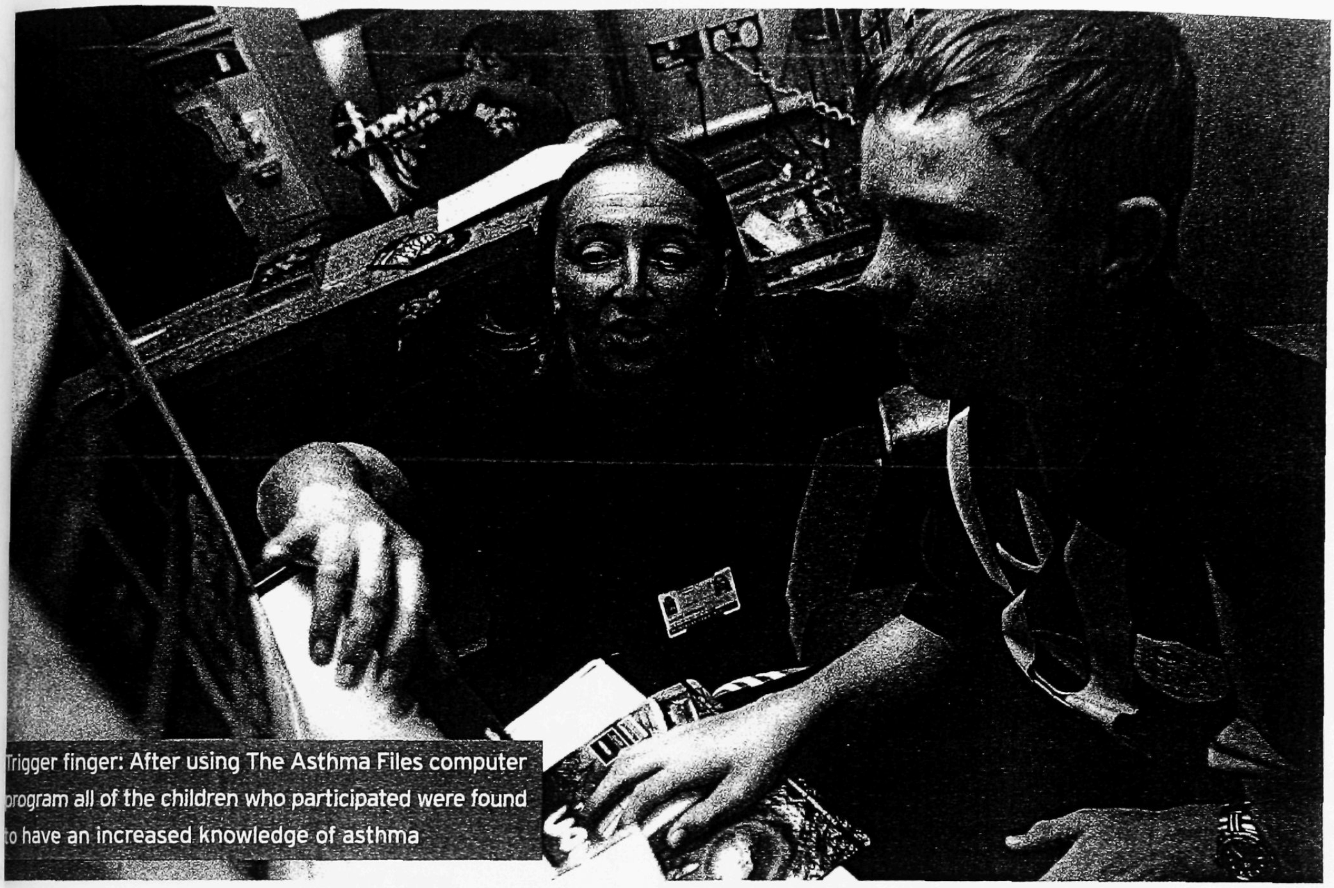
Nevertheless, asthma is considered a reversible disease that usually responds to treatment (McLean 1998). In fact most children can lead a normal life, provided they take the prescribed medication (Lloyd 1996) and undertake regular medical reviews (British Thoracic Society et al 1997).

Central to good asthma management is the avoidance of 'triggers' that exacerbate the patient's asthma. Common triggers in children are exercise and viral infections, as well as smoke, dust-mites, pollen and cold weather (Kanabar 2000).

Studies have demonstrated that poor self-management is directly associated with asthma morbidity (British Thoracic Society 1982, Wesseldine et al 1999) and increasingly, professionals in the field of asthma management agree that patient education is crucial to achieving good control of asthma symptoms. Effective communication, patient education, written information and 'self-management' asthma plans have been found to have a positive effect on the management and control of asthma (Partridge 1996), and can reduce fear and stress (Rushforth 1999). However, although asthma education is advocated there is still some argument as to the impact it has on readmission rates (Bemard-Bonnin et al 1995, Kaur 1998).

Effective management cannot be achieved by simply giving advice and explanation. Effective education requires considerable time and commitment, and a multidisciplinary approach is advocated (Riley 1997, Wesseldine et al 1999). Innovative means have been sought to educate children with chronic illness, and educafional computer packages are becoming increasingly popular. They are particularly suited to paediatric education because they combine familiar technology with interesting graphics which hold childreris attention (Evans et al 1998, Rubin et al 1986). These have been targeted at a variety of health problems, including diabetes (Brown et al 1997, Castaldini et al 1998), nocturnal enuresis (Evans et al 1998), as well as asthma (Bartholomew et al 2000, Homer et al 2000, Rubin et al 1986) and many have reported positive outcomes on childreris knowledge of their illness.

The study aimed to evaluate childreris knowledge of asthma tiiggers and to assess the impact of using The Asthma Files', an interactive, educational computer program, on childreris knowledge. It was hypothesised that use of the trigger section of the program would be associated with a significant improvement in knowledge about asthma triggers.


Trigger finger: After using The Asthma Files computer program all of the children who participated were found to have an increased knowledge of asthma

. From this initial sample, a convenience ple of 13 children used the computer gram, out of which 10 children used the ger' section (the remaining three helped other sections of the program). All 10 who i the trigger section were male. They had edian age of II years (range of 7-14 years) had been attending the clinic for a median 5 years (range 0-12 years). One participant attending the clinic for the first time.

cedure

arrival for an appointment, the researcher ted the child and confirmed that the project rmation pack had been received by post. ental consent and the child's assent was ined and the child was weighed and sured as part of clinic routine.

U children attending the asthma clinic see paediatric respiratory nurse at every visit to TO their medication and check inhaler nique. This nurse session can also be used dentify any parent or child information ds. After seeing the respiratory nurse, the d was taken to a quiet side room and made ifortable. Using the Knowledge and Appraisal Questionnaire, they were asked what they knew about triggers for asthma, and specifically, whether they could name anything that might trigger an asthma attack. It was stressed that this shouldn't just be restricted to their own asthma triggers.

The child was then given a brief explanation about how to use the computer and was given a short demonstration. It was emphasised that the program was in development, that their opinions were important and that there was no right or wrong way to use the computer The section on triggers was started and the child was encouraged to explore wherever he or she preferred. After this instruction, the researcher gave very little assistance, but made detailed notes on how the child used the computer

When the child had finished exploring the triggers section, the computer was turned ofi" and the child was given the same task of explaining what triggers were and naming as many triggers for asthma as possible.

The child was thanked for participating and taken back to the waiting room until their appointment for the doctor.

The data were analysed using the Wilcoxon signed ranks test, as this is particularly suited for testing differences in related data when a normal distribution and an interval scale cannot be assumed.

Results

Initial knowledge levels about asthma triggers were low. The median score before using the computer was 2.5 (range 0-3). After looking at the computer program knowledge levels had increased significantly (median= 5.5, range=2-8). AH ten participants (100 per cent) improved their score and 70% could name five triggers or more. This improvement was statistically significant (T= o; pxo.005).

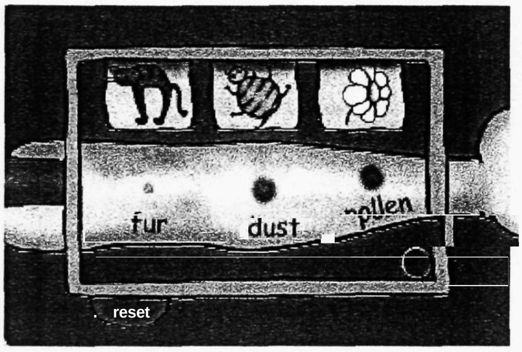
Conclusions and discussion

Our study found very low levels of knowledge of specific asthma information in children attending an asthma outpatient's clinic, despite the majority of attendees having had contact with asthma specialists for several years. This concurs with other research which has found low levels of asthma knowledge in this population (Leiria *et al* 1999). However, some of these children had been very young on first

Fig. 1. Screenshot of the 'triggers' board

Users must decide which are triggers for asthma and 'drag' them into the box in the middle. They can then indicate which are their own triggers.

Fig. 2. Screenshot of skin prick test



Users press each picture to 'scratch' the arm with the potential trigger In this case house dustmite and pollen have shown up as triggers.

Method

Pilot work using an educational computer package was carried out at Nottingham City Hospital with children attending the paediatric outpatient asthma dinic Ethical approval had been granted from the hospitals ethics committee prior to commencing the pilot study. To be eligible to take part partidpants had to be between seven and 14 years old and have a diagnosis of asthma. Every eligible child over five weekly dinics was contaded by post prior to their appointment with a project information sheet and an invitation to join the study.

Intervention

'The Asthma Files' computer program has been devdoped by a multidisciplinary team involving medical, nursing, psychology and multimedia workers, in conjunction with the National Asthma Campaign. It aims to teach children about asthma and its management and is suitable for use on most computers. Information is grouped into eight sections which are linked by a 'secret agenf theme.

There are numerous interactions, quizzes and games throughout the program that help to reinforce key messages. One section addresses triggers of asthma by asking the child to:

- select common asthma triggers from a range of images on a 'trigger board';
- identify their own triggers;
- obtain a more detailed description of the triggers from a 'one-armed trigger bandit'; and
- take part in a demonstration of a skin prick test (See figures 1 and 2 for 'screenshots' of the trigger board and skin prick test)

Throughout the program, the user can enter personal information, i.e. peak flow and triggers, which is incorporated into a printable self management plan. A more detailed description of 'The Asthma Files' CD-ROM can be obtained from the authors.

Instruments

A portable laptop computer with a CD-ROM drive and external mouse were used to demonstrate the asthma computer program to the children. The 'Knowledge and Appraisal Questionnaire' was developed by the authors to determine the child's feelings about the program and to ascertain how much information they retained. This allowed observers to take detailed notes on how the child was using the program in order to identify problem areas, for example, if children were repeatedly clicking in the wrong place, or were unable to access a particular interaction. After using the program, children were asked which parts they liked best and least, what they would change, how useful it had been to them and any other comments they wished to make.

A set of simple open-ended questions were incorporated into the questionnaire to be asked before viewing the program and again afterwards. As part of this, the children were asked to explain what a trigger was and list as many triggers as they could. To assess the answers, each trigger listed scored one point, with a maximum score of nine points.

Participants

Thirty-one children who met the study's criteria (i.e. aged between seven and 14 years and had been diagnosed with asthma) were identified from weekly asthma dinic lists over fives weeks and contaded by contact, so it is possible that their parents received the education on behalf of their children. It is vital, then, that children are involved in their treatment from an early age and educational 'booster' sessions or updates should be integrated into the child's care plan (Gebert *et al* 1998).

'The Asthma Files' look promising as an educational package for children with asthma. It can be seen as an additional tool to augment existing education delivered by the paediatric respiratory nurse, which may not be effective in a busy clinic environment

The children in the study enjoyed using the package and demonstrated increased knowledge about triggers of asthma after using fee program. This early work supports previous studies which have found fliat children are able to extract rdevant information firom multimedia sources (Evans et *al* 1998, Oliver and Perzylo 1994). Educational theory holding that interactive education confers particular advantages, and that children should be encouraged to partidpate actively in their learning (Becker et *cd* 1994), fits well with the ethos of this study. Furthermore, multimedia packages such as 'The Asthma Files' are inherently child-centred, which is a fundamental concept in modem children's nursing (Jones 1995, Wilkinson 1998).

However, because of the short duration between viewing the program and knowledge re-testing, we do not know whether improvements in knowledge are retained in the long term. When evaluating the finished package, a longer period of time is planned between using the program and assessing knowledge gains.

It must also be noted that only boys took part in this study, despite non- discrimination on the part of the researchers. Although girls have been involved in the development of ''The Asthma Files' program, none used the 'triggers' section during the course of this particular study. This was due, in large part, to the high proportion of girls who did not attend their clinic appointment during the study period. Further work of this nature should investigate gender differences in the use of multimedia education.

Although we, and others, have demonstrated that knowledge of asthma can be improved through education, the essential question that remains largely unanswered is what role knowledge plays in influencing compliance. Research suggests that certain conditions are necessary for knowledge to enhance behaviour (Rubin *et al* 1989), and it is hoped that fuller evaluation of tiiis computer package will reveal which children will benefit most fi-om using The Asthma Files' PN

Acknowledgements

Thanks go to the CD-ROM development team, including Claire James of Willow Wong General Practice and Ian and Deborah Crook of Showme Multimedia Ltd. Particular thanks go to the children - and parents who took part in the study, and all the staff at Nottingham City Hospital paediatric outpatients' clinic.

This study was funded by an unrestricted, educational grant from Merck, Sharp and Dohme Pharmaceuticals.

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Appendix 20

Self- management plan given to children in intervention group[2].

[2] Peak flow figures completed by researcher using child's best or predicted peak flow.

Your Self-Management Plan

Best peak flow when well	

OK

If peak flow is above ☐

and you feel fine, continue with your usual treatment.

Caution

If your peak flow is less than ☐ or you have been coughing or wheezing more than usual then:

- **Take your usual dose of reliever**
- **Wait S minutes**
- **Take peak flow**

If you do not feel any better and your peak flow has not improved much then:

- **Carry on taking your usual dose of reliever every 4 hours**
- **Double your dose of preventer**

Carry on checking your peak flow twice a day until it stays above ☐ for 2 days in a row.

Then go back to your usual treatment

Danger

If your peak flow falls below ☐ or you are coughing, wheezing & breathless then:

- **Take up to 10 puffs of reliever slowly through a spacer**
- **Wait 5 minutes**
- **Check peak flow again**

Then:

If you feel better and your peak flow is above ☐

- **Take up to 10 puffs of your reliever through a spacer every 4 hours**
- **Double your dose of preventer**
- **Make sure you see your GP the next day**

OR

If you do not feel better and your peak flow has not improved then:

- **Take 10 more puffs of your reliever through a spacer**
- **See your GP straight away**
- **Start steroids if you have been told to by your GP**

You are aiming to get your peak flow above ☐

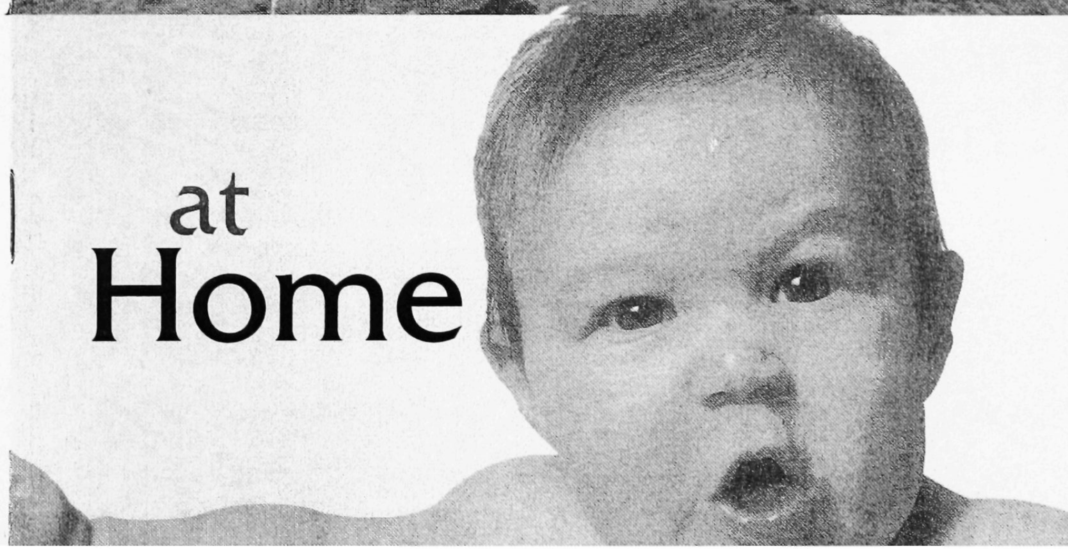
EMERGENCY

If you are not feeling better after working through this plan and taking your treatments, call your GP, or go to hospital or the Accident & Emergency department.

Appendix 21

"Asthma at Home" booklet.

Asthma at Home



SOUTHERN DERBYSHIRE ACUTE HOSPITALS NHS TRUST

Nottingham Children's Services

City Hospital

WORKING TOGETHER FOR CHILDREN AND YOUNG PEOPLE

d by Mono Design01332343646 September 1999

Names & Numbers

This booklet belongs to: ______________________

____

Hospital/Ward: ______________ Tel: ______________

Hospital Consultant: ______________ Tel: ______________

Asthma Nurse: ______________ Tel: ______________

G.P. ______________ Tel: ______________

National Asthma Campaign's Helpline :

0 845 7 01 0203

9.00 am - 7:00 pm Monday - Friday

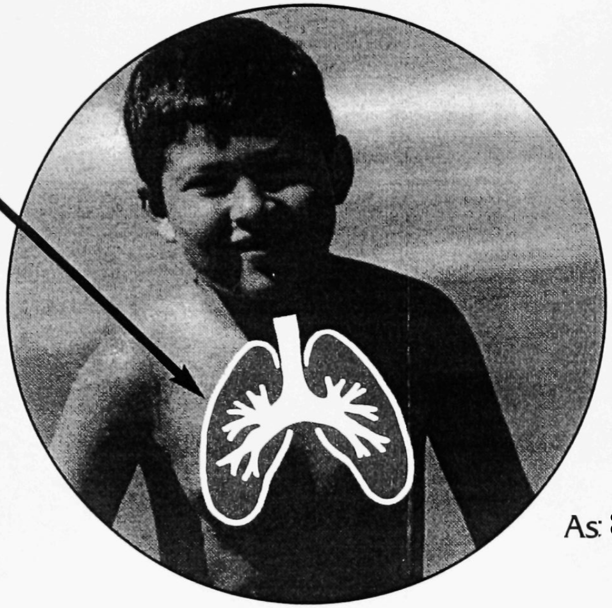
Contents

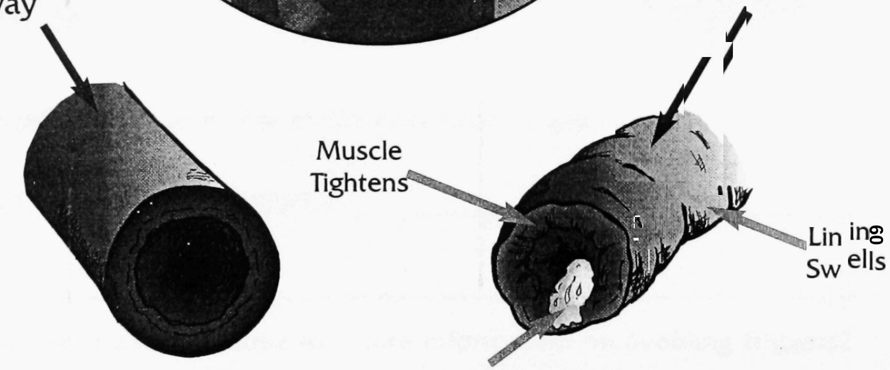
What Happens in Asthma

The lining of the airways become swollen and inflamed.

The airways produce thick mucus. The muscles around the airway tighten and make the airways narrower.

This means it is more difficult to breathe.





Common Symptoms

- **Short of breath**
- **Wheezing**
- **Coughing**
- **Tightness of Chest**

  (your child may complain of tu[redacted]ache)

What are your childs warning signs? ______

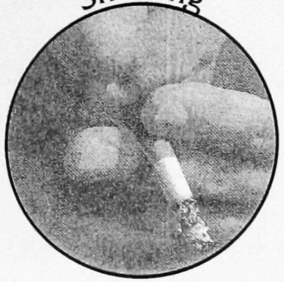
______

Asthma Triggers

Contact with triggers causes the sensitive asthmatic airways to become swollen, produce a lot of mucus and tighten up. This leads to the symptoms of;

Short of breath, coughing and wheezing.

Smoking



Exercise

Animal Fur/Feathers

Pollen

Common Cold

House Dust Mite

Remember these are the most common triggers.

What are your child's triggers? ______________________

____

Please ask your asthma nurse for more information on avoiding triggers?

Asthma Treatment

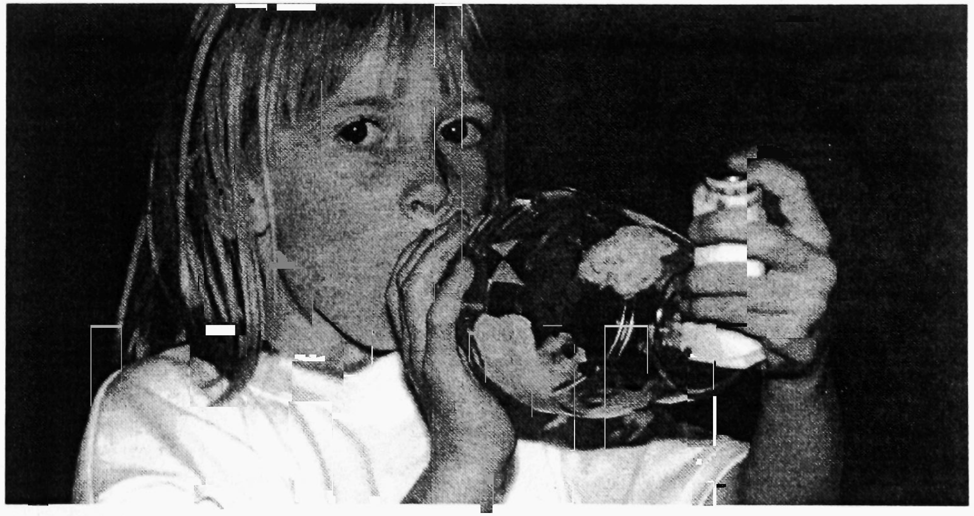
There are two main types of medicines for asthma - Relievers and preventers. Almost all asthma medication is given by inhaler.

Relievers (usually blue)

Relievers treat a symptoms by relaxing the muscles around the airways. A common reliever is Salbutamol. They work within 5 - 10 minutes. Use the reliever when your child is wheezy, coughing or breathless, or before exercise. It is given only as necessary.

Preventers (usually brown or orange)

Prevent asthma symptoms by stopping the inflammation and swelling in the airways before it causes symptoms. Preventers must be taken every day.



Asthma Treatment

Remember to clean your child's teeth or give them a drink after taking the preventer to stop a sore mouth.

Can you name your child's reliever and preventer?

____

____

There are new preventer medicines which are available as tablets.

These are called **Anti-Leukotrienes.**

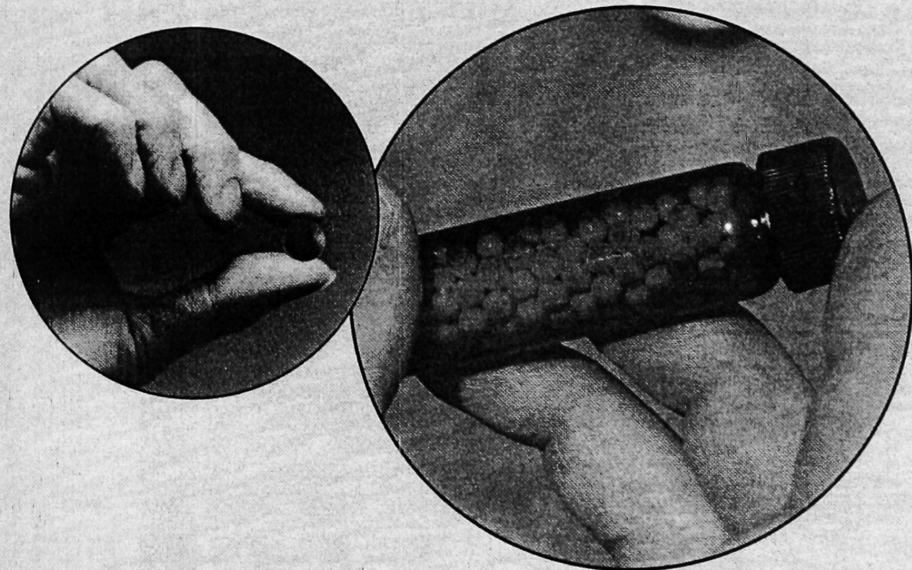
Protectors (usually green)

Protectors are long acting inhalers that may help to reduce troublesome symptoms during exercise and at night.

This long acting inhaler must be given regularly with your preventer.

Medicines Taken by Mouth

There are very different to the steroids that some body builders use (anabolic). The ones used in asthma are known as **corticosteroids.** They work by reducing the amount of inflammation, mucus and swelling in the air passages. A short course of steroid tablets (3-5 days) is sometimes needed to treat an attack in addition to the preventers and relievers.



Talk to your asthma nurse if you have any worries about your child's asthma treatment.

Inhalers

It is very important to use the inhalers correctly to get the medication to the airways.

You and your child should use the inhaler in the same way that the nurse has demonstrated.

Have you been shown how to use the inhaler?

Here are a few of the many inhalers.

Can you spot your child's inhaler?

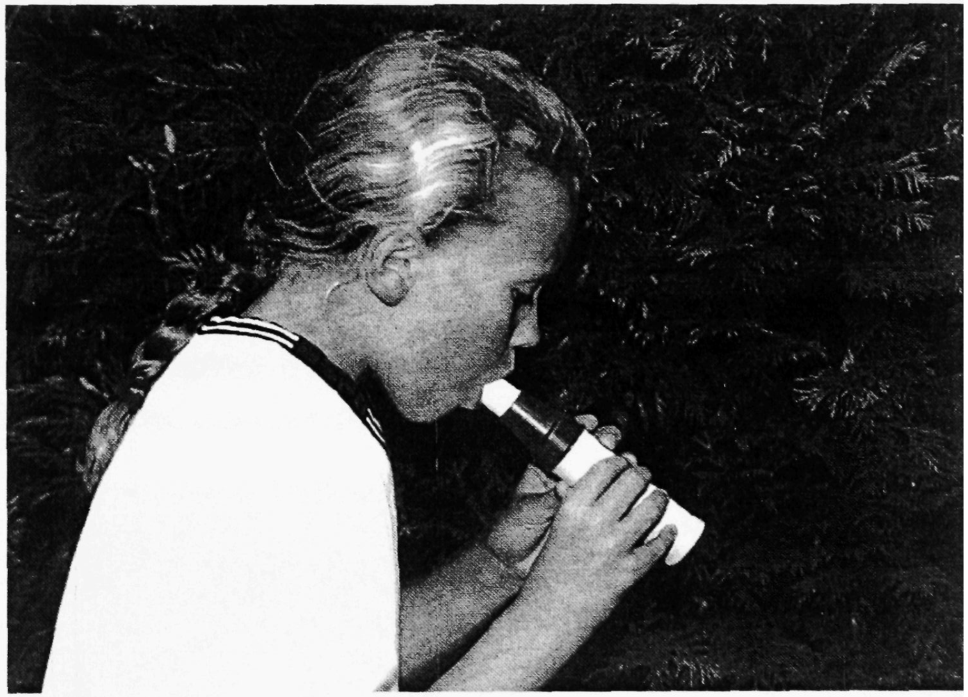
Please ask your asthma nurse about the best way to care for the spacer device.

If you or your child is unsure about inhaler technique please ask!

Peak Flow Meters

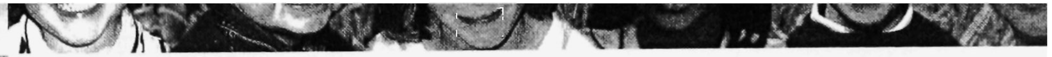
For over 5 year olds

The best way to monitor your child's asthma is by using a **Peak Flow Meter.**



How fast your child can blow out will depend on whether the airways are wide or narrow. If they have become narrow because of asthma it will be difficult to blow out.

It would be useful to the doctor/nurse if your child kept a Peak Flow Diary for a few weeks before their appointment.



Coping with An Asthma Attack

As soon as your child develops warning signs e.g. has a COld, start using their reliever. Give it regularly every 4 hours.

WHAT TO DO;

Stay Calm - Don't Panic!

Encourage your child to take deep slow, breaths.

Give the reliever. You can give it again after 5 - 1 0 minutes if needed.

See your GP if the reliever is not lasting for 4 hours.

DANGER SIGNS

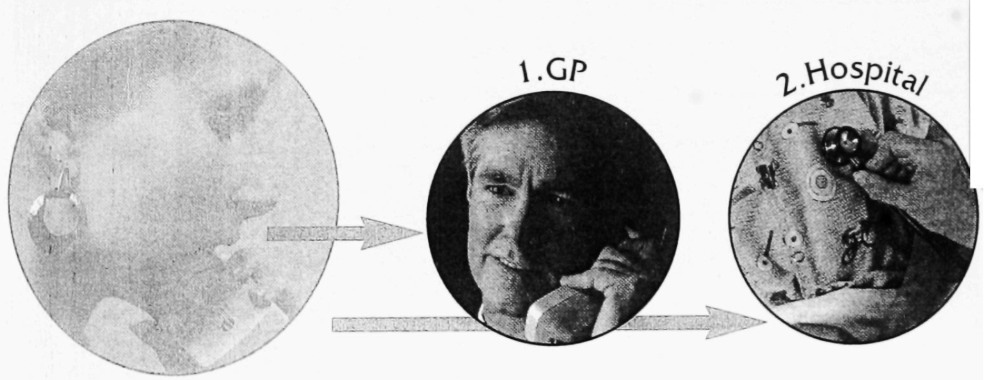
Very distresised by coughing/wheezing

Too breathless to feed or talk

Lips going blue

WHAT TO DO?

Call for medical help **immediately.**



In an emergency you can give your Child up to 10 puffs one at a time - with metered dose inhaler + spacer over 5 - 10 minutes.

Self Management Plan

Take control of your asthma by using your **self-management plan!**
Your Asthma Nurse will discuss this with you.

Best Peak Flow ____________________

Double up your preventer if your peak flow drops to 75% of your best ____________ and give your reliever regularly.

If your peak flow drops to 50% of your best ____________ you will feel unwell and need to see your doctor.

Your Child's Usual Treatment

Reliever Name ____________________

Dose ____________ How Often ____________

Use this when wheezy, coughing or out of breath.

Preventer Name ____________________

Dose ____________ How Often ____________

Use this every day, as requested by your Doctor or Nurse.

Any other inhalers ____________________

Dose ____________ How Often ____________

Oral Name ____________________

Dose ____________ How Often ____________

Questions for your Doctor or Nurse:

Booklet written by Debra Forster & Rebecca Galloway